

CONSEIL NATIONAL DU SIDA 7 RUE D'ANJOU 75008 PARIS T. 33 [0]1 40 56 68 50 F. 33 [0]1 40 56 68 90 CNS.SANTE.FR

PREVETION, SEXUAL BEHAVIOUR

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THOSE LEFT ASIDE BY PREVENTION PROGRAMMES: REPORT FOLLOWED BY RECOMMENDATIONS ON THE MENTALLY HANDICAPED, SEXUALITY AND HIV

Having completed its Report, and as a preface to its recommendations, the National AIDS Council wishes to emphasize the extreme diversity of the situations encountered, a diversity related both to the degree of independence enjoyed by mentally handicapped individuals and the character of the institutions caring for them.

The National AIDS Council notes the desire expressed by some leaders of associations of relatives of the mentally handicapped, in particular the UNAPEI Ethics Committee, to raise the issue of HIV within specialist institutions: this testifies to a determination to bring more information, transparency and objectivity to the debate on sexuality in such institutions.

However, the Council notes the following:

- 1. the absence of any epidemiological study of HIV in the mentally handicapped population;
- 2. an increase, due to the institution, in the vulnerability of the most independent mentally handicapped individuals in relation to the risk of HIV infection;
- 3. the fact that the application of HIV risk reduction policy is lagging behind in specialist care establishments.

The National AIDS Council therefore makes the following recommendations:

- 4. a genuine debate on the rights of the mentally handicapped should be initiated, leading to recognition of a true right to privacy for them;
- 5. a series of general measures :
 - Institutions

the National Advisory Council for the Disabled should be reactivated and more publicity given to its work;

a working group on handicapped adolescents should be set up in preparation for the creation of specialized institutions for adolescents;

training schemes should be organized in schools for young people with special needs with a specific focus on the issue of the sexuality of the mentally handicapped.

Research

research should be undertaken in the social sciences regarding sexuality, AIDS and STDs in specialist care contexts on the basis of a call for tenders made by the ANRS, which should look at methods modelled on those used to study sexual behaviour in the general population, young people and French territories in the Americas;

non-correlated epidemiological surveys (of Prevagest type) should be carried out in the mentally handicapped population.

• At the practical level

activities focused on issues related to the body and health should be organized as part of welfare/education programmes;

the provision of private spaces for residents should be improved inside institutions;

regional meetings on all these issues should be organised for teachers of young individuals with special needs;

discussion and information groups should be set up for family members.

6. pragmatic attitudes:

systematic, compulsory HIV screening should not be imposed on the residents of institutions;

if an HIV test is prescribed by a doctor, generally accepted rules of confidentiality must be followed, and the results should be given only to the person concerned or possibly to his or her legal guardian, in addition to those they may consider it necessary to inform.