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NEW AIDS DEFINITION WILL SIGNIFICANTLY INCREASE
NUMBER OF CASES REPORTED BUT MAY STILL FAIL
TO ADEQUATELY CAPTURE SOME MAJOR RISK GROUPS

A new definition of acquired immunodeficiency syndrome (AIDS), expected in 1992 from the Centers for Disease Control (CDC), would increase the number of cases reported but could still leave some major risk groups underrepresented, says the congressional Office of Technology Assessment (OTA) in a background paper released today.

The AIDS case definition, first developed by the CDC in 1982 and revised in 1985 and 1987, is the primary public health surveillance tool used to determine the scope of the AIDS epidemic. The 23 AIDS-defining conditions in the current definition, including Kaposi's sarcoma and *Pneumocystis carinii* pneumonia, mark the final stage in the progression of HIV infection. These AIDS-defining conditions are rarely found in persons whose immune systems are not compromised. Persons who have any of these AIDS-defining conditions and who meet other condition-specific criteria, (e.g., an age requirement or the requirement for a positive HIV antibody test), are considered to have AIDS.

Some critics have faulted the current definition of AIDS for not including some severe manifestations of HIV infection that are found more often in women and injection drug users -- a disproportionate number of whom are African Americans or Hispanics-- thus resulting in an underestimation of the impact of the epidemic on these populations and hindering their access to Federal programs.

The CDC's proposed AIDS case definition will include all HIV-infected persons who have any one of more of the 23 AIDS-defining conditions included in the current definition. In addition, the case definition will be expanded to include all HIV-positive persons with CD4⁺ lymphocyte counts below 200 cells per cubic millimeter (/mm³) of blood. The CD4⁺ lymphocyte count is a laboratory measure of the progression of HIV-related immunosuppression.

The inclusion of a laboratory measure of immunosuppression in the case definition will have several advantages for AIDS surveillance, says OTA. AIDS surveillance data will better reflect the extent of severe immunosuppression due to HIV infection in the U.S. population. The CDC estimates that the proposed expansion in the AIDS case definition will increase the total number of AIDS cases in the United States by 52 percent, and State and local health departments estimate that the increase will range from 36 to 135 percent. AIDS case reporting may be simplified because it is a standard of clinical care for physicians to monitor the CD4⁺ lymphocyte counts of their HIV-infected patients. AIDS surveillance may be facilitated by enlisting clinical laboratories that perform CD4⁺ testing to help identify potential AIDS cases.

OTA notes that despite its advantages, the CD4⁺ lymphocyte count is not a perfect AIDS surveillance tool. Because many HIV-infected persons with a CD4⁺ lymphocyte count below 200 cells/mm³ will be symptom-free and may not seek health care, the completeness of reporting may be difficult to assess. Furthermore, populations with better access to testing will be overrepresented among identified AIDS cases. HIV-infected women and injection drug users are on average poorer than members of other AIDS risk groups, and may have less access to CD4⁺ testing. The proposed definition will, however, capture an increasing proportion of profoundly immunosuppressed HIV-infected women and injection drug users who do not have AIDS-defining conditions.

In the first years after the proposed case definition is implemented, epidemiologists anticipate that the CDC will lose its ability to follow trends in the incidence of AIDS. However, once all prevalent cases (those HIV-infected persons who currently have a CD4⁺ lymphocyte count below 200 cells/mm³ but who do not have one of the 23 AIDS-defining conditions) are reported, the CDC will regain this ability.

The proposed change in the AIDS case definition raises privacy concerns because there will be an increased number of persons with AIDS who will be reported by name to State and local health departments. In planning to implement the new definition, States should reassess current laws and operational procedures that protect the confidentiality of CD4⁺ test results. In addition, several States have proposed to have clinical laboratories report the names of persons with low CD4⁺ lymphocyte counts to State and local health departments. The State and local health departments can then follow-up with the treating physician to determine whether the person should be reported as an AIDS case. Because the CD4⁺ lymphocyte count can be depressed in other diseases, some persons reported as likely AIDS cases may not be infected with HIV.

The CDC case definition has also been used as a clinical definition by physicians, in research protocols, and in the allocation of Federal funds under the Ryan White Comprehensive Resources Emergency Act of 1990 and the AIDS Housing Opportunity Act of 1990. It is not clear the change in the CDC definition of AIDS will have an impact on clinical care, and OTA maintains that clinicians need to be aware that there is a broader spectrum of HIV-associated conditions than is included in the AIDS surveillance definition. Because the number of AIDS cases will increase, more metropolitan areas will qualify for funding under the Ryan White Comprehensive Resources Emergency Act of 1990, and the increase in AIDS cases may alter the distribution of funds among metropolitan areas and States. In addition, more cities and States will be eligible for funds from the AIDS Housing Opportunity Act of 1990, although the U.S. Department of Housing and Urban Development has yet to distribute funds under the act.

The CDC definition has been used as a measure of disability in benefit programs administered by the Social Security Administration (SSA) in the Department of Health and Human Services. The use of the CDC surveillance case definition of AIDS as a disability definition by SSA, a purpose the definition was not intended to serve, says OTA, has resulted in considerable controversy and at least two legal challenges. Advocates for HIV-infected persons alleged that some HIV-infected women and injection drug users were being wrongly denied disability benefits because their illnesses were not included in the AIDS case definition. For many people, eligibility for Social Security disability benefits also enables them to obtain Medicaid, a Federal/State-funded medical insurance program. The Social Security Administration has strongly denied these allegations and notes that close to 50 percent of HIV-infected persons who apply for disability benefits are awarded these benefits. Nonetheless, the numerous examples of HIV-infected women and men who were denied disability are unexplained.

The SSA recently issued regulations substantially revising its disability criteria for all HIV-infected persons, including persons with AIDS. The new criteria, which have been criticized by medical groups and AIDS advocates as being too restrictive, demonstrate that the change in the CDC definition of AIDS will not directly result in additional HIV-infected persons obtaining disability.

Copies of the 93-page background paper *The CDC's Case Definition of AIDS: Implications of the Proposed Revisions* for congressional use are available by calling 4-9241. Copies for noncongressional use can be ordered from the Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402-9325; phone (202) 783-3238. The GPO order number is 052-003-01293-6; the price is \$5.50.

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