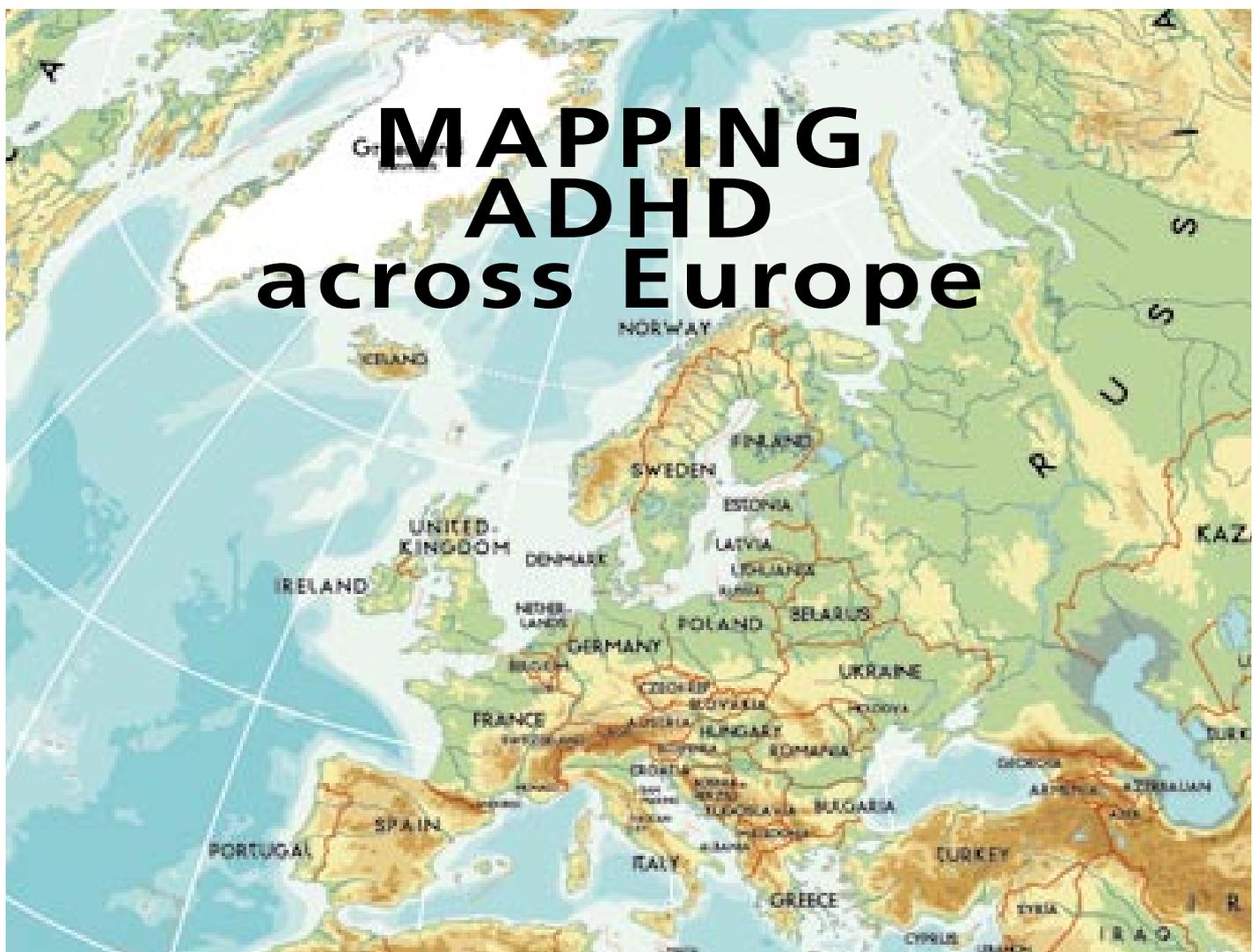


# Knowing Me, Knowing You

An ADHD Project funded by  
the European Commission



**KNOWING ME, KNOWING YOU**

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# Foreword

This is the first report published by the project “Knowing Me, Knowing You”. The project started December 1st, 2000 and ended March 2002 and is a collaboration between national associations in Denmark, the Netherlands, Finland, Sweden and United Kingdom. Norway is associated to the project on its own expense.

The European Commission, Employment and Social Affairs DG, has funded the “Knowing Me, Knowing You” project to identify the level and types of social exclusion associated with ADHD (Attention Deficit Hyperactivity Disorder) across Europe. The project will identify 1) key national ADHD groups and organisations 2) the extent and types of social exclusion 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. “Mapping ADHD across Europe” is the first and it 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. The 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](http://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.

This report: “Mapping ADHD across Europe” provides a first glance of the situation concerning ADHD across Europe. It gives information about how the ADHD organisations across Europe currently experience, understand and work with ADHD and matters concerning social exclusion. It is based on the analysis of the data of a questionnaire designed by the project and sent out to 17 European countries.

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.

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# 1. Introduction

Children and adults with ADHD frequently experience social exclusion as the society around them reacts negatively to their inability to understand and abide by the prevailing “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 may 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 about the size, diversity and complexity of ADHD and also about the diagnostic and treatment implications of such a complex condition. The level of understanding and resources required are misunderstood by the general public, groups and associations of people with ADHD and by professionals within the whole of the public and voluntary sector across Europe.

ADHD is possibly one of the most under diagnosed and under treated mental health conditions facing European children and adults. The cost of not diagnosing and treating ADHD can be very expensive in terms of reduced quality of life and can also lead to a very large financial burden for the community and society as a whole. The early identification, diagnosis and treatment of ADHD can prevent: family breakdown, exclusion from school, isolation from the community, entry into anti-social lifestyles and behaviours, involvement in crime, substance and alcohol abuse, unemployment and long term benefit claims. A strategic preventative approach could substantially reduce the very expensive lifetime cost of ADHD which can include such costs as: alternative expensive schooling, police and probation services, courts and prison services.

## 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 over-activity, impulsivity, impatience and poorly managed consistent focus of attention.

ADHD can be caused by several different pathologies, amongst which a genetic susceptibility seems to be the most common.

The diagnostic features are:

- Inattentiveness - very short attention span, over-frequent changes of activity
- Over-activity - 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 rule-breaking

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 have been made that ADHD is purely a social stigma applied to a child who is difficult. However, overwhelming professional views and research points to ADHD being a genetically inherited neurobiological brain dysfunction.

People and parents who are living with ADHD and groups and organisations working with ADHD are aware that the reality is that ADHD is a diverse and complex condition which can have a detrimental impact on child and adult development and family relationships. It requires early diagnosis and a multi-modal holistic treatment programme to meet the needs of the individual.

ADHD is characterised by an 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 in 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).

### 3.

## The first challenge: An overview of the ADHD-organisations

The first challenge for the project was to provide an overview of the European ADHD organisations working with ADHD. In recognition of the role of organisations working with persons with a disability - Rule 18 of the United Nations Standard Rules on the Equalisation of opportunities for persons with disabilities say's:

*“States should recognise the rights of organisations of persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognise the advisory role of organisations of persons with disabilities in decision-making on disability matters”*

The “Knowing Me, Knowing You” project started from scratch. It is truly a pioneering piece of work which has never been attempted before and mapping the whereabouts of organisations working with ADHD across Europe is the first important step. Each of the partners helped to locate ADHD groups and organisations across Europe. The information gathered was entered into a European Mapping ADHD Contacts database. This represents the very first overview of the European ADHD organisations. None of the partners actually expected there to be so many ADHD groups and organisations across Europe.

The list of groups and organisations can be seen at the website connected with the European Interactive Support Network for individuals and families affected by ADHD [www.adhd-europe.org](http://www.adhd-europe.org)

It has been important to the project to gather information about the national ADHD organisations in Europe. Knowing each other is the basis for the

necessary future European co-operation. Such co-operation is necessary to develop and implement common European diagnostic criteria, legislation and public sector policy and guidelines for the treatment of ADHD.

### **3.1. Different diagnosis/names**

One of the difficulties surrounding this condition and the mapping exercise is that the organisations do not use the same term, and that the term ADHD is not always found in the name of the organisation. Terms used by European groups and organisations include:

- ADHD (Attention Deficit Hyperactivity Disorder)
- HS (Hyperkinetic Syndrome)
- ADS (Aufmerksamkeitsdefizitstörung)
- DAMP (Deficits in Attention, Motor Control and Perception)
- MBD (Minimal Brain Dysfunction)
- Aufmerksamkeitsdefizit Syndrom mit/ohne Hyperaktivitaet
- Dysfonctionnement neuropsychologiques
- Etc

European diagnosis is based on the 10th edition of International Classification of Diseases (World Health Organisation, 1992) which only mentions Hyperkinetic Disorder. The American classification system DSV-IV diagnostic criteria is used for ADHD.

### **3.2. Different traditions**

In the Scandinavian countries it is common that there is one national organisation for each specific condition group. New groups start out and then organise themselves into national organisations. In some countries - such as UK - several support groups have worked for many years independently and they are now trying to establish the ADHD National Alliance. However, some groups would prefer to remain alone and work at their local level. In Germany there are several national organisations that are now trying to establish an umbrella organisation. In other European countries - such as Belgium - one will find several organisations/groups due to language differ-

ences (English speaking, French speaking, Dutch speaking). In other countries - Greece and Portugal - we have not been able to find organisations or groups. One will also find that the ADHD problem has been integrated with other related handicaps (ECIC in Belgium and Balans in The Netherlands for children with learning difficulties).

## 4. The questionnaire

The first part of the questionnaire deals with information about the organisation/group. The second part is focusing on social exclusion. Finally there is room for the organisation to include any comment they consider relevant.

The questionnaire was sent to all organisations on the list. 14 countries have returned the questionnaire: Austria, Belgium, Denmark, England/UK, Finland, France, Germany, Italy, The Netherlands, Northern Ireland/UK, Norway, Spain, Sweden, Wales/UK.

17 questionnaires came back.

The following organisations have returned the questionnaire:

|  |                 |
|--|-----------------|
| The ADHD National Alliance               | England/UK      |
| Verein Adapt                             | Austria         |
| Ouderwerkgroep "Zit Stil" vzw            | Belgium         |
| European Children in Crisis asbi         | Belgium         |
| ADHD Support Group<br>(English speaking) | Belgium         |
| DAMP-foreningen                          | Denmark         |
| The Finnish association for MBD          | Finland         |
| Coridys                                  | France          |
| BV-AÜK                                   | Germany         |
| AIDAI                                    | Italy           |
| Gruppo di Cavoro ADHD<br>(GL-ADHD)       | Italy           |
| Balans                                   | The Netherlands |
| ADHD-foreningen                          | Norway          |

|                                |                     |
|--------------------------------|---------------------|
| The ADHD National Alliance     | Northern Ireland/UK |
| Fundación Privada Adana        | Spain               |
| National Association Attention | Sweden              |
| West Glamorgan & West Wales    |                     |
| ADHD Family Support Group -    | Wales/UK            |

Not all of the participating organisations/groups are national, nevertheless, all answers have been included.

## 5. The European ADHD-organisations

Fourteen of the organisations are national, two are local and one is a European voluntary organisation. The oldest was founded in 1975 and the newest was founded in 2001. Six were founded in 1999 or later.

The number of members ranges from 11 (group) to 20.500 (association also for learning disabilities). In the Scandinavian countries the number of members is between 2000-3000.

Three organisations have not answered the funding question. All other organisations have membership fees. For the majority of organisations membership fees in percentage of the total amount of financing the organisation/group is 10% or below. However for four organisations the percentage is between 60-80%.

National Government funding in percentage of the total amount of financing the group/ organisation:

- 5 organisations receive no national Government funding
- 3 organisations receive between 24-25 %
- 2 organisations receive between 40-45 %
- 1 organisation receive 60%
- 3 organisations receive 80%

Key objectives can be gathered in the following headlines:

- supporting people with ADHD and their families
- raising awareness
- influencing policy
- providing information

Fourteen of the organisations have newsletters, eleven have fact-sheets, specific publications, training and counselling. Twelve arrange conferences. Services are provided for adults, families, professionals, social services departments, education departments and schools and health services. No organisations have specific services for ethnic groups. One organisation has specific services (seminars) for males and females.

All of the organisations want to expand their work in accordance with their key objectives. Many especially want to work with adults with ADHD. Several want more international collaboration regarding diagnosis and research and they would also like to work within a European-wide dimension.

All groups and organisations are in need of more resources. In order to expand, it is essential for them to attract capital and revenue funding from Government or EU-funding to meet their aims and objectives. Also to build and maintain links with other ADHD groups and organisations across Europe.

## 6. Social exclusion

The second part of the questionnaire gathered information about social exclusion and ADHD across Europe. The purpose is to gather specific information about ADHD and how it relates to social exclusion of children, families and adults in the different countries.

## 6.1. Types of social exclusion and ADHD

Children, adults and families can be excluded from society in a variety of ways and this can lead to involvement in a range of anti social lifestyles and behaviours. In the questionnaire it was possible to answer “very little”, “sometimes” or “often” to the questions about social exclusions. The answers were as follows:

### **Children**

#### **Pre-school**

The general picture is that children with ADHD “sometimes” or “often” are excluded from pre-school groups. This appears to be underpinned by the lack of understanding of ADHD for pre-school staff, which can lead to children becoming temporarily and/or permanently excluded due to “bad” behaviour resulting from their hyperactivity, impulsivity and inattention.

#### **School**

Most of the organisations said that children with ADHD are “sometimes” and “often” are excluded from school. Special needs/tuition is very common, but home tuition is seldom offered.

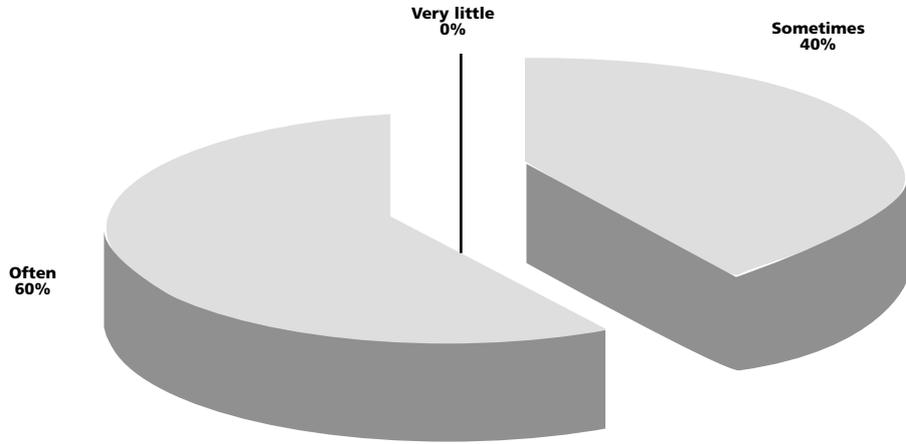
### **Adults**

Estimates, regarding the prevalence of ADHD amongst adults, vary across Europe. Many organisations believe that most children with ADHD continue to have the condition throughout their lives. Whilst no factual data exist, many ADHD groups and organisations are concerned that there are high numbers of undiagnosed and untreated adults in all European countries. It is clear that there are very few or no specialists in ADHD in adults. The respondents were concerned about adults who have ADHD.

#### **Labour**

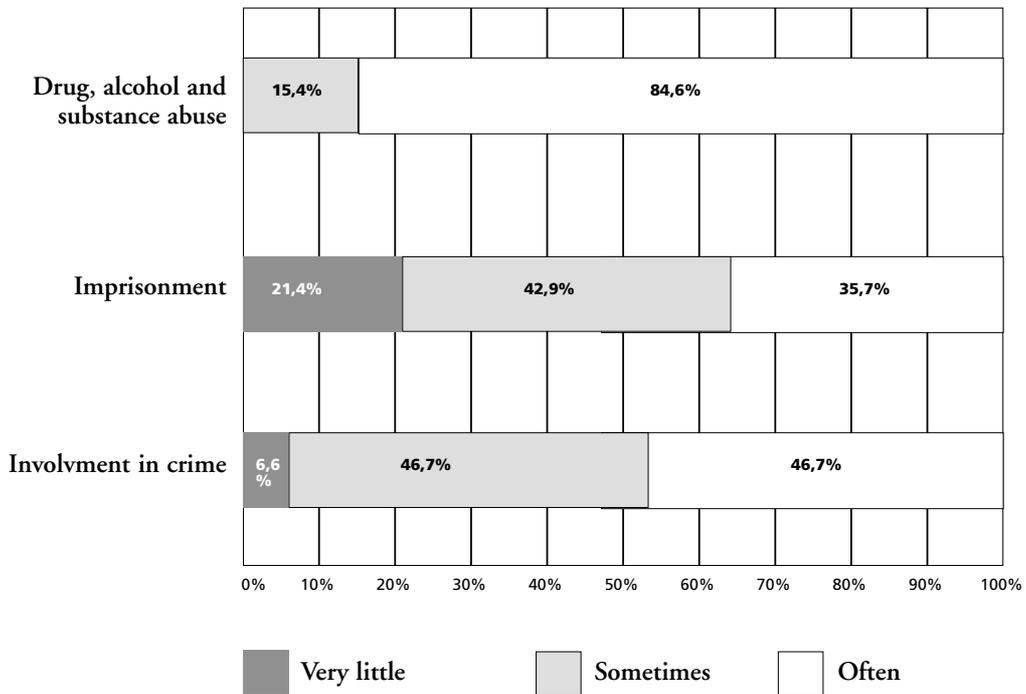
Unemployment and failure to reach full potential is very high. Everybody has answered “sometimes/often”.

### Unemployment



### Increased risk of anti-social lifestyle and behaviour

About 85% find that people with ADHD are “sometimes” or “very much” at risk of drug, alcohol and substance abuse. This is a high risk, but research outcomes point to different kinds of abuse being common amongst adults with ADHD.



The reasons why 21,4 % say “very little” to increased risk of imprisonment against only 6,7% saying “very little” to increased risk of involvement in crime could be that crime connected with abuse often is not leading to imprisonment. Or maybe the courts take ADHD into consideration so people with ADHD are punished in other ways. It is beyond this mapping exercise to answer that question.

### Stigmatism and homelessness

The picture is muddy, as some organisations say “often”, some “sometimes” and others “very little”. It might be that this kind of exclusion is very much depending on the social security system in the different countries. But taken into consideration that adults with ADHD are often not able to handle money, the handicap itself indicates a higher risk for stigmatism and homelessness.

## 6.2. Knowledge of ADHD

The organisations were asked to give a percentage to indicate *the extent of acknowledgement of ADHD as a disability*. The answers do not lead to a clear picture of the acknowledgement of ADHD in Europe.

The average percentage is 32,7%. The lowest is 1-2% and the highest is 75%. Most of the answers are in the interval 25-33%.

If one looks at the geographical differences the picture is

|   |       |
|---|-------|
| Scandinavia (DK, S, F & N)                      | 58,3% |
| Mid- and Centraleurope<br>(A, G, B, F, UK & NL) | 29,2% |
| The south of Europe (ES & I)                    | 17,3% |

What percentage of the *general public are aware of ADHD as a disability*? The organisations find that the general public know something about ADHD in children. As a whole the general public in the different countries do not know, that the children do not necessarily grow out of it. And that this together with a general lack of professional agreement about the size and diversity leads to a big problem in terms of countries recognising ADHD in adults and subsequently providing diagnostic and treatment services.

What percentage of *different kinds of professionals* acknowledge ADHD as a disability? The answers vary a lot so instead of the figures we will mention some of the remarks:

- my answers are more or less qualified guessing
- cannot define percentage

- it varies very considerably - service provision for parents is a lottery
- ADHD is scarcely recognised as such in this country. The symptoms are attributed to family problems

### 6.3. Diagnosis of ADHD

The estimated percentage of school age children who have ADHD is between 3 and 5%. Except for one organisation with 20-30% and another with 5-10%.

When it comes to adults the estimated percentage is 1-2%.

The given answers about children are all based on international reports and studies mostly from USA and Canada and for the Scandinavian countries on several population based investigations from Sweden and Norway. Several organisations answer: "There are no statistics on ADHD in..." or "estimated - no data". As for adults there are no investigations in Europe according to the organisations and the estimated percentage is based on international literature.

In order of priority children are most often diagnosed by psychiatrists. 3 organisations say psychologists and 2 paediatricians. All organisations but one find that psychiatrists are responsible for diagnosing adults. 1 says neurologists.

The average age of children being diagnosed ADHD is between 5-10 years. Very few children are diagnosed at the age of 0-4 at in the age from 19 to 25 or later than that. Almost all of the organisations believe that ADHD should be diagnosed as early as possible and before school entry. Many of the children can be recognized even earlier so the child's behavior can be understood and the parent-child interaction can be supported.

The organisations were asked what other related conditions are most commonly coexisting with ADHD. The answers are in order of priority:

1. Dyslexia
2. Learning Disabilities
3. Anxiety
4. Oppositional Defiant Disorder
5. Conduct Disorder
6. Tourettes Syndrome
7. Depression
8. Aspergers
9. Obsessive Compulsive Disorder
9. Dysphasia
10. Bipolar Disorder

And furthermore: Borderline Personality Disorder Symptoms, Attachment Disorder, Allergic Reaction, Fatal Alcohol Syndrome, Syndrome of von Recklinghausen, Pervasive Development Disorders/Autism Spectrum Disease, Fragile X Syndrome, Syndrome of Marfan, Syndrome of Williams.

## 6.4. Treatment

About the existing treatments of children different kinds of therapy are mentioned (Behavioural, occupational, cognitive, psychotherapy). Information to parents and teachers, parent management training/school teacher training and school intervention is also mentioned by many. Medication (Ritalin) is given by up to 75% organisations.

For adults the answers are even more difficult to gather and compare. Many organisations have chosen not to answer the questions. One organisation mean that medication is the treatment for 90% and behavioural therapy 10%. Another organisation says 98% psychotherapy and 2% medication.

## 6.5. National policy concerning ADHD

The overall answer is a big NO to the question about a national policy concerning ADHD. Only the Netherlands is different. A report from the Health Council of the Netherlands: Diagnosis and treatment of ADHD was pub-

lished in 2000. It has meant that a lot of study groups, conferences and guideline committees were set up.

## 7. Making change happening

This is the first report from the “Knowing Me, Knowing You” project. It is based on a mapping exercise and it gives a picture of the ADHD-organisations and information about ADHD and how it relates to social exclusion of children, families and adults.

The “Knowing Me, Knowing You” Mapping exercise will hopefully make a positive contribution to the future development of ADHD across Europe. Below we will record the most important points arising out of the mapping exercise and it is recommended that they will be taken into account for future plans across Europe.

The next two reports will go more into details than this report is able to and suggest which steps must be taken to prevent social exclusion which is a painful reality for thousands of people with ADHD.

### 7.1. Lack of data about ADHD

There is an overall lack of data about the size, complexity and diversity of ADHD and how it affects the social exclusion of children, adults and families across Europe and the negative impact that this can have on communities and societies as a whole.

Except for a few countries the mapping exercise clearly shows that the lack of facts, figures and research concerning ADHD is a huge problem for children, parents, adults living with ADHD and for professionals working with ADHD.

## 7.2. Lack of awareness and knowledge

Throughout Europe there is a lack of awareness and knowledge about ADHD. There is a need for specific concerns about the lack of recognition and services for adults who have ADHD and those who are underdiagnosed and the extent to which they are excluded. ADHD is a hidden disability which can lead to family breakdown, school exclusion, social isolation and involvement in substance, alcohol and drug abuse, homelessness, crime and a range of anti-social lifestyles and behaviours.

## 7.3. No clear recognition of ADHD as a disability

Comments from the questionnaire include:

*“In our country there is a very polemic debate on ADHD”*

*“Negative is often the meaning from the general public and the press/media”*

*“So many psychiatrists fail to diagnose obvious (to us) ADHD. They only blame the parents”*

Across all European countries there are still strong forces who want to renounce the existence of these condition. All countries have experienced tiresome media debates which deeply offend all those suffering from ADHD and their relatives.

An important theme is whether ADHD is considered being a disability or not. Still too many professionals believe that ADHD is not a real disorder but a social stigma applied to a child or an adult those environment find it difficult to handle or understand. Parents are told that if only they treated their child right they would not have problems. Adults are told that they are not handicapped, they just have to concentrate! You can if you want to!

ADHD is a syndrome, a descriptive category. But this is not special for ADHD; it applies to all psychiatric syndromes like autism, asperger or schizophrenia. And criteria for ADHD are as well defined as any other psychiatric disorder.

## 7.4. There is a need for...

The “Knowing Me, Knowing You” project have listed the key regional and national ADHD groups and organisations involved with ADHD across Europe. Other main issues, concerns and problems identified by the project include:

- need for common terms of reference for ADHD as a disability
- need for a European country policy and guidelines for the public sector
- need for research to fully explore the lifetime cost of ADHD and the cost benefit of providing early intervention and a range of preventative and holistic services
- need for adoption of a single diagnosis for ADHD
- need for professional training
- need for multi-modal holistic range of treatment services
- need for an ADHD charter in Europe

Last but not least there is a need for a new charitable organisation - the European ADHD Alliance - to implement the above and ensure that all countries across Europe have the opportunity to participate, to receive appropriate factual information and to be able to learn from each other.