

Opinion on the management of autistic persons in France. Report.

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Opinion

The question of the management of autistic persons in France was referred to the CCNE by the Autisme-France Association in a letter dated 19 September 1994. In October 1994, the Association also dealt with this question in a white paper addressed to the French Ministries for Social Affairs, Health and Municipal Affairs, to the National Council of the Order of Physicians and to our Committee.

After hearing and discussing the report drafted by the working group on the Neurosciences which had been asked to investigate this question, the CCNE noted that the present situation in the field of autism is characterized by insufficient scientific knowledge, and by uncertainty. It endeavoured to examine the ethical consequences of this situation and formulated recommendations which take into account the anxiety expressed by parents' associations, the point of view of the professional staff involved, and the framework of the evolution of autism in France. The Committee's recommendations concern two points : (1) research on autism and (2) the management of autistic persons.

I. Scientific research on the autistic syndrome

1) According to present knowledge, autism is considered to be a disorder in the development of the central nervous system and to have many causes. It is a syndrome which may be difficult to diagnose because it has a large range of clinical forms which cover a very vast field, from extremely serious handi to situations compatible with appreciable levels of socialization. Only very precise clinical investigation can enable a detailed diagnosis of autism to be formulated and substantiated. Such formulation must, moreover, take account of another particular factor, i.e. that a clinical behavioural picture of typical autism may correspond to very different anatomical, genetic and even metabolic features.

These comments also led the Committee to stress the problems posed by the fact that the diagnostic criteria used in France only correspond in part to those of the international classification. This situation is the cause of a regrettable lack of understanding amongst researchers, medical practitioners, families and health organizations.

2) Research in neurosciences has recently made great progress in analyzing the cognitive and emotional disturbances of autistic subjects. Nevertheless, much work remains to be

done in research on the genetic, neurobiological and pharmacological aspects of autism, in order to define better diagnostic criteria and clarify the physiopathological mechanisms involved in this condition.

3) Once autism has been diagnosed, clinical research should make it possible to define the exact nature of the disturbances, to ensure that management is well adapted to each child. Specialized centres should be set up which should function both as clinical research centres and reference centres capable of giving expert advice.

4) As is the case for all complaints whose treatment is so far unclear, the dispersed and sometimes contradictory nature of the present management of autism is bewildering for patients' families, and makes them fear that " their" patient is not being given the best possible chances. In view of the present absence of sufficiently effective therapies for the autistic syndrome, all methods of management must imperatively be evaluated on a strictly scientific basis which should be both objective and comparative and should apply to medication, psychotherapy, educational methods and what is termed institutional treatment, or any combination of these procedures. The results of the evaluations of their effectiveness should be regularly published, to provide parents and professional staff with guidelines enabling them to make the choices that they must remain free to determine.

II. Management of persons suffering from autism

1) In view of the absence of definite knowledge concerning the nature and etiology of the autistic syndrome, and of the absence of curative treatment, the quality of the care dispensed must be strictly supervised and every effort made to avoid, in particular, anything in a method of treatment which might possibly induce feelings of guilt in patients or their families and thus add to their distress. This means that any procedures or conditions in the methods of management which in practice prove ineffective or harmful should be eliminated.

The pluridisciplinary management recommended by the report of the IGAS (General Inspection of Social Affairs) and by the ministerial circular does not mean that all methods are equally good or bad, but should make it possible to avoid the general use of a particular method without adequate precautions, and favour the use of methods adapted to the specific deficiencies observed in each child.

2) As is usually the case for other handi, those in charge of autistic patients must be recognized as competent and possess a valid professional qualification, in the same way as specialists in other branches of health care.

3) The positive role of the associations of parents of autistic persons must be stressed and encouraged. These associations make it easier for families to obtain information, to take action in the light of the diagnosis and often to obtain admission to appropriate institutions. Such associations have contributed a great deal to the recent evolution of the situation of the autistic in France.

Report

Referral to the CCNE

1) As the Autisme-France Association considered that the problems posed by the deficiencies in the management of autistic persons in France " affect the foundations of ethics" , it referred the question to the CCNE in a letter dated September 19 1994, in which it denounced the following :

The apparent difficulties in obtaining an early accurate diagnosis, partly due, it seems, to the use by the French medical community of its own classification of mental diseases, and not the " international diagnostic classifications recognized by the scientific community as validated and reliable" .

The failure to recognize the " organic" origin of autism by most French psychiatrists, who seem to give preference to the theory that its origin is psychogenetic ; thus, most autistic children appear to be directed to the psychiatric sector and are managed by basically psychoanalytic methods, instead of benefitting from " specialized education specific to their handicap permitting the maximum development of their personality when they reach adult age" .

These points were expanded in a white paper drafted by the Association from evidence supplied by the parents of autistic children, entitled " Report on the experiences of the autistic and their families in France at the dawn of the 21st century" and dated October 1994. The report was intended for the Ministry of Social Affairs, and also the Council of the Order of Physicians and the National Consultative Ethics Committee.

The position of Autisme-France was defined at a meeting of the CCNE's working group on the neurosciences, during which the Association's President explained the following points :

There is, she stated, a considerable lag between France and other countries, especially those of the English-speaking world, in the conception of autism.

Since the first clinical description of the autistic syndrome by Kanner in 1943 and the widespread positive reactions to the psychoanalytic explanatory theory developed by Bettelheim, the hypothesis that the origin of autistic developmental disturbances is organic has given rise to new methods of management, such as the TEACCH method developed by Schopler in North Carolina. This method is based on accurate evaluation of the child's handicap and different cognitive capacities, in order to elaborate an educational project which is adapted to him and enables him to acquire a certain degree of autonomy. This method, which involves management within an educational framework by specialized instructors, is advocated by the Autisme-France Association, but the access to this type of management in France is at present beset with the following difficulties :

the effectiveness of the educational project is linked to early management, which requires the diagnosis to be early and accurate as well. However, contrarily to the World Health Organization and American classifications, which no longer use the term " psychosis" to define autism, the French classification still includes it in the general category of child psychoses. Classification in this category, which according to a typically French terminology includes symbiotic and dysharmonic psychoses, evolutive forms of dysharmony and personality disorders, does not permit the necessary accuracy. Thus, different physicians often formulate different diagnoses for the same child. In France, only a few centres are capable of making a diagnosis and evaluation which conform to international standards and lead to an educational form of management.

nearly all the children are sent to the psychiatric sector, where management based on non intervention, and a psychoanalytic approach centred on a policy of " waiting for desire to emerge" deprive them of the social attainments and schooling from which they could otherwise benefit. Some certainly go to medicoeducational institutes, but in the absence of a previous precise diagnosis it is not possible to elaborate a specialized educational project for them.

In conclusion, the ethical problems raised by Autisme-France are the following :

" Regard for the human rights of autistic persons is not ensured, because such persons

- do not have access to a diagnosis that corresponds to present scientific knowledge,
- do not have access to the right to education, and
- are only offered the solution of admission to the psychiatric sector, in which more than 50% of the autistic subjects are on neuroleptics, compared to only 4 to 8% in North Carolina, where they can benefit from the TEACCH method.

In the absence of more precise knowledge concerning the origin of the syndrome it is unethical and contrary to the interests of autistic persons and their families to give preference to theories that make the parents responsible for the disorder. These theories have not been scientifically validated, and the progress in research during the last twenty years makes them even less acceptable today" .

2) The point of view of another association of parents of autistic persons was also explained to the working group on the neurosciences, by a representative of the Fédération Française Autisme et Psychoses Infantiles (French autism and infantile psychoses federation) better known as Sesame-Autisme, the name of its journal.

This Association's position is in agreement with that of Autisme-France as regards the need for early diagnosis, which is often formulated too late. It considers that this would require greater sensitivity on the part of general practitioners and paediatricians, whose training with respect to autism is presently insufficient. With regard to management, the Association considers that quantitatively speaking, the lack of an appropriate organizational framework for autistic persons from adolescence onwards, and even more at adult age, constitutes a serious problem. On the other hand, with regard to quality, it does not consider that France lags behind countries like the United States or Britain. It believes that all approaches to autism include positive elements of which the maximum possible use should be made in pluridisciplinary management that should include education, health care and socialization. Given the present state of knowledge, no method of management should be excluded, except for what are termed aversive methods, and no form of management, be it psychoanalytic, educational or otherwise oriented, must ever be exclusive, because that would be restrictive. Nevertheless, the Association thinks that one can no longer say at the present time that management of the autistic in France is exclusively psychoanalytic, even if this was true in the past of certain hospitals.

After the information conveyed at these two meetings, the CCNE's working group considered that before replying to the referral by Autisme-France, it was necessary to review the knowledge so far acquired concerning autism and its methods of management. With this in view, it consulted different experts (1) and acquired information about recent work in this field.

3) Since the referral to the CCNE, three reports have been published at the request of the Ministries for Social Affairs, Health and Municipal Affairs :

The report by the IGAS dated October 1994, on the Management of Autistic Children and Adolescents, describes the State of the Art as regards the different theories relating to autism, and the situation in France concerning the detection, orientation and management of young autistic subjects. The report advocates solutions for the improvement of this situation.

The report by the Agence Nationale pour le Développement de l'Evaluation Médicale (ANDEM, National agency for the development of medical evaluation) dated November 1994, and entitled " Autism" , containing an analysis of the international literature concerning estimations of the frequency of autism and infantile psychoses in France and the long and short-term evaluations of the results of therapies and of the present methods of management. ANDEM states that its report concerns a stage in the process of complete

evaluation.

The report by the DAS (Direction de l'Action Sociale du Ministère des Affaires Sociales) dated December 1994, entitled " Proposals for the care of autistic adults" .

In response to the conclusions and proposals of these reports, the Ministry of Health, in its circular n° 9512 of April 27 1995, published a plan of action for the management of autistic children, adolescents and adults. The plan provides for the setting up, within five years, of a management network within the framework of regional plans of action designed to deal with autism. In particular, these plans will have to provide for the implementation of a programme for early diagnosis, as well as the organization of management which will have to conform to the choice of parents, and include therapy, schooling and education adapted to autistic children and to each age group. Improvement of the care of autistic adults, which must be both qualitative and quantitative, should constitute a priority.

Scientific data

I. Definition of autism. Diagnostic classifications

The American psychiatrist Leo Kanner was the first to give a clinical description of the child autism syndrome in 1943, after observing, for five years, eleven patients with sufficiently specific associated symptoms to distinguish them from other retarded or psychotic children.

The clinical picture described by Kanner was the following :

autistic isolation characterized by the child's inability to communicate and establish normal relations with other persons, and to react to situations normally since the beginning of life ;

the need for immutability, and resistance to change, and

the presence of " islands of aptitude" such as, in some cases, an exceptionally good memory.

Since this all-important description, the diagnostic criteria of autism have been further refined and form part of the different classifications used in psychiatry as clinical or research tools.

These classifications are the following :

the WHO International Classification of Diseases (ICD) ;

the classification of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM) ;

the Classification Française des Troubles Mentaux de l'Enfant et de l'Adolescent (CFTMEA), published in 1988.

The international and American classifications (ICD-10 and DSM-IV) were revised in 1992 and 1994, and are in good agreement. Both classify autism in the category of " invasive developmental disorders" . Another separate category of " atypical autism" was created for subjects who do not completely fulfil the diagnostic criteria.

Contrarily to the American and WHO classifications, which no longer use the term " psychosis" , the French classification includes autism in the general category of " infantile psychoses" . The criteria of autism are narrower and reflect the type of autism described by Kanner. Another category entitled " other forms of infantile autism" groups together forms of Kanner's syndrome which are incomplete or appear later.

According to many research scientists (e. g. E. Fombonne : *Diagnosis and classification of autism : Current issues and controversies*, Links, 1994, 13-17), the chief modern descriptive concepts found in the American and WHO classifications are lacking in the French classification, which does not correspond to the international classifications.

The IGAS report also considers the CFTMEA's definition too restrictive in view of the progress made in identifying the risk factors associated with autism. This progress is taken into account in the DSM-IV and CIM-10 classifications, which recognize the existence of close links between behaviour, cognition and neurobiological organization.

The IGAS report stresses two drawbacks to the French classification :

the absence of certain criteria used in English-speaking countries which allow a more precise approach to the child's condition, thus facilitating the choice of management method and allowing objective evaluation of the progress made, and

the difficulties experienced by French psychiatrists in presenting their work abroad.

The ANDEM report makes a synthesis of the WHO, American and French classifications, in which it gives the following definition of autism :

" the infantile autism syndrome is an overall early developmental disorder which appears before the age of three and is characterized by deviant and/or retarded functioning in the three following domains : social interaction, verbal and non-verbal communication, and behaviour."

II. Prevalence of autism

The ANDEM report reviews twenty three studies of prevalence conducted throughout the world, four of them in France. The differences between the rates reported in these studies can be explained by the differences between the definitions and classifications chosen, the methodology used and the age of the subjects.

If the results for these publications as a whole are extrapolated to France, the rate of prevalence is 4 to 5.6 per 10 000 subjects aged from 0 to 19 years. This gives about 7 000 children or adolescents suffering from autistic disorders, and about 20 000 persons aged from 0 to 55 years.

These figures constitute a rate estimated at 20 per 10 000, if one includes in the definition children with a partial syndrome such as that sometimes observed in those with severe mental retardation (E. Fombonne, *Etudes épidémiologiques de l'autisme infantile*, 1995, 1171-1199).

The sex ratio is three boys to one girl, but the girls have more severe disorders.

Mental retardation is observed in 75-80% of autistic persons, whose I.Q. is below 70, as evaluated by standard non-verbal intelligence tests.

About 50% of autistic persons do not use verbal language.

Epidemiological studies show that autism has no connection with social class.

III. Evolution of autism

Epidemiological studies show that autism is a lifelong handicap. When there is no intellectual retardation, or when the latter is minor, the prognosis depends on the stage of

social language development at five years. The more developed it is, the greater the autonomy which the adult will be able to acquire. When intellectual retardation is moderate or severe, children will become assisted adults.

At adolescence, 25% of autistic subjects develop various forms of epilepsy, a specific evolutive feature of which it is important to be aware.

IV. Origin of autism

In France, two theories on the origin of autism coexist : the psychoanalytic theory, which gives preference to psychogenetic causes, and the organic theory.

1) The psychogenetic causes

a) psychoanalytic theory

According to this concept, autism is due to " dysharmony" in the early interactions between the mother and child, and the autistic syndrome constitutes a particular modality of psychic organization in response to this dysfunction.

The psychoanalytic theory was elaborated in the fifties, at a time when the present means of investigating the central nervous system were not yet available. It was not constructed from scientific data, but is based on case studies and proposes models which explain the symptoms using psychoanalytic concepts. There are no epidemiological studies to substantiate this theory.

b) psychogenetic factors

Environmental factors such as depression in the mother have been incriminated as causes of autism (P. Ferrari), but the studies conducted since 1970, mostly in the English-speaking world, show that there are no arguments in favour of this association. On the contrary, observation of the children of mothers suffering from severe recurrent depression shows that it is not connected with autism. Children brought up in an extremely unfavourable environment, such as those in institutions or those deprived of affection, are not over-represented in autistic populations, and the psychopathological features they develop are different from those of autistic children and are sometimes reversible (E. Fombonne, *Etudes épidémiologiques de l'autisme infantile in Nouveau Traité de Psychiatrie de l'Enfant et de l'Adolescent*, Paris, PUF, 1995, 1171-1199).

2) The theory of the organic origin of autism

The epidemiological studies conducted have supplied the following data :

a) infectious factors

The influence of these factors has not been demonstrated. The autistic-like symptoms observed in certain cases of congenital rubella regress in the course of development, contrarily to what is observed in autism.

b) prenatal and perinatal complications

Autistic infants have been observed to have twice as many problems during the prenatal and perinatal periods as normal infants. However, it is difficult to interpret this observation, because the types of problem vary considerably and do not have common physiopathological features. One theory, substantiated by studies of twins and by familial studies, is that the genetically predisposed foetuses are those which experience more frequent problems than others during pregnancy, as occurs for well known genetic anomalies like Trisomy 21 or the fragile X syndrome.

c) genetic factors

1) Familial genetic studies have shown that in families with an autistic child there is a 3% risk that autism will recur among the child's siblings, which is about 60 times higher than in the general population. Among first degree relatives, there are also high incidences of developmental anomalies of language or social relations (10% for parents and 20% for siblings). These incidences are very similar to those observed in autism (10% for parents and 20% for siblings), but they are less severe, thus indicating that autism possesses an extended phenotype. Studies of twins show a concordance of 60 to 70% among monozygous pairs which rises to 90% if the extended phenotype is taken into account. Among dizygous twins, the concordance is 3 to 4% and 10% if the extended phenotype is considered.

2) Autism is associated with identified genetic diseases in about 10% of cases, distributed as follows :

1 to 4% of autistic children have tuberous sclerosis (an autosomal dominant disease) and 20 to 40% of the children with this disease have an autistic syndrome. This is an interesting line of research for the possible detection of a genetic or neurological mechanism common to tuberous sclerosis and autism. However, the former is an autosomal disease whose mode of transmission does not account for the large over-representation of boys in autistic populations.

About 5% of autistic children have a fragile X syndrome, but this percentage is no higher than among non-autistic mentally retarded children. Conversely, 30 to 40% of the boys with the fragile X syndrome are autistic.

A relationship between phenylketonuria and the presence of autistic symptoms has been reported in a large number of cases, but the symptoms regressed when diets were free of phenylalanine. A few other rare diseases have been described.

Autism is considered the most frequently transferred psychopathological disorder, and consequently, genetic factors seem determinant. The data available suggest that it is not a monogenic disease. In addition, the number of girls affected is too large for the syndrome to be exclusively connected with the X chromosome.

d) neurobiological factors

Longitudinal studies of subjects aged from 2 to 12 years have shown that the levels of blood serotonin in autistic children are higher than in the controls.

These results led to the conclusion that the system producing and regulating catecholamine production might be involved in the physiopathology of the autistic syndrome (investigations by Unit 316 of the INSERM (National Institute for Health and Medical Research) at the CHU (University Hospital Centre) of Tours).

e) brain dysfunction and cognitive deficiencies

So far, research using brain imagery has not led to the same conclusions on brain dysfunction in autism. One study of cerebral blood flow showed an abnormally small frontal flow in autistic children of three years. However, another examination of these children three years later showed that the flow had become normal. These results suggest that in autistic children, the metabolic maturation of the frontal lobes is delayed (explorations by INSERM Unit 316).

The results of certain experimental psychological tests enabling the psychological development of children to be evaluated have shown that autistic subjects do not possess the " tools" which would allow them to attribute mental states to others. Thus, the results of

various intelligence tests showed that autistic children are quite capable of completing all the tasks for which the stimuli must be isolated, but fail in those whose stimuli must be linked, contrarily to normal children with the same IQ or children who are retarded but not autistic. These results suggest that at a critical period in the child's development, autism involves dysfunction of the processing of information, which in turn affects the central mental process responsible for the coherent interpretation of heterogeneous items of information (U. Frith, *L'énigme de l'autisme*, Paris, ed. Odile Jacob, 1992).

In conclusion, autism is considered, according to present knowledge, as a developmental disturbance of the central nervous system with multiple causes.

V. Methods of managing autism

In France, autistic children of 0 to 3 years are cared for in centres for early medicosocial action, medicopsychological centres (MPCs), or hospital child psychiatry departments.

Children of 3 to 12 years are cared for within the interdepartmental framework of infantojuvenile psychiatry, or in the medico-educational sector. Management in hospitals may be full time or part time, or a few hours a week in the MPCs or in part time therapy centres (PTTCs). Various treatments are available in the fields of re-education involving language and psychomotricity, education and schooling, and psychotherapy. Personal psychotherapy or meetings within the framework of contacts with families are proposed for parents. There are also therapy classes which form part of certain kindergarten or primary schools, and some twenty of them function on the basis of the TEACCH method.

After the age of twelve, specific forms of management are rarer. Most adolescents are cared for in medicoeducational institutes (MEIs) with, in some cases, an additional psychological follow up. There are a few daytime hospitals and PTTCs for adolescents.

The facilities offered to adults are homes, daycares centres which may or may not provide education, entertainment, etc., centres for assistance through work, sheltered workshops and homes run by parents' associations.

The different reports all stress the quantitative and qualitative inadequacy of the management of autistic persons.

In the face of this admission, it is not possible to ignore the fact that working with the mentally handicapped is not simply a question of training. To give optimal results, it also implies that instructors must be highly motivated, because the work is difficult, often considered unpleasant and not very rewarding. This being said, conditions can change radically if it proves possible to recruit experienced teams of extremely competent workers with complementary skills, and if their work revolves around a coherent therapeutic project that is efficiently implemented and whose results are regularly evaluated. Under these conditions, work with the handicapped can acquire a significance and value which will make it attractive.

VI. Evaluation of treatments

The classification of treatments in this section is the one used in the ANDEM report.

1) Medical treatments

After studying the international literature on medical trials, the conclusion drawn by ANDEM is that there is no specific medication for the autistic syndrome. Neuroleptic and other psychotropic drugs are used, but their effectiveness is confined to one or several non-specific symptoms, and their side effects limit their use on a long-term basis.

2) Behavioural and psychoanalytic treatments

a) treatments based on psychoanalysis

The ANDEM report stresses that " as far as we know, the international literature contains no published studies in which the results of exclusively psychoanalytic treatment of a group of autistic children are systematically evaluated. There are case studies of children followed up during individual cures by psychiatrists and/or psychoanalysts. These monographies are of interest for observing the changes that a child undergoes with time and following the course of the analytical procedure, but they do not enable the effectiveness of psychoanalysis to be evaluated in statistical terms, comparatively to other therapies."

The evidence supplied by those we consulted on the differences between methods of treatment implies that the therapists who use treatments based on psychoanalysis aim to open the child's mind to relationships with others by giving him the means of constructing a coherent personal history. As regards the therapists practising methods based on cognition, this evidence implies that their objective is the same, but that they try to reduce the handi by inciting the child to reproduce concrete actions which give him a minimum of mastery over his environment.

In this case, what is defined as psychoanalytic treatment is only distantly related to a traditional psychoanalytic relationship, which implies linguistic and communication abilities and a level of relational development that are lacking in autistic persons.

b) behavioural treatments

These treatments, which use first positive and then negative reinforcement (i.e. stimuli in the form of rewards or punishments), aim to enable the subject to learn elementary skills, and to reduce behaviour based on self-stimulation and self-mutilation. Few studies have evaluated precisely the efficacy of behavioural treatment in autism. Although certain authors have shown that it improves certain autistic forms of behaviour, the latter usually reappear when the treatment stops.

The ANDEM report concludes that " there is certainly a deficiency in the evaluation of treatments based on psychoanalysis and to a lesser degree on behavioural treatments." It considers that it is " indispensable to institute a methodology for evaluating the different forms of treatment, especially psychoanalytic forms" .

3) Specific educational methods

The best known is the TEACCH method.

Its authors consider that autism is an organic deficiency of the cognitive functions. The method consists of evaluating, for each child, his handi, sensory integration problems, initiation capacity, verbal and non-verbal comprehension, and cognitive capacities that do not involve communication. On the basis of this evaluation, the method aims to give the child a tool for communication such as an object corresponding to an action, in order to create a structured environment, and the time necessary to give information a concrete form by going to a particular place to do a particular thing, and to learn how to vary images and actions (the variations can range from very concrete symbols to words). This programme, like other educational programmes, attributes great importance to cooperation between parents and professional staff, whose training is provided for within the framework of the method. Children undergo regular tests to evaluate their progress.

The implementation of this programme is therefore accompanied by evaluation of its efficacy, but there are no studies in which the results of the TEACCH method are compared to those obtained by other management methods.

4) Methods of re-education

Studies of re-education methods concerning language and psychomotricity show an improvement in the verbal and motor capacities of autistic children.

5) Other methods

The facilitated communication method enables autistic persons to communicate with others via a device consisting of a panel comprising pictures, letters of the alphabet or a typewriter or computer keyboard. Autistic subjects are assisted by a " facilitator" . Experiments have been conducted with this method to test its validity, and the results usually indicate that in general the responses obtained are voluntarily or involuntarily induced by the facilitator. Various methods of sensory re-education have been elaborated, but they have not been scientifically evaluated.

6) Institutional treatment

Institutions for autistic children provide overall management that includes psychotherapy, re-education in the fields of orthophony and psychomotricity, and specialized education. A study of 119 pre-adolescents in 12 centres in France, including 49 autistic subjects, gave a retrospective longitudinal two-year evaluation of the different methods of management. The results showed little improvement in development, communication capacities, adaptative social behaviour or educational level (E. Fombonne, *les troubles sévères du développement : le bilan à l'adolescence* , ed. du CTNERHI, Paris, 1995, 250p.).

The conclusions of the ANDEM report concerning assessment of the efficacy of different therapies and methods of managing autistic persons stress the inadequacy of studies evaluating most of these programmes. Although certain behavioural treatments, and certain systems of re-education or specialized education, used separately or together, improve certain symptoms of autism and favour the development of communication, the absence of comparative studies does not permit any conclusions to be drawn as to the possible superiority of any one method of management. The report considers that even if it is difficult to make comparative assessments, they are in fact possible.

The IGAS and ANDEM reports, as well as the opinions of the experts consulted, indicate that the present position in France in the field of autism is characterized by insufficient scientific knowledge and by uncertainty.

An examination of the ethical consequences of this situation led the CCNE to express an opinion whose chief points concern research on autism and the management of autistic persons.

The establishment of an early accurate diagnosis of autism is essential, to allow the management best adapted to each child. However, the wide range of clinical forms of the autistic syndrome and the fact that a typical behavioural clinical picture of autism may correspond to very different anatomical, genetic or even metabolic characteristics, can make diagnosis difficult. The use in France of diagnostic criteria which are only in partial agreement with those of the international classifications can also be a source of difficulty.

A great deal of research on the genetic, neurobiological and pharmacological aspects of autism remains to be done in order to define better diagnostic criteria, and should be encouraged. It would be desirable in this connection to institute specialized centres which would act as clinical research centres and reference and advisory bodies.

The management of autistic patients must be ensured by experienced teams of experts with recognized valid qualifications. Care should be taken to maintain high standards by

avoiding, in particular, anything in a method of treatment which could induce guilt feelings in the patients or their families and thus increase their distress.

In the absence of definite knowledge of the nature and etiology of the autistic syndrome, and in view of the present lack of sufficiently effective therapy, all methods of treatment, whether by systems of education or "institutional" treatments, and whether they are used singly or together, must be subjected to a strictly scientific evaluation.

The results of these evaluations should be regularly published, so that parents and professional staff can obtain objective criteria on which to base the choices they must remain free to make.

APPENDIX

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Notes

1. see list in the appendix