

<u>833rd meeting – 26 March 2003</u>

Appendix 26 (Item 6.4)

Reply to Parliamentary Assembly Recommendation 1562 (2002) on Controlling the diagnosis and treatment of hyperactive children in Europe

(Adopted by the Committee of Ministers on 26 March 2003 at the 833rd meeting of the Ministers' Deputies)

- 1. The Committee of Ministers notes Recommendation 1562 (2002) of the Parliamentary Assembly "Controlling the diagnosis and treatment of hyperactive children in Europe". It appreciates the Assembly's concern about diagnosis and treatment of hyperactive children in Europe, which contributes to awareness raising and research on this topic.
- 2. The Committee of Ministers has received **comments on the Recommendation from the Pompidou Group** (the Co-operation Group to Combat Drug Abuse and Illicit Trafficking in Drugs, a Council of Europe partial agreement), representing the governments of 34 member states of the Council of Europe. The comments, which the Committee of Ministers consider as highly relevant, are appended to this reply.
- 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".
- 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.
- 6. The Committee of Ministers notes with concern that the Assembly has **not taken** account of the positions expressed and recommendations made at the 1999

meeting, which have since received corroboration from a number of other meetings and scientific papers. It regrets that adoption and publication of Recommendation 1562(2002) and the accompanying report might allow the "Church of Scientology" to refer to them as authoritative on the strength of seeming consensus within the Council of Europe, thus misleading, in particular, non-specialists such as parents and teachers, but also some doctors and pharmacists unfamiliar with the problems of diagnosing and treating children suffering from ADHD/HKD.

Research

7. However, the Committee of Ministers agrees with the Assembly, and with the Pompidou Group, that in the light of the serious individual problems connected with ADHD/HKD and the adverse effects which these disorders have on family and social life, it is necessary to **step up research** into the causes and possible remedies so as to further improve diagnostic methods and criteria and identify appropriate treatments.

Control

8. The Committee of Ministers also agrees with the Assembly, and with the Pompidou Group, that **control must be exercised over diagnosis and treatment** of ADHD/HKD. It appears that the situation differs in this respect from country to country and that, in some countries, treatment of ADHD/HKD by methylphenidate is not allowed. In other countries a need for greater supervision cannot be ruled out. Like the Pompidou Group, the Committee of Ministers takes the view that there is a need for **training and in-service training** for doctors involved in the diagnosis and treatment of ADHD/HKD. It also agrees that 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.

Guidelines and information

- 9. As suggested by the Assembly, the Committee of Ministers invites the Pompidou Group in co-operation with the appropriate international organisations, to strengthen **guidelines on the promotion of psychotropic substances**. It notes that the Group will consider the possibility of including this in its 2003-2006 work programme. It also notes that the World Health Organisation has already shown interest in cooperating with the Pompidou Group on this.
- 10. 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" (see page 15 of the proceedings).

Appendix

Opinion of the Pompidou Group (the Co-operation Group to Combat Drug Abuse and Illicit Trafficking in Drugs (PG), a Council of Europe partial agreement) on Recommendation 1562 (2002) of the Parliamentary Assembly "Controlling the diagnosis and treatment of hyperactive children in Europe"

The Pompidou Group (the Co-operation Group to Combat Drug Abuse and Illicit Trafficking in Drugs, a Council of Europe partial agreement) appreciates the Assembly's showing concern about diagnosis and treatment of hyperactive children in Europe, which contributes to awareness raising and research on this topic. These questions were the subject of a meeting which the group held in Strasbourg on 8 and 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".

The PG therefore regrets that it must take issue with various points in the recommendation and the report on which it was based. It considers the points in question to be at variance with the views held by the vast majority of the scientific community and even that they are dangerously close to certain well-known theories which the "Church of Scientology" has championed for some time but which do not stand up to serious scientific scrutiny. 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.

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.

This general point is not invalidated by the differences noted in paragraph 3 of the recommendation between the diagnostic criteria used on the one hand in the Diagnostic and Statistical Manual (DSM-IV) of the American Psychiatric Association and on the other in the International Classification of Diseases (ICD-10) of the World Health Organisation.

The World Health Organisation has stated that such an activity would be valuable: the American Psychiatric Association is in the process of revising its DSM-IV definition with a view to bringing out a new definition (DSM-V) in a year or two, and this would seem a good time to attempt a common approach taking into account WHO's ICD-10 definition.

In general the PG regrets that the Assembly has taken insufficient account of the positions expressed and recommendations made at the 1999 meeting, which have since received corroboration from a number of other meetings and scientific papers. It also deplores that adoption and publication of Recommendation 1562(2002) and the accompanying report allowed the "Church of Scientology" to refer to them as authoritative on the strength of seeming consensus within the Council of Europe, thus dangerously misleading, in particular, non-specialists such as parents and

teachers, but also some doctors and pharmacists unfamiliar with the problems of diagnosing and treating children suffering from ADHD/HKD.

In particular, in addition to the above comments, the Pompidou Group has the following observations:

Paragraph 1

The Assembly expresses concern that increasing numbers of children in some Council of Europe countries are being diagnosed as suffering from attention deficit/hyperactivity disorder, hyperkinetic disorder or related behavioural conditions and treated by means of central nervous system stimulants such as amphetamines or methylphenidate (a substance better known by the brand name Ritalin).

This statement suggests that, in the countries concerned, the number of diagnoses and prescriptions is growing dangerously. It disregards the fact that, in general, the increase is the result of doctors becoming more familiar with the condition and ways of treating it, which is bound to increase diagnosis and treatment, but in the welcome direction of giving children affected more access to appropriate treatment. There is nothing to indicate that, in general, in Council of Europe countries there is overdiagnosis or over-treatment. Equally, although there is no evidence of excessive diagnosis of ADHD/HKD or of over-prescription of stimulants, the trend needs careful monitoring.

Further on, paragraph 1 connects growing diagnosis and treatment with listing of the drugs concerned in Schedule II of the 1971 United Nations Convention on Psychotropic Substances "because", it says, in WHO's view, they are "liable ... to constitute a substantial risk to public health and to have little to moderate therapeutic usefulness". This presentation of the matter tries to make out that WHO has criticised Ritalin as such. The consensus, however, is that on the contrary Ritalin, if prescribed in accordance with medical rules, is a treatment that gives excellent results. If that is so, the Pompidou Group takes the view, in line with the Council of Europe's basic principles, which include access to health (see Article 11 of the European Social Charter), that children, including those suffering from ADHD/HKD, are entitled to the best possible medical treatment.

Paragraph 4

Like the Assembly, the Pompidou Group cannot but underline the serious individual problems connected with ADHD/HKD and the adverse effects which these disorders have on family and social life. It accordingly considers it necessary to step up research into the causes and possible remedies so as to further improve diagnostic methods and criteria and identify appropriate treatments.

Paragraph 6

The Pompidou Group cannot but subscribe to the general recommendation that "stricter control" be exercised over diagnosis and treatment of ADHD/HKD. It points out that the situation differs in this respect from country to country and that, in some countries, treatment of ADHD/HKD by methylphenidate is not allowed. In other countries a need for greater supervision cannot be ruled out.

Paragraph 7

The Pompidou Group cannot endorse the judgment about the pharmaceutical industry as it stands, regarding it as too sweeping and unspecific. However it recognises here that there are certain difficulties as regards providing the public generally and the medical community in particular with appropriate information and it draws attention to the recommendation made at the 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" (see page 15 of the proceedings).

Paragraph 8.ii

The Pompidou Group wishes to express its readiness to assist as far as possible, in co-operation with other competent organisations, in strengthening guidelines on promotion of psychotropic substances and will consider the possibility of including it in its 2003-2006 work programme. The World Health Organisation has already shown interest in co-operating with the Pompidou Group on this.

Paragraph 8.iii c)

The Pompidou Group fully agrees with the Parliamentary Assembly recommendation "to produce information material designed for parents of hyperactive children explaining what possibilities exist for improving their condition" and takes the view that it is important to greatly 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 prejudice resulting in dangerous misuse of the drugs in question.

Paragraph 8.iv

Concerning the last paragraph of the Recommendation, the wish to harmonise the WHO definition (ICD-10) with that of the American Psychiatric Association (DSM-IV) is almost certain to increase the rate at which such disorders are recognised in Europe as the criteria used by DSM-IV are somewhat broader than those of ICD-10. Many studies have clarified the similarities and differences between ICD-10 and DSM-IV criteria.

However, it would no doubt be necessary to consider the possibility of reconciling the two approaches by harmonising the differences between ICD-10 and DSM-IV criteria for ADHD and hyperkinetic disorders. The American Psychiatric Association is in the process of revising its DSM-IV definition with a view to bringing out a new definition (DSM-V) in a year or two, and this would seem a good time to attempt a common approach taking into account WHO's ICD-10 definition.

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."