

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. 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 Patient’s 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 Patient’s 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 it’s 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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