



CONSEIL NATIONAL DU SIDA
25-27 RUE D'ASTORG
75008 PARIS
T. 33 [0]1 40 56 68 50
F. 33 [0]1 40 56 68 90
CNS.SANTE.FR

REPORT

PUBLIC ACTION

EN

2001 JANUARY 9TH

THE NATIONAL AIDS COUNCIL IN 2001 : CURRENT OVERVIEWS AND FUTURE PROSPECTS

The National AIDS Council (NAC) was set up in 1989 as part of a new institutional structure specialising in the fight against HIV/AIDS and adopted following the report of Professor Got. This structure included the setting up of three new institutions dedicated respectively to prevention, research and ethics. As a complement to the French Agency for the Fight against AIDS (AFLS) and the National Agency for Research into AIDS (ANRS), the National AIDS Council was assigned the task of "to advise on all AIDS-related societal problems and to put forward to the Government all and any relevant proposals" (Article 1 of Decree no. 89-83 of February 8, 1989).

The composition of the NAC is somewhat similar to that of the National Advisory Committee on Ethics (CCNE). However, the Council has fewer figures from the world of science and medicine appointed for their expertise, and proportionately more from civil society. In addition to the Chairman, who is appointed by decree by the President of the Republic, the 22 members of the NAC are grouped into 4 colleges : those representing the main philosophical and devotional tendencies, appointed by the President of the Republic (5 members) ; the representatives of the legislative assemblies, designated by the respective Speakers (2 members) ; experts, appointed by the Prime Minister, half at the suggestion of the Minister of Solidarity and Health (8 members) ; and prominent figures designated by the presidents of the various representative institutions (7 members). The National AIDS Council is assisted by a small permanent team, which currently includes 5 individuals.

Half of the membership was renewed in 1992, 1994, 1997 and 1999, and the National AIDS Council is now beginning its second decade of existence in an epidemiological and institutional context which has undergone significant change.

The major changes in the AIDS epidemic during the 1990s, in France as in all developed countries, are well known. The advances in treatment methods which have been made, particularly since the introduction of protease inhibitors in 1996, have enabled improvements in the clinical and biological state of health of HIV-positive individuals, irrespective of the stage the illness has reached, and a delay in the time taken for the infection to become AIDS. The number of new cases of AIDS diagnosed has fallen from around 5,700 in 1994 to around 1,800 in 1998 and approximately 1,500 in 1999 ; likewise, the number of deaths caused by AIDS, which was around 4,100 in 1994, was estimated as being in the region of 700 in 1998 and approximately 600 in 1999. These estimates, which are still provisional, demonstrate a considerable reduction in the number of new cases of AIDS diagnosed and of deaths due to AIDS, even if the rate of decrease has been slowing since 1997. Inasmuch as hundreds or thousands more individuals are infected each year (we have no precise figures), the number of asymptomatic HIV-positive individuals and of individuals suffering from AIDS is increasing, as is the number of patients receiving treatment (the hospital active waiting list has increased by 25 % since 1996).

At the institutional level, some of these developments relate to the public organisations responsible for the fight against AIDS.

The activities of the AFLS ceased in 1994, following the report by Professor Montagnier, the definition of action to be taken concerning prevention then being assigned to the AIDS Division (set up at that time) within the General Health Directorate (DGS).

In July 2000, the administration of the Ministry of Employment and Solidarity was thoroughly overhauled.

The AIDS Division became a "Fight against HIV" bureau (6A) within the 6th sub-division "Health and Society" of the DGS ; infectious diseases became the concern of a bureau (5C) in another subdivision ("pathologies and health").

The "AIDS Task Force" set up in 1987 within the Hospitals Directorate (DH), after having been changed in January 1998 into a "pathologies and healthcare organisation" bureau with wider coverage (AIDS, Hepatitis C, cancerology, drug addiction), has now disappeared as such : hospital treatment of AIDS (and of Hepatitis C) is now the responsibility of the "quality and safety of healthcare in health establishments" bureau (E2) of the "health establishment quality and operation subdivision" of the Directorate of Hospitalisation and Healthcare Organisation (DHOS), which has replaced the DH.

These successive developments should be seen as part of the process of 'normalisation' of public action in the field of HIV-AIDS, so that ad hoc type structures are tending to disappear (cf. AFLS) or to lose their specific role and/or prominence (AIDS Division, Aids Task Force), in favour of integration into structures with wider remits.

Another significant development in the process of 'normalisation' of public action concerns the extension of the remits of structures involved with HIV to include Hepatitis C : this is the case not only for DHOS but also for ANRS. This coupling of HIV and Hepatitis C, which can be justified by the proximity of the two types of virus and the growing number of co-infections, can also be observed at very different levels (the press organs of not-for-profit associations, whether generalist or specialising in healthcare information, the special telephone help line of AIDS Info Service, and so on.).

The voluntary associations involved in the fight against AIDS – whose role in encouraging the authorities to act and in developing public policy, as well as their action in the field, has been decisive in containing the HIV epidemic – have also undergone important changes.

They are currently experiencing difficulty in recruiting activists and volunteers, financial problems (in 1999 'Vaincre le sida' closed down, and there are considerable delays in receiving public authority grants), and problems in relations with the authorities (decline in dialogue and co-operation).

Many such associations have publicly voiced their regret at the present government's low level of commitment to, and even, in some cases, its withdrawal from the HIV-AIDS field, and they are awaiting the definition of new guidelines in response to the new challenge which the epidemic poses for French society and for those already infected.

These associations also see in the absence of any clear, visible policy direction for the fight against HIV-AIDS one of the factors explaining the growing indifference of public opinion and the media with regard to the "AIDS issue" (e.g. the relative decline in numbers attending the demonstrations of December 1, or at 'Sidaction').

However, a certain number of goals and issues have appeared recently on the political and administrative agenda, both national and international, which underline how important a challenge HIV-AIDS remains today. Without claiming to be exhaustive, the following points can noted :

- the relaxation of prevention-focused behaviour in sexual relations ;
- the appearance and the worsening of the phenomenon of therapy failure (resistance to antiretroviral multitherapy) ;
- a reorientation of policy for the fight against drug use to take account of lessons learned on risk reduction ;
- the identification of migrants as a group particularly at risk where HIV is concerned ; the recognition of the link, currently growing, between social insecurity or vulnerability and HIV infection ;
- the emergence or upsurge of chronic illnesses associated with HIV, such as tuberculosis or hepatitis B and C, in population groups whose situation is highly insecure ;
- work and discussions on the question of access to insurance cover for individuals suffering from serious medical conditions ;
- new measures concerning access to contraception and termination of pregnancy ;
- conflict surrounding the definition of the compulsory declaration of HIV-positive status ;
- international mobilisation against the explosion of the HIV epidemic in developing countries where treatment is unavailable ;
- the implementation of a Temporary Use Permit (ATU) in the European Union.

Some of these goals and issues, over and above their specific nature, raise the question of the 'normalisation' of AIDS as a social problem, in other words, the process whereby AIDS is becoming an everyday event, against the background of an overall change in the perception of the risk it represents. They are also part of a wider context : that of the redefinition of public health policy, which can be considered from the ethical standpoint (cf. the forthcoming overhaul of legislation on bio-ethics), from that of health safety or from the point of view of "healthcare democracy" (cf. the white paper on the rights of patients). The direction taken by policies on the fight against HIV is inseparable from this general context.

The questions which this report on the past and future activities of the National AIDS Council must address are, therefore, concerned with the continuation or the re-examination of the tasks which it is assigned. It is not the job of the National AIDS Council to give an appraisal of its activities, which can only be done by an external body, or on the justification for its existence, which depends on the political choices made by the elected representatives of the nation. On the other hand, it is possible, and useful, for it to reflect on the appropriateness of its missions in view of the scale of the problems HIV-AIDS poses for French society today, bearing in mind the double process of normalisation as outlined above (firstly in terms of the perceived risk involved with HIV, and secondly in terms of the direction given to the specific structures dealing with public action which were set up in France at the end of the 1980s).

Are the functions which the National AIDS Council has carried out for the last 10 years still needed ? Is the HIV-AIDS epidemic sufficiently 'under control' to be handled by generalist or routine structures rather than specific ones ? Do the debate and the activities concerning hepatitis C, now seen as a major public health hazard and as constituting a not inconsiderable epidemic risk,

form the first step towards a widening of the scope of those organisations involved in the fight against HIV to include other medical conditions ? Does the move towards "healthcare democracy", which is beginning to take shape in legislative circles, strengthen the need for general-purpose organisations, handling the entire range of medical conditions and handicaps ? These are the main issues which will be considered in this report.