

Knowing Me, Knowing You

An ADHD Project funded by
the European Commission

CURRICULUM for our future



KNOWING ME, KNOWING YOU

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Foreword

This is the third report published by the project “Knowing Me, Knowing You”. The project started December 1st, 2000 and continues until the end of March 2002. Project partners are national associations in Denmark, the Netherlands, Finland, Sweden, United Kingdom. Norway is associated to the project on its own expense.

The European Commission, Employment and Social Affairs DG, has funded the project “Knowing Me, Knowing You” to identify the level and types of social exclusion associated with ADHD (Attention Deficit Hyperactivity Disorder) across Europe. The project will identify 1) all key national ADHD groups and organisations 2) the types of social exclusion and the extent to which it happens across Europe and 3) key resource needs of organisations to combat social exclusion at local, regional and national level.

The project will deliver three reports. The first is based on a mapping exercise - via questionnaire - of the situation across EU regarding people with ADHD. Parents views on the ideal way to diagnosis and early intervention is published in the second report. This third report is about adults with ADHD: How to unlock society’s knowledge for people with ADHD who are intelligent but often are excluded from employment opportunities and from taking part in activities which enable them to reach their potential for themselves and for the community’s in which they live.

The three reports are meant to be read independently of each other. Therefore the reader will find that the introduction to ADHD and the description of ADHD as a diverse and complex condition are repeated in each report.

In addition, an informal European “inter-active” support network for individuals with ADHD and their families has been set up: www.adhd-europe.org . At the site adults with ADHD as well as parents to a child with ADHD can provide and gather information about the situation in Europe. The website

provides the opportunity for individuals and professionals to communicate with each other and to learn from each other.

The ambition of the project "Knowing Me, Knowing You" - time and money considered - is huge. This has only been understood since the project started. None of the partner countries were aware of the diversity, complexity and the large number of Europeans affected by ADHD and the large number of local, regional and national organisations working with the condition.

Overall, the project will only scratch the surface. However, it is already becoming clear that the Mapping Exercise has generated a lot of interest on the part of many national organisations throughout Europe to work together and to establish more appropriate and more effective communication, co-operation and consistent action concerning ADHD across Europe in the future.

13 European nations were represented at the conference in Stockholm March 2002, adults with ADHD and professionals with special interest in ADHD. Each nation contributed with an overview of the current situation for adults with the condition in their country. There are differences between the nations but in many ways the situation is comparable across Europe. Hence the conference participants were able to identify areas of problems facing adults and to list how these adults are socially excluded, which this report will describe.

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1. Introduction

Children and adults with ADHD frequently experience social exclusion as society around them reacts negatively to their inability to understand the “social code”.

It is currently estimated that up to 5% of school age children are affected by ADHD. The majority of these children will experience problems adapting to the school environment and this may lead to educational underachievement. As a result, as many as 60% of these children will find it difficult to find, and sustain, paid employment after leaving school.

This situation is characterised by huge gaps in knowledge and awareness across the EU on the part of the general public at large, but also by groups and associations of people with ADHD regarding who and what exists elsewhere in the EU.

2. ADHD - A diverse and complex condition

Most countries in Europe have (more or less) adapted the American concept ADHD (Attention-Deficit/Hyperactivity Disorder) since this is the most common pattern of disabilities found and is increasingly the most familiar diagnostic concept. ADHD is characterised by overactivity, impulsivity, impatience and poorly managed attention in consistency.

The syndrome can be caused by several different pathologies, among which a genetic susceptibility seems to be the most common.

The diagnostic features are:

- Inattentiveness - very short attention span, overfrequent changes of activity
- Overactivity - excessive movements, especially in situations expecting calmness such as classrooms or mealtimes
- Impulsiveness - affected person will not wait his/her turn, acts without thinking, thoughtless rulebreaking

The symptoms and characteristics of ADHD have been known for more than 100 years. Still knowledge and understanding of ADHD remains patchy and numerous professionals disagree about the condition. Several claims that ADHD is purely a social stigma applied for a child who is difficult.

People and parents who is living with ADHD and their organisations know that the reality is that ADHD is a diverse and complex condition. It affects children and adults, it is handicapping, and has a significant and oftendetrimental impact on child and adult development and family relationship. It requires a multidisciplinary perspective and a multimodal approach to its treatment.

ADHD is caused by interplay between genetic and environmental factors, with the genetic factors being most important. The questions not yet answered are: How does a certain genetic endowment cause ADHD and under which circumstances? and: What environmental influences will prevent the development of ADHD? (Page 24 in Attention Deficit/ Hyperkinetic Disorders: Their diagnosis and treatment with Stimulant. Council of Europe, March 2000).

ADHD is not a benign disorder. For those it afflicts ADHD can cause devastating problems. Follow-up studies of clinical samples suggest that sufferers are far more likely than normal people to drop out of school (32-40%), to rarely complete college (5-10%), to have few or no friends (50-70%), to under perform at work (70-80%), to engage in antisocial activities (40-50%), and to use tobacco or illicit drugs more than normal. Moreover, children growing up with ADHD are more likely to experience teen pregnancy

(40%) and sexually transmitted diseases (16%), to speed excessively and have multiple car accidents, to experience depression (20-30%) and personality disorders (18-25%) as adults, and in hundreds of other ways mismanage and endanger their lives.

3. Conference in Stockholm – Curriculum for our future

The aim for the conference was to engage adults with ADHD themselves and professionals to develop visions for the future - embracing the testimonies and the experiences of consumers with innovative practice and commitment of motivated professionals.

Each country could nominate 2 participants; one adult with ADHD and one professional. In countries with more than one organisation or group a common decision was preferred. In case of disagreement the project leader had the final decision.

To be nominated participants should meet some criteria:

- a strong interest in changing attitudes and services regarding ADHD
- respect for different opinions
- knowledge and opinions to express
- speak and understand English

Adults with ADHD

- own diagnosis

Professionals

- appropriate knowledge of adults with ADHD
- professionally work with adults with ADHD

The conference was attended by 32 participants representing 13 different nations. 14 persons participated as adults with ADHD, 12 as professionals working with adults and 6 persons represented the project partners.

Conference agenda:

- Presentation of the current situation concerning adults in each country
- Identification of main areas of problems facing adults
- How and why are adults with ADHD socially excluded

4. Presentation of the current situation

"It's not good – but there is hope" seems to be the headline of the situation for adults with ADHD across Europe.

All speakers mentioned:

- low/no awareness – low/no recognition on ADHD in adults in society and among professionals such as adult psychiatrists
- low/no research – lack of facts and figures
- no common criteria for the condition – different names
- lack of policy and guidelines for diagnosis and treatment

Other topics mentioned:

- adults with ADHD need support to succeed in education and in workplaces, but they are seldom supported
- lack of special housing to adolescents and adults, who cannot manage to live alone
- professionals working with substance abuse do not recognize ADHD in clients
- the connection between ADHD and crime is neglected
- women with ADHD are at high risk to be misunderstood and therefore receive wrong or no treatment

- medication such as stimulant treatment is restricted or forbidden
- media debate often contributes to misinformation and a negative image of ADHD

4.1 Excerpt from the national reports

We have chosen to let the participants use their own words in describing the national situation and pass on excerpts from their reports.

Austria

Constance Bruckner, Verein ADAPT, Austria

Situation Of Diagnosis and Treatment of ADHD Adults in Austria

"It is not good. But there is hope"

(...)

How adults with ADHD obtain help.

The approaches to help seem to take one of two ways.

I am told at the meetings of adults with ADHD:

The parents, upon receiving the diagnosis and subsequent reading of information on the topic become aware that they too have had this problem.

Upon approaching the paediatricians or psychiatrists treating their children and asking about treatment for themselves, many are told that it is merely a disorder of childhood.

If they were lucky and the doctor had some knowledge or was willing to be informed by them that this was not the case, then they might be referred to a psychologist who often in turn has never heard of the term ADHD or if yes is of the same opinion as many, that if there is no hyperactivity then it cannot be diagnosed as such and all other symptoms the patient mentions at the initial interview are a result of other disorders. Often depression or bipolar disorder are cited as a more likely possibility, sometimes schizophrenia and in some cases, unfortunately, medication for these illnesses are prescribed.

Prescription of methylphenidate for adults is not foreseen in the Austrian manual for doctors unless there is a diagnosis of narcolepsy or depression. If the parent is supremely lucky the paediatrician will prescribe an extra amount of medication for the child and recommend that the patient selfmedicate.

Young adults and older adults who suspect, after reading an article or hearing about it in the media, that they might have continuing symptoms as adults and begin a search for diagnosis and treatment on their own (many times they have already gone several rounds of failed psychotherapy and alternative medication), end up with the final “aha effect” of finally knowing what it is that they have had all their lives and are relieved to find that they are not alone and are happy to have a vast source of information that we can offer them.
(...)

Belgium

Phillipe Lenares

ADHD in adulthood – current view on the Belgian situation...

Although Kohen and Cahn described a group of adults with ‘organic drivenness’ even in 1934, the world of mental health and psychiatric intervention is not recognizing ADHD as a disorder persisting in adulthood even not today.

Three major concerns are worthwhile building this paper upon:

- ADHD if not seen in childhood is seldom recognized nor as a separate neither as a underlying mental condition or disorder: a call for clear diagnosis!
- There is a great lack of professional aid for adults with ADHD: a call for intervention!
- There is no research done concerning the topic of adults with ADHD: a call for knowledge!

(...)

Denmark

Inge Beese, Psychologist

Main topics concerning adults with DAMP/ADHD in Denmark

In Denmark we use the concept DAMP as known from Professor Gillberg. DAMP means Deficits in Attention, Motor control and Perception, it is almost the same as ADHD + DCD (Developmental Coordination Disorder).

Generally there is an insecurity about the diagnosis as the ICD-10 does not include the terms DAMP/ADHD. Denmark has a so-called reference program concerning the criteria for DAMP in children, however as regards adults there is much insecurity and heterogeneity.

As DAMP/ADHD has been considered a development at disorder, a diagnosis made after the age of 18 will rather be considered a psychiatric disorder and the problems would be considered a kind of personality disorder. This means that only little attention is paid to the cognitive aspect as well as the difficulties that have been present while growing up.

Adult psychiatry knows too little about the difficulties which are the main problems. Knowledge is highly needed in this field.

Other important issues are:

- a) Who can diagnose? - is diagnosis made only within the medical system or is it also made and recognized within the social system if made by other professionals such as neuropsychologists?
- b) What tools are available for diagnosing? We do not have programmes until now, but we use some neuropsychological tests and scales. A translation of Tom Brown scales is under preparation just now.

- c) What is the purpose of a diagnosis? - naturally, first of all it serves to help the research in the field and improvement of the condition, but also to achieve means of support in everyday life - perhaps medication, perhaps therapy, perhaps assistance regarding education, work and housing. Perhaps - not the least - to improve understanding of other persons' way of thinking and acting.

To see and understand that DAMP/ADHD is not a matter of will, the result of a weak character, low moral standard or low intelligence, but it is a neurobiological disorder.

(...)

Finland

Matti Wallin, M.D. specialist in psychiatry

(...)

The situation today

- The awareness about ADHD among adult psychiatrists is slowly growing
- Psychostimulant prescriptions are increasing
- Currently, the number of adults treated with stimulants is bigger than that of children and adolescents

Major obstacles

- Lack of knowledge, lack of training, prejudices
- ADHD is thought of as a "fad", a fashion disease, not existing in adults
- Psychostimulants are considered dangerous

What to do?

- A national ADHD project should be launched and guidelines for diagnosing and treating ADHD developed
- Training for personnel in health, social and education sectors
- Increasing awareness among ADHD persons and their relatives, and among the general public
- Developing effective psychosocial treatments: peer support or selfhelp groups

Germany

Esther Rodhe-Köttelwesch, Psychologist

Problems of ADHD adults in the past and right now in Germany:

1. no awareness of ADHD adults. There is about a 6-11% of ADHD population. Kids are better supported and help provided than adults in diagnosis, therapy and medication.
2. little knowledge of diagnosis, less people are diagnosed, many fail diagnoses by professionals, many self-diagnosis by Internet, or misunderstanding because other psychiatric disorders are given because of misinterpretation and less knowledge about ADHD in adults
3. no health service providence - less therapy possibilities
4. no directions or knowledge about medication and doses
5. few research in ADHD adults and their problems
6. social exclusion because of:
 - a) attention deficit
 - b) behavioural problems like bad frustration management, impulsive reaction and restlessness which leads to:
 - underachievement in school/education
 - under-employment
 - unemployment
 - often job changes
 - difficult relationships in family and friends
 - bad time management
 - structurless and struggle with everyday routine
 - suffering
 - drug abuse
 - belonging to criminal subgroups
 - crime/prison
 - early pregnancy

What measures are taken and support adults with ADHD:
none!

(...)

Iceland

Ingibjörg Karlsdóttir, Social worker

The current situation concerning adults with ADHD and ADD in Iceland

(...)

Since the Parents Association is concerned as well about the situation of adults with ADHD it was decided that we would participate in this conference. Unfortunately there is not much to tell about what is happening in Iceland around the issue of adults with ADHD.

There are only a few professionals mostly psychiatrists who do tests on adults to diagnose whether one has ADHD or ADD. A family counsellor who studied in the USA is doing different kinds of tests to diagnose people who suspect they have ADHD and is also offering further treatment. This family counsellor uses the 12 steps system of the AA association in his work with adults with ADHD and ADD.

(...)

Italy

Sara Pezzica, Psychologist

ADHD in Italy

(...)

In Italy (as in other countries) the proposal of ADHD diagnosis gave rise to criticism and resistance. Social critics claimed that professionals have been too quick to label energetic and exuberant children as having a mental disorder and in 1978 published the Italian translation of "The myth of hyperactive child". In this book the authors stressed the role of high conforming cultures: hyperactive behaviour arises only when compared to our cultural models.

Furthermore some psychologists and psychiatrists considered it unsatisfactory to classify broad characteristics of personality as a unitary typology based on behavioural symptoms. Nonetheless, other clinicians recognized the importance of a diagnostic frame to canalise resources in the research and treatment of ADHD. In 1989 “Attention Disorder and hyperactivity”, a cognitive-behavioural approach to the disorder was translated. At the present, several studies are focusing on the neuropsychological assessment of ADHD, cognitive-behavioural treatments are set for children and parents and schools are usually involved to manage the disorder. In 1996 Marzocchi G.M., Cornoldi C. and others formed the Italian Association for Attention Deficit Hyperactivity Disorder (A.I.D.A.I. Onlus). Since then, information on ADHD has been more readily available for clinicians, educators and families. (...)

The Netherlands

Regina van Crieking, Balans

(...)

Present:

Specials for adults.

Network of psychiatrists, who have attended extra courses for the diagnoses of adults with ADHD.

We participated as advisers for:

- Care program; the development of guidelines and regulations for the treatment of adults with ADHD. This program will be used at the Regional Ambulatory Health Care Centers.
- Training for companion's of support – and discussion groups.
- National research and advising center to the Government, for the development of a brochure for adults with ADHD.
- Home care organisation

Companion in distress care:

- Support groups, Discussion groups and ADHD café's

Publications:

- Book "In kort bestek" and a special edition of the magazine "Adults with ADHD".

Future:

With our future planning we would like to achieve the following aims:

- Promoting a positive image of people with ADHD. Regardless the sometimes very problematic situations of adults with ADHD, also small or big successes are made.
- Public health assures; involving them in the (financial) support of the services like support-, discussion-, therapy groups for adults and their family.
- Promoting the interests of our member, adults and their families;
 - Unemployment offices
 - Reintegration offices
 - Support systems
 - Barristers / Lawyers
 - Health care workers
- Highlighting the special challenges that women with ADHD face, in their personal lives and as mothers of sometimes demanding family situations.

The ultimate aim of our organisation is to achieve that the needs and interests of our members are guaranteed in the law and regulations of the national health care system and the community in general. It is obvious that we still have a long way to go, but we are working on it.

Norway

Michael B. Lenzing, Special educator

Preliminary Results from a National Study on Hyperkinetic Disorder/ADHD in Adults in Norway

Abstract: It is well known that Hyperkinetic Disorder/ADHD endures into adulthood, but the prevalence of the disorder in adults is still

uncertain. In Norway, the central stimulants methylphenidate and amphetamine are on the national list of prohibited narcotic drugs, and hence adults with HD/ADHD could not be treated with them. After a private proposal of a member in the Norwegian Parliament and a unanimously voted proposition in the Parliament, the Health Authorities in 1997 decided to open up for the treatment with stimulant medication for adults with HD/ADHD. The National Board of Health (NBH) designed guidelines for diagnosing and treating this group of patients. The NBH erected 3 competence teams located in Oslo, Bergen and Trondheim. The teams should secure safe use of central stimulants. All members in the competence teams work part time.

The Oslo team decided to run an outpatient clinic, where we until now have examined approximately 150 patients. The NBH asked the teams to design a follow up study with the purpose of collecting data from all patients being treated for at least 2 years with the stimulant medication. In March 2000 the first evaluation was presented.

(...)

Preliminary conclusions: During a period of 3 years the total number of referrals is lower than expected. There is a regional difference regarding number of referrals. The sex distribution (4:1) is somewhat surprising. Many patients have not been able to establish an appropriate relationship with a medical specialist. There is a great number of discontinuation during a treatment period of 24 months.

Spain

Angela Magaz, Psychologist

Most of the adults with ADHD in Spain who know that they have this disorder is because they have children with ADHD or through self-diagnosis after having read about it. As there are many adults without diagnosis, they can be suffering the effect of not

having been diagnosed in their childhood with consequent deficiencies in social skills, anxiety problems, lack of education and training, excess of self-criticism,... This may be the reason why in Spain, as in most other countries, we are making a big effort to diagnose early ADHD in order to reduce these situations in the future.

The psychosocial problems in adults with ADHD could be prevented if they and the people around them recognized the characteristics, especially the relationship conflict in couples and in the working environment.

(...)

Sweden

Kjell Modigh, Psychiatrist

Since ADHD has received considerable attention in the media during the last years the awareness of the disorder is probably rather high among people in general. Therefore and since more young adults have been diagnosed during their childhood, a gradually increasing number of adults realize that they have or might have ADHD and ask for help in the psychiatric units.

A few teams for adults with ADHD and other neuropsychiatric disorders have been built up in connection to psychiatric clinics. In addition a unit has started in Göteborg, initiated by professor Christopher Gillberg and supported by a national fund. The few existing teams are overloaded. Patients may have to wait for years, in order to get access to them. At present, however, several more psychiatric clinics are starting or planning such units. Hopefully a majority of the adult psychiatric clinics in Sweden will have developed sufficient neuropsychiatric competence in the near future.

Since a few years, central stimulants can be prescribed to adults with ADHD, after individual permissions from the Swedish drug authority (Läkemedlsverket). Till now a few hundred such licenses

have been given – a very low figure of course, in relation to the number of potential patients.

The many treatment centers for substance use disorders have been even slower than the general psychiatry to incorporate ADHD in their theoretical frames, in spite of the fact that a considerable number of their clients have the disorder. There are however a few hopeful signs of increasing awareness. The same holds true for the prison and probation service. These authorities now recognize, what is known from several studies, that neuropsychiatric disorders (in combination with personality disorders and substance abuse) are highly overrepresented among their clients and the ambition seems to be to focus more on the treatment and (re)habilitation aspects. The awareness of ADHD is also increasing among social workers. (...)

Switzerland

Udo Sollberger

Problems and Key Issues in Switzerland

Awareness

The awareness of the existence of ADHD is generally low. In about 50% of the cases the parents of children with ADHD have difficulties finding recognition of their children's ADHD and support from the education community and even from school psychiatrists and education counsellors. This situation is now slowly improving.

The situation is a lot worse for adult ADHD. There are very few psychiatrists and therapists knowledgeable about adult ADHD. Those that know about it resist dealing with it themselves and refer the patients to the few known professionals that diagnose and treat adults with ADHD. From adults diagnosed with ADHD we have many reports of a series of misdiagnoses and mistreatment prior to the proper diagnosis.

Naming

ADHD in Switzerland is widely known as POS – Psycho-Organic

Syndrome. This causes a big problem with adults, as adult POS is a completely different degenerative disease of the brain in old age.

Official Acceptance

There are just a few single cases where adult ADHD has led to a pension for invalidity from the social insurance. In these cases ADHD was stated as a co-condition with the main condition being depression, dependency or others. ADHD is currently not accepted as a condition justifying disability pension.

Ritalin Criticism

Among parents of ADHD children and adults with ADHD there is a fairly big resistance towards treatment with Ritalin and other stimulant medication. Some alternative treatments are propagated that lack proof of effectiveness. On the other side, we have reports from family physicians prescribing Ritalin without proper diagnosis or additional behavioural treatment.

(...)

Doris Ryffel, Psychiatrist and Psychotherapist

The key problem in Switzerland is the lacking awareness of ADHD in adults. The general public, the media, even the majority of professionals, psychiatrists and psychologists are, so far, not willing to accept the facts and recognize ADHD in adults as a legitimate disorder. The consequences are obvious, the mildly affected may be regarded as having just "normal" difficulties. The more deeply affected undergo years of therapies getting nowhere as to the origin of their difficulties nor solving their problems. There is no understanding for the self-doubts, depressive and anxiety reactions of these affected individuals. Those who get themselves involved in criminal activities because of their uncontrollable impulsive behaviour end up with no adequate treatment. The same can be said about ADHD adults with substance abuse problems.

(...)

United Kingdom

PVF Cosgrove, Psychiatrist

The problems in the UK

- (1) Adult Psychiatrists do not accept that ADHD occurs in adults;
- (2) The Psychiatrist, in the only adult ADHD clinic in the National Health Service, believes that only 8% of children take their ADHD into adulthood (compared to the increasingly accepted range of 25% - 50%);
- (3) Adult Psychiatrists are “phobic” about using DOPAMINERGICS (also known as NORMALISERS);
- (4) Psychiatrists in the UK are imprisoned by the recommendations of a drug's product licence and, as a consequence, are led by the marketing behaviour of the pharmaceutical industry, which has no licences for Dopaminergics (Normalisers) to be used in adults;
- (5) Medical Education does not teach the Psychopharmacology of Childhood-Onset Disorder;
- (6) Child & Adult Psychiatrists do not talk to each other;
- (7) The fear amongst all types of psychiatrist of being disciplined, suspended and then sacked (no longer employed) by the NHS managers, who are themselves concerned about doing the right thing rather than supporting advances in mental health care;
- (8) The impossibility of getting referred to and seen by competent help on the state monopoly of the National Health Service;
- (9) Private psychiatry is minimal in the UK.
- (...)

The urgent needs and challenges for the future

- (1) To educate adult psychiatrists regarding the reality of Adult ADHD and the safe and effective use of the Dopaminergics (Normalisers);
- (2) To inform the citizens so that they can put informed pressure on the doctors and psychiatrists they meet;
- (3) To arrange conferences, meetings, email discussion forums etc. where child psychiatrists & psychologists discuss ADHD with adult psychiatrists & psychologists;

- (4) To involve drug companies with the arrangement of conferences etc., so that they are encouraged to reapply for new product licences for the use of Dopaminergics (Normalisers) in adults, and in the treatment of anxiety and of depression in adults;
- (5) To provoke discussion with governments and relevant authorities regarding the link between ADHD and crime, and regarding the evidence that Personality Disorder is none other than unrecognized Adult ADHD;
- (6) To set up a screening process in schools for the combination of aggression & hyperactivity in children aged between 4-8 years of age, and to involve the police in this because of the link with later crime;
- (7) To develop a register of all suicided people, who have been considered by relatives, friends etc. to have suffered from ADHD at any time in their lives, with the intention of making enquiries regarding the professional conduct of psychiatrists and psychologists (both adult & child), who have been in contact with those on the Register - by reason of suicide.

5. Problems facing adults with ADHD

For the 2 remaining topics on the agenda the participants were divided into 4 working groups. Two groups had members living with ADHD, and two groups had members working with the condition. A few participants could belong to both groups, they were asked to pick their own choice. Each group elected a chairperson, a secretary and some one to feedback to plenary. After group sessions the results of the discussions were presented on paper sheets and open for comments from plenary.

First task for the work groups was

Identify and prioritise 6 main areas of problems facing adults with ADHD.

Work groups of people working with the condition focused on

- lack of awareness of ADHD
- lack of joined definition of ADHD in adults
- lack of guidelines for diagnosis
- need for training of professionals
- need for availability of treatment, coaching and rehabilitation

Participants living with ADHD focused on

- lack of EU strategy plan how to have recognition
- lack of standardisation
- need for general awareness
- need for funding of scientific research
- need for an European alliance on ADHD, a network for all national groups sharing information
- financial support for self-help groups

Summary: both professionals and those living with ADHD identified the following main areas of problems

- awareness of ADHD as a neurobiological disorder
- diagnosis and treatment
- research
- professional education

Plenary session pointed strongly to the need of a European alliance as suggested several times.

Following the model: group work and later presentation and discussion in

6. ADHD and social exclusion

plenary the participants worked on the bullet point:

How and why does ADHD lead to social exclusion for adults?

The professionals pointed to the following reasons why:

ADHD adults do not fulfil the expectations of reflected mature behaviour, but have impairment in major life activities

They are socially excluded in several ways:

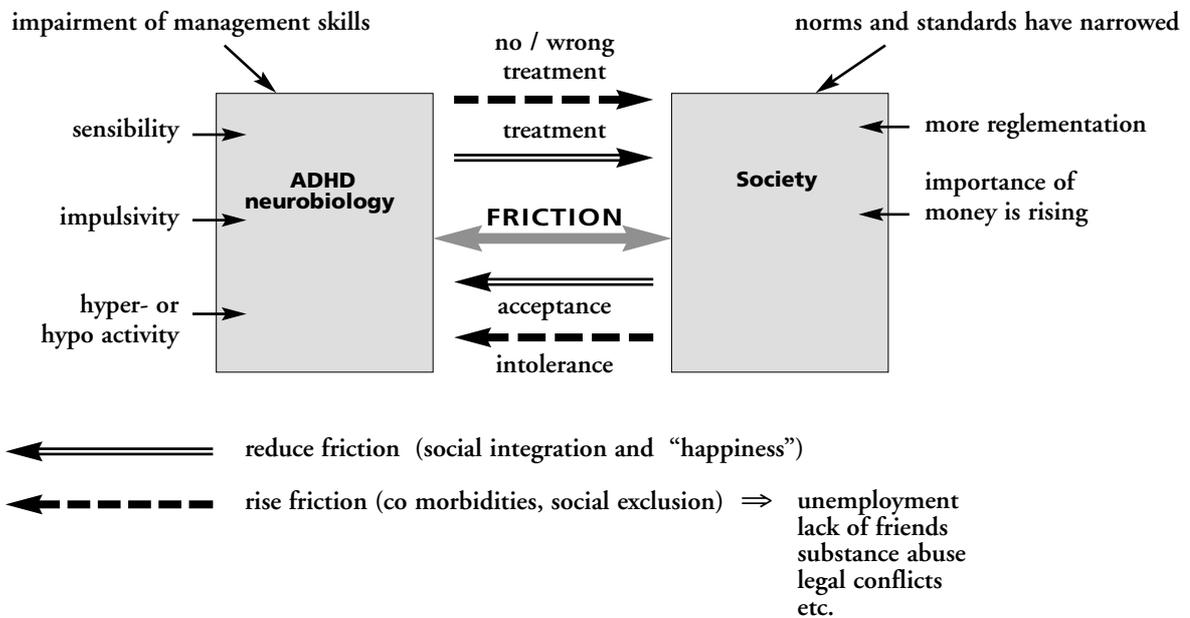
- Underachieving at work and in education
- Underemployed
- Related to social outlaw groups
- Offending behaviour
- Excluding themselves due to low self-esteem and different self perception
- Tendency to early pregnancy
- Involved in crimes
- Substance abuse

Conference participants living with ADHD pointed to following reasons why:

- gene pool
- socio-economical environment
- co morbid factors
- lack of structure
- inappropriate reactions
- self-medication ⇒ abuse ⇒ addiction
- due to low awareness of ADHD they will not find help

Through all is a "moral component" – and the question "why can't you" leads to low self-esteem.

One group made a figure that in an excellent way shows the complex interaction for adults with ADHD in society: there is a friction between norms of society and the behaviour of many adults with ADHD. Some issues rise friction, which leads to social exclusion. Other issues such as relevant treatment reduce friction.



Summary of the why and how: adults with ADHD do not fit societies demands to mature behaviour. Therefore they are reason is misunderstood, and they are looked upon in a moral way. Due to that adults with ADHD get no or wrong treatment and therefore are at high risk to get involved in crime, unemployment, substance abuse etc. – and the exclusion from social life is a fact.

7. Summary

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

7.2. ADHD - a legitimate disorder

To see and understand that ADHD is not a matter of will, the result of a weak character, low moral standard or low intelligence but a neuro-biological disorder - is the first step. Inge Beese, Denmark.

One very important issue for people living with ADHD and people working with ADHD is the need for increased awareness and acceptance of ADHD as a neurobiological disorder. An undersigned consortium of international scientists (January 2002) have stated the point that: "(...) as a matter of science, the notion that ADHD does not exist is simply wrong. All of the major medical associations and government health agencies recognize ADHD as a genuine disorder because the scientific evidence indication it so overwhelming".

7.3. ADHD - diagnosis and treatment

Which measures are taken to support adults with ADHD? None! Esther Rodhe-Köttelwesch, Germany

All citizens should have equal access and rights to diagnoses and treatment. This is not the case today for people suffering from ADHD.

ADHD is an American term. It is the most common pattern of disabilities found and it is increasingly the most familiar diagnostic concept in Europe too. Adoption of the term means adoption of the DSM-IV diagnostic criteria. In Europe the ICD-10 condition of Hyperkinetic Disorder (HD) has essentially the same symptom profile but requires more stringent criteria. Specific research has shown that the estimated prevalence of HD in children is about 1% and of ADHD about 3-5%. It is estimated that about 1% of the adult population still struggles with ADHD.

A process has started in Europe towards the use of ADHD. But we have to work on a common definition of ADHD in adults and guidelines and protocols which could have a strong positive influence on the quality of diagnosis and treatment. Professionals working in the field should be trained.

Psychiatrists and neurologist should support less specialised practitioners.

The need for treatment, coaching and rehabilitation is strong and the possibilities are very few.

7.4. Research

There is no research done concerning the topic of adults with ADHD: a call for knowledge. Philippe Lenares, Belgium.

Research is urgently needed to gather both quantitative and qualitative data on the way ADHD is diagnosed and treated. Especially studies of ADHD and adults need a higher priority with focus on the effects of different programmes of treatment. There should be “cost-effectiveness” studies on the effects of ADHD, treated and untreated, for the adult and his family and for the society as a whole (traffic accidents, unemployment, crime, addiction, teenage-pregnancy etc.)

A pan-European research project is needed. Facts and figures concerning adult ADHD is of vital importance if we are going to win the battle: Better general information and knowledge in society and - as a consequence - a different image of ADHD.

7.5. Action - the way forward

Adults living with ADHD or working with ADHD stressed that a European Alliance of national organisations for joined effort across Europe was urgently needed. And that proper funding of the alliance was crucial.