

Opinion n°95

***ETHICAL ISSUES RAISED BY PREDICTION BASED ON DETECTION OF
EARLY BEHAVIOURAL DISORDERS IN CHILDREN***

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Persons heard:

The signatories of the Group "*Pas de 0 de conduite pour les enfants de 3 ans*" (No zero-rating for misbehaving three-year olds)

The referral

Following the "Pas de 0 de conduite"¹ Group's referral to CCNE on April 6, 2006 regarding the ethical implications of prediction-based approaches when certain behavioural disorders are detected in very young children, CCNE considered the issue.

The referral called in question a collective expertise by the *Institut National de la Recherche Médicale* (INSERM) (National Institute for Medical Research) at the request of the *Caisse nationale d'Assurance Maladie des Travailleurs Indépendants* (CANAM), (national health insurance agency for the self-employed), with a view to improving screening, prevention and management of childhood² "behavioural disorders". The authors of the referral question the soundness of a recommendation to screen for such disorders in children as young as 3-4 years, in order to gain an early indication of risk factors which could later develop into violent forms of delinquency. The authors of the referral fear that such data, established for mainly *preventive and medical* reasons, could also be used for other *predictive and judicial* purposes. They harbour doubts regarding the methodological prerequisites, the choice of experts, the imprecision — not to say ambiguity — of the definition of "behavioural disorders" used in the works quoted by the expert report. They are also concerned about the risks of a procedure in which such data would be entered in medical health records, leading to moral stigma cast upon the behaviour of young children, *branding them with a "mark" that could remain with them throughout their lives*.

The expert report includes a meta-analysis (a summary of scientific and medical research on a particular subject published internationally) of available studies on early signs of future behavioural disorders in young children. It also reviews the possible factors predicting risk of subsequent delinquent developments. The expert report uses the definition of

¹ The Group "Pas de 0 de Conduite pour les enfants de 3 ans", (No zero-rating for misbehaving three-year olds) whose members are psychologists, paedopsychiatrists and representatives of associations, under the signatures of Professors Roland Gori (*président du séminaire inter-universitaire d'enseignement et de recherche en psychopathologie et psychanalyse* - President of the Inter-University Seminar for Education and Research in Psychopathology and Psychoanalysis), Gérard Schmit (*président du collège de pédopsychiatrie de la fédération française de pédopsychiatrie* - President of the College of Paedopsychiatry of the French Paedopsychiatry Federation), Pierre Delion and Bernard Golse (*chefs de service de pédopsychiatrie* - Consultants in Paedopsychiatry), Doctors François Bourdillon (*président de la société française de santé publique* - President of the French Society for Public Health), Christine Bellas Cabane (*présidente du syndicat national des médecins de PMI* - President of the National Association of Doctors involved in Health Protection of Mothers and Children), Pierre Suesseur (*vice-président de ce syndicat* - Vice President of the above Association) and Dominique Ratia-Armengol (*vice-président du syndicat national des psychologues pour la petite enfance* - Vice President of the National Association of Psychologists for early Childhood).

² <http://ist.inserm.fr/basisrapports/trouble-conduites.html>

"behavioural disorders" given in the DSM-4 and CIM-10³ classification, based on a set of symptoms concerning the repetition and persistence of behaviours which may conflict with social rules, with the fundamental rights of others and which could lead to violent forms of delinquency.

It concludes with recommendations on the possibility of minimising such developments by screening for risk factors and consigning them to the child's personal health record so as to offer prevention and treatment.

CCNE's considerations

The conclusions of the report and their possible applications raise several ethical issues, because they are based on a linear approach which confuses risk factors and causality and is therefore reductionist of human behaviour:

1. In epistemological terms: ambiguity of the definition of "behavioural disorders":

The ambiguity of the definition given in DSM-4 and CIM-10 for "behavioural disorders" must be emphasised because it tends to blur the frontier between pathology and delinquency, between medical and judicial considerations. In the preliminaries, the expert report does remark on the ambiguity ("The question therefore arises of knowing the relationship between the behavioural disorders and delinquency as a social phenomenon"), but neither raises nor mentions the matter again. The summary² of the report explains that: *"The expression 'behavioural disorders' covers behaviours which involve a transgression of social rules. The disorder is therefore situated at the interface and intersection of psychiatry, social issues and justice. Historically, since the advent of Lombroso's 'born criminal', childhood behavioural disorders raise the issue of borderlines between responsibility and guilt and between law and medicine".* A logical consequence to this finding would have been to call on human and social science experts to make their contribution to the report.

Another epistemological problem is connected to the very different nature of behaviours considered to be symptoms and diagnostic criteria of "behavioural disorders". Can one — without giving the matter a second thought — consider as given and obvious that the tantrums of a child of three or four are early symptoms predicting a linear progression, ten or fifteen years later, to violent conduct (rape, armed robbery, etc.) arising from the same biological causality?

The temptation to simplify, categorise and hierarchize all the dimensions of a complex set of human behaviours, based on a single template for classification, and using the result to predict individual fates is not a novelty. Anthropologists at the end of the 19th century and the early

³ DSM-4: "Diagnostic and Statistical manual of Mental Disorders" by the American Psychiatric Association; ICD-10: WHO (World Health Organization) "International Classification of Diseases".

20th century thought that phrenology (a study of cranial 'bumps') could reveal a person's identity and future. Today, some people believe that a child's entire identity and fate is to be found in a study of the child's behaviour, gene sequences or by an analysis of cerebral activity imagery. The history of science teaches us that attempting to reduce to a single criterion the determination of someone's future is doomed to failure. A single-dimensioned template for analysis is a "Mis-measure" of man⁴.

Confusion between causality and correlation is an ever present temptation and a pitfall for any kind of research. Comparison of a few criteria, which appear to be highly significant because they are related, may lead to an erroneous belief in causality. Biological examples of such false causality abound in the history of medicine, but behavioural studies are particularly prone to this confusion, so that purposeless individual preventive action can be constructed on the foundation of merely probabilistic statistical projections.

The report also points out — although it does not entirely take it into account — an important concept:: the onset of early symptoms of the "disorder" in children does not appear to correlate with the social, economic and cultural background of the family. Well-off and underprivileged families are equally affected. Inversely, a number of studies clearly indicate that a large proportion of young adults and minors in custody spent their childhood in underprivileged social, economic, cultural and educational⁵ circumstances. The expert report's tendency to find genetic causes or cerebral susceptibilities of a neurobiological nature playing a preponderant role in future development to violent forms of delinquency, would seem to postulate and beg the question rather than take full account of the available data. Social or environmental factors would seem to be at least as decisive a factor for ulterior behaviour as the individual genetic, neurobiological or psychological factors affecting a particular child.

2. On a scientific level, does the INSERM report take sufficient account of environmental factors affecting the appearance of behaviours?

The experts' report states that 50% of "behavioural disorders" are inherited and of a genetic nature. All then that would remain to be done would be to identify in children the genetic sequences involved in the development of this "disorder"...

One of the main arguments put forward by the expert report in favour of "behavioural disorders" governed by genetic heredity is based on a traditional interpretation of the findings of scientific research on twins. The degree of correlation for the "disorder" in genetically identical twins, is not the same as in non-genetically identical fraternal twins exposed to the same environment during gestation. This agreement is traditionally interpreted as

⁴ Stephen Jay Gould. *La Mal-mesure de l'homme* (1981). Le livre de Poche, 1997. Et *La Structure de la Théorie de l'Evolution* (2002). Gallimard, 2006

⁵ See CCNE's Opinion n°94, *Health and Medicine in Prison*.

proof of the existence of dominant genetic causality. In fact, such agreement does not signify necessarily that there are specific genes responsible for behavioural disorders. It may simply be evidence of a similar response to exogenous factors present in the maternal environment, as has been demonstrated in animal models (cf. Annex I).

More generally, the expert report ignores a whole body of significant research in the last ten years in an important branch of biology, which is the relationship between genes and the environment. This is one of the important aspects of biological research on the relationship between innate and acquired characteristics, which is advancing at a great pace and reveals that the environment may modulate, even during embryonic development, the way in which genes operate.

3. The risk of stigmatising children

One of the risks of biomedical research and of medical practice, particularly in fields where the way in which a person is regarded may be modified, particularly when that person is a child, is that they may have a harmful effect on those which the research thought to designate neutrally and objectively. It is therefore essential when a reliable item of information on a child's state of health is known, a diagnosis of genetic disease for example, to avoid carefully any attitude which could stigmatise the child. When the information is to some degree unreliable, obviously an even greater degree of prudence is essential. Would not three to four year olds, considered (for how long?) to be "at risk" of progressing towards violent forms of delinquency, run the risk of being isolated and stigmatised, of being seen as children who are "different" and dangerous and to be, both in and out of school, in a lasting situation of loss of opportunity and exposed to exclusion?

A number of studies show that a negative view of a child can have negative consequences on that child's capacities (Annex 2).

Preventive medicine with a view to early and well adjusted treatment for children who are presenting signs of psychic distress is not to be confused with predictive medicine which, paradoxically, would imprison such children in a future that would not have materialised for most of them if they had not been *screened* and *identified*. The danger is that such prophecies can be self-fulfilling, in other words, to make something happen merely by predicting it.

There are circumstances — and therein lies the problem with "behavioural disorders" — where the medical professions may be tempted to step into the shoes of the judiciary and decide to devote their time to preventing delinquency, forgetting that their primary mission is to alleviate suffering. And when the sufferer is a very young child with behavioural problems, a doctor's first duty is to view that child as distressed and endangered, needing help, and not as a potentially dangerous child — a future delinquent — from whom society must be protected.

CCNE is reiterating on this occasion its opposition to medicine used to protect society at the expense of individuals, particularly when those concerned are very young children.

4. The respective roles of the medical professions and third parties

When human behaviour is under consideration, the involvement of non-medical actors (teachers, parents, administrative authorities) may be desirable as long as their role is limited to contributing to an evaluation of the means of prevention and does not imply imparting diagnostic information, which must continue to be protected by the principle of medical confidentiality.

Prescribing psychotropic or anxiolytic drugs to young children, for the treatment of symptoms as part of a preventive strategy, is an easy option which society must beware of. Apart from the social and medical assistance mentioned above, there is no known validated therapeutic strategy at the present time for reducing the risk of violence connected to behavioural disorders. Prescribing psychotropic or anxiolytic drugs for very young children could simply mask behavioural disorders and obscure symptoms without treating their underlying causes.

5. The advantages and limitations of meta-analysis

Summaries of international scientific and medical publications — meta-analyses — are extremely useful to judge the progress of knowledge on a given subject at a given time. They are one of the foundations of evidence-based medicine, but they cannot be simply accepted in the absence of any critical examination since they are themselves the subject of research and constant fluctuation. Several possible stumbling blocks must be considered.

On the one hand, as mentioned previously, it is important to go further than a simple inventory of scientific and medical international publications in a restricted area of research; scientific progress in other fields must also be considered (the example of the effects of their environment on identical twins is a good illustration of this point). To make a critical and multidisciplinary approach possible, the expert group's membership itself must be sufficiently multidisciplinary.

Finally, an expert opinion based entirely on meta-analysis could produce a backward-looking view ignoring recent progress on the subject under study.

Although taking stock on a continuous basis of the progress of scientific knowledge is essential, such inventories must be viewed not as the definitive status of a branch of knowledge, but as a starting point on which to base reflection, practices and research.

6. The selection of experts

The referral queries the selection of experts and requests CCNE's opinion on the subject. In this case, the absence of any contradictory expert report or of initial consideration regarding the significance of the question, raises an ethical problem. The selection of experts, the formulation of the questions put to them and the methods they use do have some incidence on the nature of their conclusions. As it stands, it may seem regrettable (and for that matter members of INSERM did express such reservations in a symposium⁶ on the subject of "behavioural disorders" organised by the Institute on November 14, 2006), that almost all the experts in the group represented the single interface of biology and psychiatry. In fact, the matter raised by CANAM covers multiple issues and concerns related to scientific, medical, human, psychological and sociological dimensions. Broaching themes as complex as "deviant attitudes", "selfish" or "detrimental to others' rights" requires adequate tools for evaluation and the participation of psychologists and experts in the human and social sciences. In fact, the group of experts selected did not satisfy this multidisciplinary requirement. These considerations, already put forward by INSERM's Committee of Ethics, do not of course only apply to the single report which was the object of the present referral. They also apply globally to all collective expert reports with a bearing on societal issues. But they reinforce the ethical reservations expressed by CCNE concerning the conclusions of this report.

Recent developments in collective expert reporting within INSERM, as announced at the 2006 symposium on behavioural disorders, take account of the need for prior consultation of INSERM's Committee of Ethics on the subject of the selection of experts.

In conclusion

The report tends to confuse risk factor and effective causality. It is based on a postulate which gives prominence to the innate (genetic factors, cerebral predisposition, etc.) at the expense of the acquired (economic, social, cultural, educational and family-related environmental factors, etc.). It suggests a linear and reductive approach of human behaviours and thus raises several epistemological and ethical problems.

There seems to be a fairly general consensus that, leaving aside some serious diseases and infirmities, most childhood behavioural disorders are connected to environmental or family-related factors rather than discernible genetic or somatic characteristics. The identification of such possible factors, which could prove to be predictive of the persistent or transient nature of these behavioural traits and of their possible progression to violent and delinquent behaviour, is still subject to a degree of uncertainty. In the circumstances, prevention based on screening for predictive evidence of this

⁶ See http://www.inserm.fr/fr/questionsdesante/rapports/trouble_conduites.html; and a summary of the discussion in *Pour La Recherche, Bulletin de La Fédération Française de Psychiatrie* n° 51, December 2006, pp 2-7

type, together with the establishment of a written record, cannot be justified by the hypothetical benefit that might be expected of it. The supposed advantages remain doubtful, or at least minimal, compared to the unquestionable ethical risk of burdening a child by early stigmatisation, which would be difficult to invalidate and which could aggravate the child's distress instead of alleviating it.

Nevertheless, CCNE remains convinced of the extreme importance of the psychological risks to which a growing number of young children are exposed. Controlling such risks is one of the major challenges of the public health system. As several studies [*family-related factors [...] and dysfunction within the family are predominant*], quoted in the INSERM report have underlined, a precarious environment for a young child, exposure to physical or moral violence, or the spectacle directly or via the media of such violence, a state of crisis in the transmission of values, are the most potent factors affecting the risk of behavioural disruption in adolescents.

These considerations concur with those of previous reports⁷ recommending substantive action, in particular:

- Improving the psychological and medical assistance and counselling provided to parents in difficult circumstances: underprivileged mothers (several studies have demonstrated that they obtain much less help and care than the population at large), adolescent pregnancies, drug addiction, a history of violence, etc.) by closer coordination between medical professionals and social workers before, during and after birth;
- Giving children living in economically, culturally or emotionally precarious environments additional support as a complement to existing structures (crèches specialising in prevention, therapeutic kindergartens).

Recommendations

CCNE therefore:

- Insists on the need to make a clear distinction between prevention and prediction; in particular when such prediction is of a probabilistic nature and has no individual pertinence.
- Emphasises that in this case, the person suffering is a child; protection of the child must be viewed as a priority.
- Draws attention to the serious ethical issues that hasty interpretation and inadequate explanation of the studies mentioned in

⁷ Report « Périnatalité et Parentalité » submitted in February 2006 to the Minister for Social Security, the Elderly, the Disabled and Family Matters by Senator M.T. Hermange.

the INSERM report could cause, since they recommend a medicalisation of problems which are mainly related to factors affected by the social, economic and cultural environment. The utmost caution must be exercised when faced with the risk-laden option of relying too heavily on psycho-pharmacological treatment. There is a still poorly evaluated risk that such treatment could generate drug dependence and the future development of a child put in jeopardy. There is no tangible evidence that such medication is a sensible course in the absence of other accompanying management.

- Considers unjustified the communication of biological or medical data to institutional representatives and in more general terms, possible exceptions to the rule of medical confidentiality, which could lead to stigmatising individuals on the basis of criteria for which the connection to subsequent behaviour is not established. Simplifying a person's character to fit fragmentary parameters always contains a risk of arbitrary interpretation and exclusion. Creating a medical record containing such information could well increase the risk of stigmatisation.
- Underlines the major importance of effective prevention based on correcting environmental factors which contribute to psychic distress or behavioural disorders judged to be deviant. CCNE strongly recommends the early implementation of validated preventive measures, in particular extending to all the population concerned, (specially people in a precarious situation) the benefit of parental and infant protection.
- Considers to be most desirable that all the actors of prevention — parents, paediatricians, psychologists, paedopsychiatrists, teachers, nursery nurses, vocational counsellors, teachers, doctors and school nurses — be associated in the design and follow-up of such measures. CCNE insists on the importance of encouraging the development of paedopsychiatry and in particular increasing the possibilities of recourse to paedopsychiatrists.
- Considers positive the proposal to appoint a coordinator with the task of ensuring that all participants work in harmony and with due regard for the interdisciplinary nature of their activity.
- Considers important an evaluation of the methods used for the management of children with a view to achieving appropriately adjusted counselling.

In conclusion, CCNE cannot approve the intention of situating preventive medicine within the sphere of repression, so that a child is seen as a danger and *de facto* loses the status of victim to become guilty by presumption. An

approach which consists in predicting an evolution to violent forms of delinquency based on early behavioural disorders is not substantively pertinent in the present state of scientific knowledge. It must therefore be proscribed since available parameters are not sufficiently significant to rid the process of the taint of social and ideological prejudice still prevalent in our societies. Reflection on the differences between prediction, counselling and prevention should be encouraged in all sectors of society, in particular by those involved in the management of children.

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Annex 1

The studies compare the degree of concurrence of these disorders in identical and fraternal twins, i.e. genetically-identical and non genetically-identical twins. As in both cases, embryonic development is simultaneous and therefore exposed during pregnancy to the same environment-related factors, a greater degree of concurrence in identical twins is traditionally interpreted as the proof of a genetic cause playing a direct role in certain specific genetic sequences leading to development of the disorder.

However, the fact that two genetically-identical children display a given characteristic more frequently than two non genetically-identical children does not necessarily signify that they possess the genes "corresponding" to that characteristic, in this case the genes directly involved in the development of "behavioural disorders". In fact, although twins may be genetically identical, the same modification of their environment during intra-uterine development, delivery or immediately following birth — hypoxia (lack of oxygen), a maternal hormone, a toxic product, etc. — would have a greater probability of having the same effect, which might have similar expression after birth, without any of their genes being involved in causing this expression, except in so far as there is similarity in the response threshold to a modification in the environment. Furthermore, recent research using animal models shows that when particular genetic sequences are involved in such effects, they may, in an apparently paradoxical manner, be maternal genetic sequences. These genetic sequences would seem to have an indirect influence on the cerebral development of identical twins during pregnancy or during delivery, by modulating for example the quantity of certain neurotransmitters or hormones released by the mother⁸. The genetic sequences themselves may be absent in the children.

In other words, even when the causality sequence implies genetic factors, recent research indicates that the causality sequence is not as easy to interpret as is suggested by traditional notions regarding heredity.

The expert report insists on the importance of lessons that could be drawn from the study of animal models. However, the report fails to mention recent results obtained from animal models relating to the role of epigenetics in determining behaviour. Various forms of epigenetic heredity involved in certain forms of behaviour have recently been evidenced where it is the environment which modifies the way in which genes are put to use during development in each generation of newborns and even foetuses. In these forms of heredity, or to be more precise these forms of re-emergence of certain behavioural traits over several generations, the effects of the environment on the way in which certain body cells use their genes are involved, not a particular gene sequence⁶.

⁸ See for example Cote F *et al.* *Proc Natl Acad Sci USA* (2007)104:329-334 ; and Tyzio R *et al.* *Science* (2006) 314 :1788-1792

The geneticist Richard Lewontin wrote: "The inside and the outside do indeed interpenetrate and the organism is both the product and location of that interaction."⁹. One cannot be content with examining one or the other without an understanding of the fact that they are inextricably connected. This is all the more true when it refers to the complex development of most human behaviours, where cultural, family-related, social, psychological, educational, anthropological, legal, economic — and many more — dimensions play an essential role.

⁹ Richard Lewontin. *The Triple Helix: Gene, Organism, and Environment*, Harvard University Press (2000).

Annex 2

In a recent study in India, for example, children aged 11-12, either "higher" caste or "lower" caste, were asked to solve a problem. Their caste had no statistical influence on the quality of results. But when the test was performed after their caste was made known, the results given by lower caste children were significantly worse¹⁰. And so it was shown that the simple fact of imagining the negative influence that an item of information could have on the examiner affects the child and produces an increase in the probability of failing the test.

¹⁰ Hoff K, Pandey P. World Bank Policy Research Working Paper. Report n° 3351. Washington DC : World Bank, 2004