

ADHD-Europe
Contribution to the EC Green Paper
on improving the Mental Health
of the population

MAY 2006

Mental Health with ADHD?

Rachel, age 12, speaks for herself:

She has always voiced her own opinions and concerns surrounding her disability and how the world and the people she meets within it perceive her. She has struggled to gain acceptance and understanding and is always keen to talk about her problems and these are the thoughts she has expressed to her parents:

- *Why am I different?*
- *Why do I have this disability?*
- *Why do people talk about me and not to me?*
- *I don't understand lots of things at school but feel unable to express this*
- *I can't cope with how I feel sometimes and get very angry and stressed*
- *Why do I never get invited to meetings?*
- *I am not a mental case*
- *I am Rachel and I have needs and wants*
- *School wants to give me a detention because I forget my shoes or forget to do my homework*
- *I feel picked on and I feel I am made to feel like a troublemaker and lazy because of ADHD*
- *My sister calls me a troublemaker and headcase*
- *I am normal in every sense of the word, just my brain gets mixed up now and then ...*

(Ref. 1 - Knowing me Knowing you: Diagnosis and early intervention 2002)

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Introduction of ADHD-Europe

ADHD-Europe represents 27 organisations concerned with ADHD (patient, parent and adult advocacy groups) from 18 European countries, who have been meeting and cooperating together since 2005 for the improvement of the situation for those affected by ADHD.

As Markos Kyprianou, Commissioner for Health and Consumer, mentioned at the launch of the “Green Paper on improving the Mental Health of the population” (*Ref. 2 - Kyprianou, 2005, October*), the input of advocacy and patient groups is an essential aspect of the consultation process. Advocacy groups develop their strength and capacity from the bottom up, generally having intimate knowledge about the issues and needs of vulnerable groups from personal life experience. They are committed and passionate about their communities and the people they work with who often confront difficulties regarding access to early and accurate diagnosis, effective treatment, essential support networks and monitoring of therapy. Involvement of patient and advocacy groups results in informed public opinion at national and European levels, realizing a bigger influence on multi-stakeholder groups (*Ref. 3 - Arnauts & Partners, 2005*). Therefore ADHD-Europe, helping to build the capacity of individuals affected by ADHD, increasing their empowerment, supporting the need for the realisation of the full potential of their lives and being a expert ”watchdog”, is pleased to be given the opportunity to contribute to the Green Paper on improving the Mental Health of the population.

I. ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)

ADHD is a chronic disorder requiring long-term treatment

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

ADHD 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 ADHD, 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. (Ref. 4 - *European Interdisciplinary Network for ADHD Quality assurance [EINAQ], 2004*)

Remarks

It is interesting to note that, although the Helsinki conference (Ref. 5 - WHO European Ministerial Conference on Mental Health; 2005) addressed issues of mental health of children and adolescents, ADHD, the psychiatric disorder most often diagnosed in children and adolescent, is not mentioned in the EC Green Paper.

The Green Paper hopefully can stress the many different aspects in mental health conditions: illness, disability, handicap, disease, disorder, taking into account the acuteness of the condition or its chronic life-long effects. We would appreciate thus a more extensive list of conditions, including ADHD, be cited in the Green Paper, as Annex II mentions only a limited range.

Many disabilities are disabling without being visible. This gives people the opportunity to hide their problems to avoid unjustified dismissal, to avoid stigmatisation ... But hiding these problems can create new stress factors, leading to other mental health issues.

There are disparities across the European Union in regard to awareness, diagnosis, treatment and management of ADHD. These differences are reflected in the lack of, and often outdated professional knowledge, the limited access to medication, as well as few resources and social support. These discrepancies must be addressed.

What are the causes of ADHD?

ADHD is a neuropsychiatric disorder with a genetic risk (70-80 %), and is influenced by environmental factors. Genetic tendencies for ADHD often interact with the environment in complex ways. (Ref. 6 - *International Consensus Statement on ADHD*, 2002).

ADHD 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 ADHD** although they play an important role in its outcomes often making the symptoms and associated problems worse (Ref. 4 - *EINAQ*, 2004).

Best clinical practice for diagnosis and treatment of ADHD

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 ADHD by qualified health care 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 (Ref. 7 - *American Psychiatric Association*, 2000).

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 comorbidities, 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 ADHD. 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.

(Ref. 4 - *EINAQ*, 2004).

(Ref. 8 - *A healthy start to life: Mental health and disorders of children between 6 and 12 years old*, 2005)

(Ref. 9 - *Ralston & Lorenzo*, 2004)

Remarks

*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** (Ref. 10 - Charter of fundamental rights of the European Union, 2005).*

It is commonly accepted that ADHD 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 ADHD (Ref. 9 - Ralston & Lorenzo, 2004).

In any case, it is crucial that children and families affected by ADHD 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 ADHD, they will be equipped with the skills and knowledge to improve the quality of care for children and adults.

What are the potential long-term effects and the 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 ADHD on an individual** with ensuing comorbidities developing. Too often social exclusion results from an accumulation of the issues related to ADHD.

Remarks

There are different outcomes possible in the adulthood of people affected by ADHD.

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 ADHD-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 ADHD 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 ADHD 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 down stream cost-saving impact for governments.

(Ref. 11 - Controlling the diagnosis and treatment of hyperactive children in Europe, 2003)

(Ref. 12 - Biederman & Faraone, 2005)

(Ref. 13 - De Ridder & De Graeve, 2006)

(Ref. 14 - Olesen., Baker, Freund, di Luca, Mendlewicz, Ragan, & Westphal, 2005)

Who is involved?

Not only do children and adults with ADHD suffer, but also those persons in their immediate surroundings are affected and have to deal with the impact and outcomes of ADHD (*Ref. 15 - Without Boundaries - The impact of ADHD on children and their families, 2005*). Partners, parents and siblings deal with the effects of ADHD at home, school workers and friends cope with it during school time, colleagues and employers deal with it at work. In fact the whole community is involved (*Ref. 8 - A healthy start to life: Mental health and disorders of children between 6 and 12 years old, 2005*).

Especially for partners, parents and siblings, living with someone suffering from ADHD can create a tremendous amount of stress which often leads to their own depression or substance abuse. (*Ref. 16 - Barkley, 2000*)

As there is a genetic component for ADHD (70 – 80 %) and if one or both of the parents are affected, the risk for their children to have ADHD is high. The family situation thus becomes more complicated and difficult. Often the parents may require treatment themselves in conjunction with parenting classes and social support in bringing up their children.

II. CONCLUSIONS AND SUGGESTIONS

The priorities for the target group affected by ADHD 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*” (Ref. 10 - Charter of Fundamental Rights of the European Union 2005).

The major points of view expressed in this contribution to the Green Paper on Mental Health are also supported by the **European Charter of Patients' Rights**. Relative to the active role of citizenship, the right to perform advocacy activities and also the right to participate in policy-making in the area of health are central to ADHD-Europe's activities (Ref. 18 - European Charter of Patients' Rights, 2002). Other important rights cited are:

- Right to Preventive Measures (1)
- Right of access (2)
- Right to information (3)
- Right to Respect of Patients' Time (7)
- Right to the Observance of Quality Standards (8)
- Right to Personalized Treatment (12)
- Right to Compensation (14)

Support for a European framework on ADHD is essential

Raising awareness and sharing good practices results in the improvement of services across all sectors for those affected by ADHD in Europe; this will avoid the reinvention of the wheel, cascade the pressure on national and European policy levels, build capacity of advocacy groups and empower individuals.

It is necessary that the predominantly conservative cultures and attitudes across Europe be recognised as limiting factors for increasing public and professional knowledge about ADHD. Awareness campaigns are needed to encourage health care professionals, educators, the media and parents to collaborate, ensuring that affected children and adults receive appropriate diagnosis, treatment and monitoring. In this regard, although ADHD falls under the umbrella of mental health and, because of the social stigma associated with ADHD, there are severe potential consequences for children, their families and for society. The high rate of co-existing pathological and developmental problems, negatively affected school careers and the underlying social problems lead ADHD-Europe to recommend that ADHD requires the development of its own very specific framework and initiatives for action in the field of mental health (Ref. 19 - National Institute for Clinical Excellence, 2006).

Within this framework ADHD-Europe will develop strategies to meet the following objectives of the European Union:

- **Increased knowledge, awareness and understanding** about ADHD using a multi-sectoral approach at all levels to improve acceptance including:
 - the general public (includes parents, siblings, partners)
 - specific focus at all levels of the education sector
 - health care professionals
 - social care services
 - policy and decision makers
 - justice and law
 - the media (*Ref. 20 - ADHD: The hope behind the hype - International media reporting guidelines on Attention Deficit Hyperactivity Disorder, 2003*).
- **Improvement of coherence and communication** between health care professionals concerned with ADHD. This objective is important not only for the individual health, but should also help to address issues surrounding social exclusion and marginalisation.
- **Emphasis on the responsibility of society** at large with regard to promoting the social integration and inclusion of individuals with ADHD thereby reducing stress and improving the quality of life for everyone.
- **Increased financial investment** in the educational and health care sectors is essential to support mental health in Europe. This investment is a priority across the lifespan, particularly in early childhood, in order to prevent the negative impact and potential long term health care burdens resulting from unrecognised and under treatment of ADHD (*Ref. 5 - WHO European Ministerial Conference on Mental Health, 2005*).
- Development of concrete actions such as educational and media campaigns to **combat stigma and discrimination** experienced by those affected by ADHD (*Ref. 21 - U.S. Department of Health and Human Services, 1999*).
- Improvement in the **equity of access to diagnosis and appropriate therapy** for all.
- **Increased knowledge and awareness about ADHD in adults** in order that they receive support and treatment for the primary cause of their mental health problems and not only for their secondary disabling symptoms (e.g. alcohol abuse, depression, etc.).
- **Provision of research funding through the 7th Framework Programme for:**
 - **Creation and development of an EU-wide network and database** - to improve the quality and availability of diagnostic services and evidence-based therapies for ADHD in the Member States.

- **Translational and social research** - urgently needed for the benefit of individuals and society as a whole and must engage all stakeholders in the sphere of mental health, particularly in relation to ADHD.
- **Health economics and outcomes research** – essential to begin to understand the ramifications of the under diagnosis and under treatment of ADHD
- The **promotion** of mental health and the reduction of the burden of mental illness must grow qualitatively and quantitatively:
 - **for the children:**
 - by support during the school age years
 - by improving parental skills
 - **for the adults:**
 - by improving work accommodations
 - by raising awareness
 - by decreasing the impact of comorbidities

Knowing me, knowing you, a European project funded by the European Social Fund, evaluated and identified reasons why ADHD leads to social exclusion for adults. Unfortunately, the national ADHD associations in the Member States were unable to follow up proposed initiatives of the project due to lack of resources (Ref. 22 - *Knowing me Knowing you: Curriculum for our future*, 2002). In all aspects this report highlighted **the urgent need for action and support for social inclusion of those persons affected by ADHD.**

In conclusion we want to stress one of the major Recommendations of the Meeting of Minds European Citizens' Deliberation on Brain Science that is applicable to all those persons affected by ADHD:

“We recommend promoting the integration of and tolerance towards children and adults with psychiatric or neurological conditions in their homes and neighbourhoods, and at school and work. The government has to provide the necessary resources to achieve this in a constructive way and should enlist the help of specialists” (Ref. 23 - *The public presentation of the European Citizens' assessment report at the European Parliament*, 2006).

ANNEX I. REFERENCES

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4. European Interdisciplinary Network for ADHD Quality assurance (EINAQ). (2004). *What is ADHD?* Retrieved March 2, 2006 from <http://www.einaq.org/adhd.php3>
5. WHO European Ministerial Conference on Mental Health. (2005, January). *WHO mental health action plan for Europe: Facing the challenges, building solutions.* Helsinki, Finland. Retrieved March 2, 2006 from <http://www.who.dk/Document/MNH/edoc07.pdf>
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7. American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders - Text revision (DSM-IV TR).* Washington, DC: Author.
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14. Olesen, J., Baker, M., Freund, T., di Luca, M., Mendlewicz, J., Ragan, I. & Westphal, M. (2005). *European Brain Council: Consensus document on European brain research.* [Electronic version]. Journal of Neurology, Neurosurgery and Psychiatry. Retrieved March 2 2006 from <http://jnnp.bmjournals.com/cgi/rapidpdf/jnnp.2006.089540v1.pdf>
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ANNEX II. DETAILS OF SPECIFIC REFERENCES USED IN THE ADHD CONTRIBUTION TO THE EC GREEN PAPER ON IMPROVING THE MENTAL HEALTH OF THE POPULATION

Reference 3: Arnauts & Partners. (2005, April). *Workshop Report: Patient Advocacy, Encouraging Dialogue and Improving Health Outcomes*. Berlin.

Transparency – The Key to Successful Partnerships

Establishing partnerships with different healthcare stakeholders, including other patient groups, professional organisations, politicians, regulators, researchers and the pharmaceutical industry, is very important not only to have a greater impact at national and international levels but also to influence stakeholder groups amongst which outdated paternalistic attitudes may still persist.

Reference 5: WHO European Ministerial Conference on Mental Health. (2005, January). *WHO mental health action plan for Europe: Facing the challenges, building solutions*. Helsinki, Finland. Retrieved March 2, 2006 from <http://www.who.dk/Document/MNH/edoc07.pdf>

We endorse the statement that there is no health without mental health. Mental health is central to the human, social and economic capital of nations and should therefore be considered as an integral and essential part of other public policy areas such as human rights, social care, education and employment. Therefore we, ministers responsible for health, commit ourselves, subject to national constitutional structures and responsibilities, to recognizing the need for comprehensive evidence-based mental health policies and to considering ways and means of developing, implementing and reinforcing such policies in our countries. These policies, aimed at achieving mental well-being and social inclusion of people with mental health problems, require actions in the following areas:

...

iv ... offer targeted support and interventions sensitive to the life stages of people at risk, particularly the parenting and education of children and young people and the care of older people; ...

Reference 8: *A healthy start to life: Mental health and disorders of children between 6 and 12 years old*. (2005). World Federation for Mental Health: World Mental Health Day. Retrieved March 2, 2006 from <http://www.wfmh.org/documents/WHDR606.pdf>

Recommendations

- *Diagnosing disorders such as ADHD early in the child's life is essential. Untreated ADHD, as well as other disorders, is often associated with likely higher rates of substance use, conduct problems and delinquency, school failure, and other adverse long-term outcomes. Behavioural therapies and certain medications can help control the symptoms of this disorder.*
 - *Parents should be partners in the treatment process for any mental distress in their children and should work with the child's doctor in developing a treatment plan.*
 - *Often the school must be a partner in the treatment of children, especially in areas such as learning disabilities.*
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Reference 9: Ralston, S. & Lorenzo, M. (2004). Attention-Deficit Hyperactivity Disorder Observational Research in Europe (ADORE). *European Child and Adolescent Psychiatry [Supplement 1]*. 36, 36-42.

Conclusions:

- *Reported results suggest that patients improved from the T1 – T2 data collection points using instruments collecting information on: number of ADHD symptoms, global functioning, emotional problems, conduct problems, self-esteem, risk taking behaviours, academic performance and peer relations.*
 - *While this improvement could be associated with many factors, the greatest improvement was shown in patients prescribed pharmacotherapy or combined with psychotherapy.*
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Reference 10: Charter of Fundamental Rights of the European Union (2000/C 364/01). (2005). Official Journal of the European Communities. Retrieved March 2, 2006 from http://www.europarl.eu.int/charter/pdf/text_en.pdf

Article 26

Integration of persons with disabilities

The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.

Reference 11: Controlling the diagnosis and treatment of hyperactive children in Europe. (2003, March). Council of Europe Meeting of Minister's Deputies: Appendix 26 (Item 6.4) - Reply to Parliamentary Assembly Recommendation 1562. (Brussels, Belgium). Retrieved March 2, 2006 from http://cm.coe.int/stat/E/Decisions/2003/833/d06_4x26.htm

3. The issues covered by the Recommendation were the subject of a meeting which the Pompidou Group held in Strasbourg on 8-9 December 1999 and which was attended by specialists from 15 European countries, the United States and the World Health Organisation (WHO). The proceedings of the seminar were published as "Attention deficit/hyperkinetic disorders: their diagnosis and treatment with stimulants".

Attention Deficit / Hyperkinetic Disorders: their diagnosis and treatment with stimulants - Proceedings, Strasbourg, December 1999

The Committee of Ministers considers that it is of utmost importance that parliamentarians, health care workers, teachers, parents and the general public, can obtain accurate and reliable information on the illnesses and on the treatments available. In particular, it takes the view that it is important to improve information to teachers and parents so as to facilitate children's access to the care they need and are entitled to and so as to avert dangerous misuse of the drugs in question. It draws attention to the recommendation made at the above-mentioned 1999 meeting: "There should be a regulatory mechanism to ensure that messages aimed directly at the consumer on ADHD/HKD by drug manufacturers or distributors are truthful and balanced, and do not contain misleading or unverifiable statements or omissions likely to induce the inappropriate prescription of psychostimulants".

4. The Committee of Ministers agrees with the Pompidou Group that, some of the points raised in the Recommendation are at variance with the views held by the vast majority of the scientific community and that they are dangerously close to certain well-known theories which the “Church of Scientology” has promoted for some time but which **do not stand up to serious scientific scrutiny**. The Pompidou Group states that these theories are not only without any scientific basis but, if acted upon, would pose serious health risks to the children in question by depriving them of appropriate treatment.

5. Among these theories, the central one plays down - indeed, disputes - **the classification of attention deficit/hyperactivity disorder and hyperkinetic disorder (ADHD/HKD) as illnesses**. Yet the overwhelming medical consensus is that, though difficult to diagnose, these disorders not only exist but are a serious lifelong handicap requiring multidisciplinary assessment and treatment by various methods, including drugs.

...

Lastly the Pompidou Group takes the view that there is a need for much more training and in-service training for doctors involved in the diagnosis and treatment of ADHD/HKD. In its view, only doctors with sufficient training for this should have the right to make diagnoses, prescribe the necessary effective drugs or engage in other aspects of the complex treatment of these disorders.”

Reference 13: De Ridder, A. & De Graeve, D. (2006). Healthcare use, Social Burden and Costs of Children With and Without ADHD in Flanders, Belgium. *Clin Drug Invest.* 26 (2), 75-90.

Conclusions:

- *Children with ADHD induce a significantly higher cost than their siblings.*
- *ADHD causes a huge financial burden to parents and to the government.*
- *The social burden of ADHD cannot be ignored.*

Reference 14: Olesen, J., Baker, M., Freund, T., di Luca, M., Mendlewicz, J., Ragan, I. & Westphal, M. (2005). *European Brain Council: Consensus document on European brain research*. [Electronic version]. *Journal of Neurology, Neurosurgery and Psychiatry*. Retrieved March 2 2006 from <http://jnnp.bmjjournals.com/cgi/rapidpdf/jnnp.2006.089540v1.pdf>

Concluding remarks

The European Brain Council has devised a three-step strategy to support brain research in Europe. Our first initiative was to calculate the burden and cost of brain disorders in Europe. Studies have revealed that brain disorders account for 35 % of the total burden of diseases in Europe, and that they cost an enormous amount of money—approximately €400 billion per year.

Reference 15: *Without Boundaries - The impact of ADHD on children and their families.* (2005). World Federation for Mental Health: Special Projects Related to Mental and Physical Health. Retrieved March 2, 2006 from <http://www.wfmh.org/documents/WHDR606.pdf>

What Advocates Can Do

The results of this research show how each of us can make a difference to the lives of those with ADHD.

Parents of children with ADHD have a very tough time and often face barriers to seeking medical advice. With accurate information, parents are empowered to demand appropriate medical attention from healthcare professionals.

Patient groups, such as the ones involved in this survey, and The World Federation for Mental Health can provide practical advice and assistance to parents.

Healthcare professionals need to be better at listening to parents' concerns and to be open to the possibility of ADHD. Children need to be referred for diagnosis as early as possible to minimise the disorder's impact.

Governments have to recognise and place ADHD on their national health agenda to ensure that children have timely access to care. Similarly, educators must work together with parents to ensure that children receive the care they need.

The media have a responsibility to reverse the myths that surround ADHD and ensure that accurate facts are presented to their audiences. The media can play a vital role by creating awareness of ADHD and the impairment it can cause the child, their family, and society in general, if unmanaged.

There is a great need to raise public awareness and understanding of ADHD to help combat the prejudices families face.

Reference 17: *Consolidated version of the treaty establishing the European Community.* (2002). Official Journal of the European Communities. Retrieved March 2, 2006 from http://europa.eu.int/eur-lex/lex/en/treaties/dat/12002E/pdf/12002E_EN.pdf

Article 152 PUBLIC HEALTH

A high level of human health protection shall be ensured in the definition and implementation of all Community policies and activities.

Community action, which shall complement national policies, shall be directed towards improving public health, preventing human illness and diseases, and obviating sources of danger to human health. Such action shall cover the fight against the major health scourges, by promoting research into their causes, their transmission and their prevention, as well as health information and education.

The Community shall complement the Member States' action in reducing drugs-related health damage, including information and prevention.

Reference 21: *Knowing me Knowing you: Curriculum for our future.* (2002). ADHD Project funded by the European Commission: Third report. Denmark.

7. 1. Adult ADHD and social exclusion

In all aspects this report shows a need for immediate action. Due to the way our societies are organized people with ADHD are not able to fully obtain their human rights and they are socially excluded in several ways.

ADHD is a handicap that is “invisible” and other people see that they do not fulfil the expectations of reflected mature behaviour but have impairment in major life activities. They think they should be able to pull themselves together - like they are able to themselves - so through all there is a “moral component”, i.e. “they could if they would”.

Adults with ADHD are socially excluded at many levels. They do not have equal opportunities and access to all services, i.e. they are underachieving at work and in education and they are unemployed. Due to low self-esteem and different self perception they are excluding themselves and they are related to social outlaw groups. Too many adults with ADHD are involved in crime and substance abuse.

Adults with ADHD demand

- *an emphasis on ability instead of disability*
 - *the provision of active support measures*
 - *inclusion in mainstreaming society*
 - *independent decision making and taking responsibility on issues which concerns them*
 - *nothing about ADHD adults without ADHD adults*
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Reference 22: The public presentation of the European Citizens’ assessment report at the European Parliament. (2006, January). Meeting of Minds: European Citizens’ Deliberation on Brain Science. Brussels, Belgium. Retrieved March 2, 2006 from

http://www.meetingmindseurope.org/europe_default_site.aspx?SGREF=14&CREF=5440

Recommendations p. 12

- *We recommend implementing a lifelong method of providing education and information so that people are aware of diversity. Awareness should be raised amongst teachers, health care professionals and social workers about diversity during their training so that they can raise the awareness of the people they meet in their professional lives Public campaigns and TV programmes should be developed to provide people with better information to prevent stigmatisation. There need to be more experts whose fields are education and school psychology.*
- *People have to be able to participate in their conventional environments, where possible. When it is not possible to integrate, we should work on acceptance. Nevertheless, we need also to recognise and accept differences and not try to integrate at all costs.*

**ANNEX III. ORGANISATIONS INVOLVED IN ADHD-EUROPE
(18 COUNTRIES/27 ORGANISATIONS)**

COUNTRY	ORGANISATION
Austria	Verein-Adapt
Belgium	centrum ZitStil
Belgium	TDAH-Belgique
Belgium	AD/HD Family Support Group in Brussels
Belgium	English speaking adult adhd support group
Cyprus	ADD-ADHD SUPPORT
Danmark	ADHD-Foreningen
Finland	ADHD-association
France	Hypersupers
Germany	BVAD
Germany	BV-AH
Germany	Bv AUK
Germany	ADHS-Lichtblicke
Hungary	Positiv
Ireland	HADD
Ireland	INCADD
Italy	AIFA Onlus (Associazione Italiana Famiglie ADHD)
Luxemburg	SCAP (Service de Consultation et d'Aide Psychomotrice)
Malta	AD/HD Family Support Group
The Netherlands	Balans
The Netherlands	Impuls
Norway	ADHD-Foreningen
Poland	ADHD-association
Spain	Federacion Espanola de Asociaciones de Ayuda al Deficit de Atencion e Hiperactividad
Spain	Adana
Sweden	Attention Sweden
United Kingdom	ADDISS