Appendix A--Glossary of Acronyms and Terms

Abbreviations

ADA --Americans With Disabilities Act of 1990 (Public Law 101-336)

AHCPR --Agency for Health Care Policy and Research (Public Health

Service)

AIDS --acquired immunodeficiency syndrome

APA --Administrative Procedure Act

ARC --AIDS-related complex

AZT --azidothymidine (now zidovudine)

CAP --College of American Pathologists

CDC --Centers for Disease Control (PHS)

CFR --Code of Federal Regulations

CNS --central nervous system

CRS --Congressional Research Service (U.S. Congress)

CSTE . --Conference of State and Territorial Epidemiologists

DDS --State Disability Determination Service (SSA)

DHHS --U.S. Department of Health and Human Services

DI --Social Security Disability Insurance

ELISA --enzyme-linked immunosorbant assay

FR --Federal Register

FY --fiscal year

GAO --General Accounting Office (U.S. Congress)

HIV --human immunodeficiency virus

HPV --human papilloma virus

HRSA --Health Resources and Services Administration (DHHS)

HTLV - III --human T-cell lymphotropic virus, type 111 (now referred to as

HIV)

HUD --U.S. Department of Housing and Urban Development

LAV --lymphadenopathy-associated virus (now referred to as HIV)

MACs --Multicenter AIDS Cohort Study

NIAID --National Institute of Allergy and Infectious Diseases (NIH)

NIH --National Institutes of Health (PHS)

OR --Office of Research (Health Care Financing Administration)

OTA --Office of Technology Assessment (U.S. Congress)

PCP --pentachlorophenal

PHS --Public Health Service (DHHS)

PID --pelvic inflammatory disease

POMS --Program Operations Manual System (SSA)

SSA --Social Security Administration (DHHS)

SSI --Supplemental Security Income

SSR --Social Security Ruling

U.S. C. --United States Code

Terms

- NOTE: # AIDS-defining condition
- Access: Potential and actual entry of a population into the health care delivery system.
- Activities of daily living: Activities related to personal care, including bathing, dressing, getting in and out of bed or a chair, using the toilet, and eating.
- Acquired immunodeficiency syndrome (AIDS): See AIDS.
- Administrative law judge: One who presides at an administrative hearing, with power to administer oaths, take testimony, rule on questions of evidence, and make agency determinations of fact.
- African Americans: Americans having origin in any of the black racial groups in Africa.
- AIDS (acquired immunodeficiency syndrome): A condition, caused by infection with the retrovirus human immunodeficiency virus (HIV), in which the primary defect is an acquired, persistent, and profound functional depression in cell-mediated immunity; this depression often leads to infections caused by micro-organisms that usually do not produce infections in individuals with normal immunity (e.g., Pneumocystis carinii pneumonia) or to the development of rare cancers (Kaposi's sarcoma, B-cell non-Hodgkin's lymphoma) that occur more frequently in immunocompromised individuals than in persons with normal immunity. HIV infection can be transmitted from one infected individual to another by means that include the sharing of a contaminated intravenous needle and engaging in unprotected sexual intercourse (i.e., intercourse without the use of a condom) with an infected person. See also CDC's case definition of AIDS.
- AIDS-defining condition: In the Centers for Disease Control's (CDC) 1987 surveillance case definition of AIDS, a person who has any of the following 23 indicator conditions -- and who meets other conditions specific criteria specified in the definition (e.g., an age requirement, a requirement for a positive HIV test)--is considered to have AIDS:
 - 1) candidiasis of bronchi, trachea, or lungs;
 - 2) candidiasis, esophageal;
 - 3) coccidiodomycosis (disseminated or extrapulmonary) ;
 - 4) cryptococcosis (extrapulmonary);
 - 5) cryptosporidiosis (chronic intestinal, with diarrhea of more than l-month's duration);
 - 6) cytomegalovirus disease of an organ other than the liver, spleen, or nodes;
 - 7) cytomegalovirus retinitis (with loss of vision)
 - 8) HIV encephalopathy;
 - 9) herpes simplex virus infection causing chronic ulcers or bronchitis, pneumonitis, or esophagitis;
 - 10) histoplasmosis (disseminated or extrapulmonary) ;
 - 11) isosporiasis (chronic intestinal of more than 1-month's duration);

- 12) Kaposi's sarcoma;
- 13) lymphoma, noncleaved small cell (Burkitt's or non-Burkitt's);
- 14) lymphoma, immunoblastic or large cell;
- 15) lymphoma, primarily in brain;
- 16) Mycobacterium avium complex or M. kansasii (disseminated or extrapulmonary);
- 17) Mycobacterium tuberculosis (disseminated or extrapulmonary) ;
- 18) Mycobacterium, other species or unidentified species (disseminated or extrapulmonary);
- 19) Pneumocystis carinii pneumonia;
- 20) progressive multifocal leukoencephalopathy;
- 21) Salmonella septicemia, recurrent;
- 22) toxoplasmosis of the brain;
- 23) HIV wasting syndrome.

These 23 conditions are strongly associated with severe immunodeficiency, occur frequently in HIV-infected individuals, and cause serious morbidity or mortality. Some of these conditions, when diagnosed definitively or presumptively (i.e., on the basis of clinical signs and symptoms), are considered indicators of AIDS only if a patient has a positive test for HIV, but some of these conditions (e.g., *Pneumocystis carinii* pneumonia when diagnosed definitively) are considered indicators of AIDS even if a patient has a negative test for HIV.

In children (under 13 years old), additional AIDS-defining conditions apply that do not apply in adults or adolescents:

- 1) bacterial infections, serious and multiple or recurrent;
- 2) lymphoid interstitial pneumonia or pulmonary lymphoid hyperplasia.
- AIDS dementia: A form of dementia that is due to brain infection by HIV.

 AIDS dementia is an AIDS-defining condition (HIV encephalopathy) if severe (e.g., interfering with occupation or activities of daily living). See dementia.
- AIDS-related complex (ARC): A complex of signs and symptoms representing a less severe form of HIV infection than classic AIDS, characterized by chronic generalized lymphadenopathy, recurrent fevers, weight loss, minor alterations in the immune system, and minor infections. The term was used for a period of time by the medical community for persons infected with HIV and experiencing HIV-associated conditions and symptoms that were not included in the CDC definition of AIDS. Recently, however, the term has fallen out of use.
- AIDS surveillance: Monitoring trends in the number and distribution of AIDS cases and in the scope of severe morbidity due to infection with HIV. The responsibility and authority for AIDS surveillance rests with individual State and local health departments; these departments share their data with the Centers for Disease Control (CDC) in the U.S. Public Health Service.
- Ambulatory medical care: Medical goods and services rendered outside of a hospital or other inpatient health care facility, including such items as physician office visits, outpatient laboratory diagnostic services, and outpatient prescription drugs.

- Anal squamous cell carcinoma: A cancer of the anus with scaly or platelike cells. See also cancer.
- Anemia: A condition that exists when the level of hemoglobin in a person's blood drops to an abnormally low level (e.g., below 11 grams per deciliter of whole blood).
- Antibody: A blood protein (immunoglobulin) produced by white blood cells in mammals in response to the introduction of a specific antigen (usually a protein). Once produced, the antibody has the ability to combine with the specific antigen that stimulated antibody production. This reaction to foreign substances is part of the immune response.
- Antigen: A specific type of substance, usually a protein or carbohydrate, that when introduced into the body of a human or other mammal is capable, under appropriate conditions, of inducing a specific immune response (including antibody production) and of reacting with the products of that response (i.e., specific antibody or specifically sensitized T-lymphocytes or both) .
- Antiretroviral therapy: Therapy to combat retroviruses such as HIV.

 Antiretroviral therapy consisting of zidovudine to treat HIV-infected persons is recommended for all persons with a CD4 lymphocyte count below 500 cells per cubic millimeter (/mm³).
- Aspergillosis: A fungal infection caused by species of *Aspergillus* and marked by inflammatory granulomatous lesions in the skin, ear, orbit, nasal sinuses, lungs, and sometimes in the bones and meninges.
- Asymptomatic: Showing or causing no symptoms.
- AZT: See <u>zidovudine</u>.
- Bacteremia: The presence of bacteria in the circulating bloodstream, an indication of severe bacterial infection.
- Bacterial pneumonia: Pneumonia caused by bacteria (e.g., Streptococcus pneumoniae). Compare Pneumocystis carinii pneumonia.
- Bacterium (pi., bacteria): Any of a group of one-celled micro-organisms having round, rodlike, spiral, or filamentous bodies that are enclosed by a cell wall or membrane and lack fully differentiated nuclei. Bacteria may exist as free-living organisms in soil, water, organic matter, or in the bodies of plants and animals. Some, but not all, bacteria can cause disease.
- Bronchoscopy: Examination of the bronchi (any of the larger air passages of the lungs) through a bronchoscope (an instrument for inspecting the interior of the tracheobronchial tree).
- #Burkitt's lymphoma: A type of noncleaved small cell lymphoma, manifested most often as an osteolytic lesion in the jaw or as an abdominal mass. The Epstein-Barr virus, a herpes virus, has been implicated as a causative agent. In the CDC's 1987 case definition of AIDS, Burkitt's lymphoma is considered an AIDS-defining condition.

- Cancer: A tumor with the potential for invading neighboring tissue and/or metastasizing to distant sites, or one that has already done so.

 Cancers are categorized into major classes by their cell types. Thus, for example, a carcinoma is a cancer of the epithelia, including the external epithelia (e.g., skin and linings of the gastrointestinal tract, lungs, and cervix) and the internal epithelia that line various glands (e.g., breast, pancreas, thyroid). A sarcoma is a cancer made up of cells resembling embryonic connective tissue, which normally develops into tissues such as muscle, fat, bone, and blood vessels; sarcomas are often highly malignant. A lymphoma is a cancer of cells of the immune system (i.e., the various types of lymphocytes).
- Candida: A genus of yeastlike fungi of the family Cryptococcaceae, order Monillales, characterized by producing yeast cells, mycelia, pseudomycelia, and blastospores. It is commonly part of the normal flora of the skin, mouth, intestinal tract, and vagina, but can cause a variety of infections, including candidiasis. Candida albicans is the usual pathogen.
- #Candidiasis: Infection with a fungus of the genus Candida. It is usually a superficial infection of the moist cutaneous areas of the body and is generally caused by Candida albicans. In the CDC's 1987 case definition of AIDS, candidiasis of the esophagus, trachea, bronchi, or lungs is considered an AIDS-defining condition.
- Carcinoma: A cancer of the epithelia, including the external epithelia (e.g., skin and linings of the gastrointestinal tract, lungs, and cervix) and the internal epithelia that line various glands (e.g., breast, pancreas, thyroid).
- Cardiomyopathy: A general diagnostic term designating primary myocardial disease, often of obscure or unknown etiology.
- Case control study: Studies that compare a group of people with a disease (or other outcome event)--the cases--to another group without the disease--the controls--and then determine whether they differ in their previous exposure to a presumed causal agent. These studies are retrospective in nature, the exposure having occurred prior to the identification of the cases and controls.
- Case report form: See AIDS case report form.
- CDC's case definition of AIDS: The definition of AIDS, set forth by the Centers for Disease Control (CDC) in the Public Health Service of the DHHS, that is used in AIDS surveillance. In 1982, before HIV was identified as the agent that causes AIDS, the CDC defined AIDS as a disease, at least moderately indicative of an underlying defect in cell-mediated immunity, occurring in a person with no known cause for diminished resistance to the disease. With the identification of HIV as the causative agent for AIDS and the availability of laboratory tests to detect HIV antibody, the case definition was revised in 1985 and again in 1987 to reflect an increased understanding of HIV infection. The 1987 case definition lists 23 AIDS-defining conditions; these are severe

- life-threatening opportunistic diseases highly specific for HIV infection in persons who are not immunosuppressed for other reasons. Under the CDC's proposed case definition, to be implemented in the summer of 1992, individuals with CD4 lymphocyte counts below 200 cells/mm would be considered to have AIDS in addition to individuals who meet the criteria of the 1987 definition.
- CDC's classification system for HIV infection: A classification system developed by the Centers for Disease Control (CDC) to categorize the spectrum of manifestations of HIV infection for epidemiologic and clinical purposes. The classification system currently in use divides HIV infection into four broad categories (and numerous subcategories) based on patients' clinical disease states. In November 1991, the CDC proposed a new classification system for HIV infection that would divide HIV infection into nine mutually exclusive categories based on combinations of three broad categories of clinical conditions associated with HIV infection and three categories that reflect different ranges of patients' CD4 lymphocyte counts.
- CDC's Adult/Adolescent Spectrum of HIV Disease Project: A project, including nine centers throughout the United States, that was designed to examine the spectrum of disease associated with HIV infection. Participants are not a statistical sample of HIV patients. However, the project includes both public and private hospitals and clinics, including hospitals and clinics with a large number of indigent patients.
- CD4 lymphocytes: T-helper lymphocytes. CD4 lymphocytes are the primary target cell for HIV infection because of HIV's affinity for the CD4 lymphocyte cell surface marker. CD4 lymphocytes coordinate a number of important immunologic functions, and a loss of these functions results in a progressive impairment of the immune response.
- CD4 lymphocyte count: The absolute number of CD4 lymphocytes per cubic millimeter of blood. This figure is number calculated as the product of the total white blood cell count (white blood cells/mm3) multiplied by the percentage of lymphocytes (number of lymphocytes/number of leukocytes * 100) and the percentage of CD4 lymphocytes (number of CD4 lymphocytes/number of gated lymphocytes * 100). Calculating the CD4 lymphocyte count requires a hematologic measurement (the total lymphocyte count) and a flow cytometry measure (the CD4 percent of total lymphocytes). The CD4 lymphocyte count has been found to be a marker of the progression of HIV-related immunosuppression (i.e. , a decrease in the number of CD4 lymphocytes correlates with an increase in the risk and severity of HIV-related opportunistic infections, cancers, and other manifestations of HIV-induced immunodeficiency) . Under the CDC's proposed case definition of AIDS, to be implemented in the summer of 1992, any person with a CD4 lymphocyte count of less than 200 cells/mm³ of blood is considered to have AIDS.
- CD4 percent of lymphocytes: CD4 lymphocytes as a percentage of total lymphocytes. This figure is calculated as the number of CD4 lymphocytes divided by the number of gated lymphocytes (flow cytometry) multiplied by 100. The CD4 lymphocyte percent has been proposed as an alternative to the CD4 lymphocyte count because there is less

- variability inherent in the measurement of $CD4^{\dagger}$ lymphocyte percent. The $CD4^{\dagger}$ percent of lymphocytes is also technically easier to obtain, because it involves only a flow cytometry measurement.
- CD4 lymphocyte testing: The use of flow cytometry and hematologic measurements to determine a person's CD4 lymphocyte count or CD4 percent of lymphocytes. In the United States, there are 600 to 1,000 labs with capabilities to perform CD4 lymphocyte testing. The CD4 lymphocyte test costs most labs about \$50 plus personnel (an additional \$50) to perform. Charges range from \$50 to \$600, but the majority of labs charge between \$100 and \$150.
- Cell: The smallest membrane-bound protoplasmic body (consisting of a nucleus and its surrounding cytoplasm) capable of independent reproduction.
- Cell-mediated immunity: Immunity resulting from increase of activity by living cells in the blood and other tissues (e.g., T-lymphocytes, natural killer cells) that directly and nonspecifically destroy foreign material. See also immunity.
- Cervical cancer: Cancer of the uterine cervix (neck). See also cancer,
- Cervical dysplasia: Abnormalities in the cells of the epitheliums of the uterine cervix (neck). Cervical dysplasia is thought to be a precursor to cervical cancer.
- Cervix: The neck of the uterus.
- Class action suit: Litigation in which a small number of plaintiffs.
 represents a class of plaintiffs which is similarly situated in terms of
 the legal claims and/or factual occurrences.
- #Coccidioidomycosis: A fungal infection caused by infection with *Coccidioides immitis*. In the CDC's 1987 case definition of AIDS, disseminated or extrapulmonary coccidioidomycosis is considered an AIDS-defining condition.
- Cofactor: Factors or agents that are necessary for or that increase the probability of the development of disease in the presence of the basic etiologic agent of that disease.
- #Cryptosporidiosis: Infection with protozoa of the genus Cryptosporidium. In humans, such infection occurs both in immunocompetent persons (especially those who work with cattle), in which it causes self-limited diarrhea, and in immunocompromised persons, in whom it is much more serious, being manifested clinically as prolonged debilitating diarrhea, weight loss, fever, and abdominal pain. In the CDC's 1987 case definition of AIDS, intestinal cryptosporidiosis of more than l-month's duration is considered an AIDS-defining condition.
- Cytomegalovirus: One of a group of highly host-specific herpes viruses that infects humans, monkeys, or rodents. Depending on the age and immune status of the host, cytomegalovirus can cause a variety of clinical syndromes, known collectively as cytomegalic inclusion disease, although the majority of infections is very mild or subclinical.

- #Cytomegalovirus disease: Symptomatic conditions caused by infection with cytomegalovirus. In the CDC's 1987 case definition of AIDS, cytomegalovirus disease other than in the liver, spleen, or nodes is considered an AIDS-defining condition.
- #Cytomegalovirus retinitis: Inflammation of the retina of the eye due to infection with cytomegalovirus. In the CDC's 1987 case definition of AIDS, this is considered an AIDS-defining condition.

cytology: The study of cells.

Cytometry: The counting of blood cells.

Cytotoxic: Poisonous to cells.

Decompensation: In psychiatry, it refers to failure of defense mechanisms, resulting in progressive personality disintegration.

- Definitive diagnosis: A diagnosis of a disease that is certainly known because it is based on conclusive indicators (e.g., histology, biopsy, culture, antigen detection, or stool microscopy, as appropriate). For public health reporting purposes, AIDS-defining conditions are considered "definitively diagnosed" if they are diagnosed by methods specified in Appendix II of CDC's 1987 revision of the AIDS surveillance definition. Diagnosis by any other methods is considered somewhat less reliable, is called "presumptive." Compare presumptive diagnosis.
- Dementia: Organic loss of mental function, which may include deterioration of intellectual function, memory loss, and personality changes, without altered consciousness. Many types of dementia are thought to involve structural and biochemical abnormalities in the nervous system.
- Disability: For purposes of the Supplemental Security Income (SSI) and the Social Security Disability Insurance (DI) programs, disability is defined as an inability to engage in any substantial gainful activity by reason of any physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.
- Disability determination service (DDS): Any of the 54 State and territorial offices that, under regulatory authority with the Social Security Administration (SSA) within the U.S. Department of Health and Human Services, make disability determinations on individual applications for Social Security disability benefits (e.g., under the Supplemental Security Income (SSI) program).

Eczema: A pruritic papulovesicular dermatitis (inflammation or irritation of the skin) occurring as a reaction to many endogenous and exogenous agents. Also called "eczematous dermatitis."

Encephalitis: Inflammation of the brain.

- Endocarditis: Inflammatory alterations of the endocardium (the endothelial lining of the cavities of the heart and the connective tissue bed on which it lies). Endocarditis may occur as a primary disorder or as a complication of or in association with another disease.
- Entitlement programs: Government programs that provide a right to benefits or income which may not be abridged without due process.
- Enzyme-linked immunosorbant assay (ELISA) or enzyme immunoassay (EIA): A method of testing for an antibody. The ELISA test for the HIV antibody has become the most commonly used screening test for HIV.
- Epidemic: A sudden increase in the incidence rate of a human illness, affecting large numbers of people, in a defined geographic area.
- Epidemiology: The scientific study of the distribution and occurrence of human diseases and health conditions, and their determinants.
- Epidemiologic studies: Studies concerned with the relationships of various factors determining the frequency and distribution of specific diseases in a human community.
- #Esophageal candidiasis: Candidiasis of the esophagus (the musculomembranous passage from the pharynx to the stomach). In the CDC's 1987 case definition of AIDS, this is considered an AIDS-defining condition. See candidiasis.
- Extraintestinal strongyloidiasis: Infection outside the intestine with S. stercoralis, a species of Strongyloides. See strongyloidiasis.
- Federal regulations: A statement by a Federal executive branch agency that implements, interprets, or prescribes law or policy or describes the organization, procedure, or practices of an agency. Federal agencies are given the authority to issue regulations to implement specific statutes, and the regulations have the same force of law as the statute. Congress requires, however, that executive branch agencies promulgate regulations in accordance with the procedures outlined in the Administrative Procedures Act.
- Fluorescence microscopy: A technique of microscopy that involves staining cells with a fluorescent dye and then examining them under a microscope.
- Flow cytometer: An instrument that will analyze thousands of particles (blood cells, in this case) individually for light scatter and fluorescence patterns. For CD4 lymphocyte determinations, it is used to determine what proportion, or percent, of the lymphocytes (identified by scatter patterns) are positive for CD4 lymphocytes (identified by fluorescence). This percentage is then used with a white blood cell count and leukocyte differential to calculate the absolute number of CD4 lymphocytes. Each clinical flow cytometer costs approximately \$80,000 \$100,000 purchased new.
- Flow cytometry: A technique for counting blood cells that involves the use of a flow cytometer.

- Functional limitations: Restrictions in the ability to perform activities of daily living and work-related activities.
- Functional limitation test: A measure of degree to which an individual's functional activities are hindered by a physical or mental impairment. The SSA has developed a functional limitation test for evaluating the degree of impairment caused by HIV infection. The SSA will examine a person's ability to engage in activities of daily living (e.g., ability to do household chores, groom, perform personal hygiene); and social activity (e.g., ability to interact appropriately and communicate effectively with others); and his or her ability to perform work-related tasks in a timely and precise manner. The SSA will also take into account whether the person has repeated episodes of illness or other symptoms that limit his or her ability to adapt to work or work-like settings.

Fungicide: An agent that kills fungi.

Fungus (pi., fungi): A general term used to denote a group of eukaryotic protists, including mushrooms, yeasts, rusts, molds, smuts, etc., which are characterized by the absence of chlorophyll and by the presence of a rigid cell wall composed of chitin, mannans, and sometimes cellulose.

Genital herpes: See herpes simplex virus infections.

Genital warts: See human papilloma virus infection.

- Granulocytopenia: A symptom complex characterized by a marked decrease in the number of granulocytes (cells containing granules, especially leukocytes containing neutrophyl, basophil, or eosinophil) and by lesions of the throat and other mucous membranes, of the gastrointestinal tract, and of the skin.
- Herpes genitalis (genital herpes): A sexually transmitted disease caused by HSV-2. Symptoms include blister-like sores in the genital region, but diagnosis is by an HSV viral cell culture or antigen detection technique. Potential complications include aseptic meningitis, recurrent infections, and possible maternal-to-infant transmission.
- #Herpes simplex virus infections: Infections caused by herpes simplex virus (HSV) type 1 or type 2 and usually characterized by the development of one or more small fluid-filled vesicles with a raised erythematous base on the skin or mucous membranes and occurring as a primary infection or recurring because of reactivation of latent infection. Type 1 infections usually involve nongenital regions of the body (e.g., herpes labialis), whereas type 2 infections more commonly causes lesions on the genital and surrounding areas (e.g., herpes genitalis). In the CDC's 1987 case definition of AIDS, HSV infection leading to chronic ulcers or bronchitis, pneumonitis, or esophagitis is considered an AIDS-defining condition.
- Herpes zoster: Also called shingles, this is an acute infectious, usually self-limited, disease believed to represent activation of latent varicella-zoster virus in those who have been rendered partially immune

- after a previous attack of chicken pox. It involves the sensory ganglia and their areas of innervation, characterized by severe neuralgic pain along the distribution of the affected nerve.
- Hispanics: Persons who identify themselves as of Hispanic origin, or, less typically, individuals with Hispanic surnames identified by others (e.g., health care providers identifying patients in surveys) as of Hispanic origin. Hispanics can be those whose families have emigrated directly from Spain, or from Cuba, Central America, or South America. Persons of Hispanic origin can be of any race (e.g., white, black, American Indian); most have been found to be white.
- Histology: The area of anatomy that deals with the minute structure, composition, and function of the tissues; also called microscopical anatomy.
- #Histoplasmosis: Infection resulting from inhalation, or infrequently, the ingestion of spores of Histoplasmosis capsulatum. The infection is asymptomatic in most cases, but in 1 to 5 percent of cases, it causes acute pneumonia or disseminated reticuloendothelial hyperplasia with hepatosplenomegaly and anemia. In the CDC's 1987 case definition of AIDS, disseminated or extrapulmonary histoplasmosis is considered an AIDS-defining condition.
- HIV(humanimmunodeficiency virus): The virus that causes acquired immunodeficiency syndrome (AIDS). Two distinct subtypes of HIV have been identified: HIV-1 was first isolated in 1983 and has a worldwide distribution. HIV-2 was first isolated in 1986 and is found mainly in West Africa.
- HIV antibody test: A test to detect the presence of antibodies to the human immunodeficiency virus (HIV) in the blood. The presence of the antibody indicates infection with the virus. See also Enzyme-linked immuno-sorbant assay and Western blot.
- HIV-associated conditions: A general term that includes medical conditions' associated with HIV infection. This term is broader than the term AIDS-defining conditions, which refers only to conditions listed in the case definition of AIDS set forth by the Centers for Disease Control.
- #HIV encephalopathy: Degenerative disease of the brain that is due to infection with HIV. In the CDC's 1987 case definition of AIDS, this is considered an AIDS-defining condition.
- HIV infection: Infection with HIV (human immunodeficiency virus). Some HIV-infected people are asymptomatic. Some people manifest conditions that are attributed to HIV infection and/or are indicative of a defect in cell-mediated immunity; or conditions that are considered by physicians to have a clinical course or management that is complicated by HIV infection (e.g., candidiasis, vulvovaginal or oropharyngeal). Finally, some people with severe HIV-related immunodeficiency manifest conditions that are strongly associated with severe immunodeficiency, and cause serious morbidity or mortality; these include the 23 AIDS-defining conditions listed in the CDC's 1987 case definition of AIDS (e.g., Pneumocystis carinii pneumonia).

- HIV negative: Not showing any antibodies to HIV.
- HIV positive: Showing antibodies to HIV (indicating infection with HIV).
- HIV-related immunosuppression: Decrease in cell-medicated immunity caused by infection with the human immunodeficiency virus (HIV). See also <u>cell-medicated</u> immunity.
- #HIV wasting syndrome: A syndrome in HIV-infected persons characterized by progressive involuntary weight loss and either chronic diarrhea or chronic fever and weakness. In the CDC's 1987 case definition of AIDS, this is considered an AIDS-defining condition.
- Hodgkin's disease (or Hodgkin's lymphoma): A form of malignant lymphoma characterized by painless, progressive enlargement of the lymph nodes, spleen, and general lymphoid tissue; other symptoms may include anorexia, lassitude, weight loss, fever, pruritis, night sweats, and anemia.
- HTLV-III: Human T-cell lymphotropic virus, type III--now referred to as HIV.
- Human immunodeficiency virus: See HIV.
- Human papilloma virus infection: A papilloma virus that selectively infects the skin or mucous membranes. These infections may be asymptomatic, produce warts, or be associated with a variety at both benign and malignant neoplasms.
- Immune: Protected against disease by innate or acquired (active or passive) immunity.
- Immune deficiencies: Any of a number of conditions (e.g., adenosine deaminase
 deficiency, purine nucleoside phosphorylase deficiency, or AIDS)
 resulting from a failure or malfunction of the bodily defense
 mechanisms, or immune system.
- Immunity: The condition of being immune (i.e., protected against infectious disease conferred either by the immune response generated by immunization or previous infection or by other nonimmunologic factors (i.e., innate immunity). See also <u>cell-mediated immunity</u>.
- # Immunoblastic lymphoma or sarcoma: A malignant lymphoma composed of a diffuse, relatively uniform proliferation of cells with rough or convoluted nuclei and scanty cytoplasm. In the CDC's 1987 case definition of AIDS, immunoblastic lymphoma is considered an AIDS-defining condition.
- Immumcompetent: Having a normal or adequate immune response.
- Immunocompromised: Having the immune response attenuated by administration of immunosuppressive drugs, by irradiation, by malnutrition, or by some disease processes (e.g., cancer, AIDS).

- Immunodeficiency: A deficiency of immune response or a disorder characterized by deficiency of immune response; classified as antibody (B cell), cellular (T cell), combined deficiency, or phagocytic dysfunction disorders. Cellular immunodeficiencies are marked by recurrent infections with low-grade or opportunistic pathogens, by graft-versus-host reactions following blood transfusions, and by severe disease following immunization with live vaccines.
- Immunophenotyping: The methodology by which cells are identified using monoclinal antibodies directed at cell surface antigens. For HIV-infected specimens, this methodology commonly involves incubating anticoagulated blood with fluorochrome-labelled monoclinal antibodies, then lysing (killing) the red blood cells, so that only leukocytes (white blood cells) remain. The cells are then analyzed by flow cytometry for light scatter patterns (which identify various leukocyte populations) and fluorescence intensity (identifying various subpopulations of cells based on the presence or absence of antigens labelled by the monoclinal antibodies).
- Immunosuppressed: Having the immune response prevented or attenuated. Also called immunodepressed.
- Incidence: The frequency of new occurrences of disease within a defined time internal. The incidence rate is the number of new cases of specified disease divided by the number of people in a population over a specified period of time, usually 1 year. Compare prevalence.
- Incident cases: New cases of a disease within a defined time interval.
- Informed consent: A person's agreement to allow something to happen (e.g., a medical procedure) that is based on a full disclosure of the facts needed to make the decision intelligently. Informed consent is also the name for a general principle of law that a physician has a duty to disclose information about the risks of a proposed treatment to a patient so that the patient may intelligently exercise his or her "judgment about whether to undergo that treatment.
- Injection drug user: A person who uses a hypodermic needle to inject illicit drugs (e.g., heroin, amphetamines).
- Inpatient care: Care that includes an overnight stay in a hospital or other medical facility.
- #Isosporiasis: Infection with coccidia from the genes *Isospora*. In the CDC's 1987 case definition of AIDS, chronic intestinal isosporiasis with diarrhea of more than l-month's duration is considered an AIDS-defining condition.
- #Kaposi's sarcoma: A multifocal, spreading cancer of connective tissue, principally involving the skin; it usually begins on the toes or the feet as reddish blue or brownish soft nodules and tumors. Previously seen in older men of Jewish or Mediterranean descent, Kaposi's sarcoma is now one of the opportunistic diseases occurring in AIDS patients.

- #Leukoencephalopathy: Any of a group of diseases affecting the white matter of the brain, especially of the cerebral hemispheres, and occurring as a rule in infants and children. Progressive multifocal leukoencephalopathy is a generally fatal disease probably of viral origin. Progressive multifocal leukoencephalopathy is an AIDS-defining condition.
- Listing: Any one of the more than 100 medical conditions that are included in the Social Security Administration's "Listing of Impairments". Also called "listed impairments."
- "Listing of Impairments": See <u>Social Security Administration's "Listing of</u> Impairments."
- Lymphadenopathy: Lymph node enlargement in a region or regions of the body.
- Lymphocytes: Specialized white blood cells involved in the body's immune response. B-lymphocytes originate in the bone marrow and when stimulated by an antigen produce circulating antibodies (humoral immunity). T-lymphocytes are produced in the bone marrow and mature in the thymus gland and engage in a type of defense that does not depend directly on antibody attack (cell-mediated immunity). Approximately 10-15 percent of the body's lymphocytes are natural killer cells.
- #Lymphoma: Cancer of cells of the immune system (i.e., the various types of lymphocytes). In the CDC's 1987 case definition of AIDS, Burkitt's lymphoma, immunoblastic lymphoma, and lymphoma of the brain are "considered AIDS-defining conditions. See also cancer.
- Medicaid: A federally-aided, State-administered program, authorized under Title XIX of the Social Security Act; that provides medical assistance to low-income elderly and disabled individuals; low-income pregnant women and children; and families with dependent children who meet specific income and family structure requirements. Medicaid regulations are established by each State within Federal guidelines, and the eligibility requirements and services covered vary significantly among the States. In general, Medicaid covers medical, nursing home, and home health care for individuals who meet the eligibility requirements for those services. In some States, Medicaid also pays for adult day care and in-home services such as personal care and homemaker services. Financial eligibility for Medicaid is determined by a means test, in which a ceiling is placed on the maximum income and assets an individual may have in order to qualify for assistance. The income and assets levels are quite low in all States.
- "Medically needy" persons (under Medicaid): Persons who meet the nonfinancial qualifications for Medicaid (e.g., the disability requirement) but whose income or resources exceed eligibility levels. Not all States allow Medicaid eligibility for "medically needy" people. The States with programs for the medically needy provide a spend-down option so that persons whose medical expenses greatly exceed eligibility income or resource levels can obtain Medicaid.
- Meningitis: Inflammation of the meninges (the three membranes that envelope the brain and spinal cord).

Mortality: Death.

Microscopy: Examination under or observation by means of the microscope.

#Mycobacterium: A genus of bacteria of the family Mycobacteriaceae, order Actinomycetales, occurring as gram-positive, aerobic, mostly slow-growing, slightly curved or straight rods, sometimes branching and filamentous. It contains many species, including the highly pathogenic organisms that cause tuberculosis (M. tuberculosis) and leprosy (M. leprae). In the CDC's 1987 case definition of AIDS, Mycobacterium avium complex or M. Kansasii (disseminated or extrapulmonary), M. tuberculosis (disseminated or extrapulmonary), and disseminated or extrapulmonary infection with other species of Mycobacterium are considered AIDS-defining conditions.

Name reporting of AIDS and HIV: The reporting of the names of persons known to have AIDS or HIV infection to State or local health departments.

Nephropathy: Disease of the kidneys.

Nocardiosis: An acute or chronic suppurative infection, usually of the lungs but with a marked tendency to spread to any organ of the body, especially to the brain; abscess formation occurs in any organ, most commonly in the lungs, brain, skin, or subcutaneous tissue. Lung abscesses tend to cavitate with time. The causative agent in most instances in Nocardia asteroids, but N. "brasiliensis and N. caviae occasional cause cases.

Non-Hodgkin's lymphoma: A heterogeneous group of malignant lymphomas, the only common feature being an absence of the giant Reed-Sternberg cells characteristic of Hodgkin's disease. See lymphoma.

Notice of proposed rulemaking (NPRM): A notice of a Federal agency's intent to issue new regulations.

Opportunistic illness: The term includes infections caused by a microorganism that does not ordinarily cause disease but which, under certain
conditions (e.g., impaired immune responses), becomes pathologic. The
term also includes cancers associated with immune suppression. Kaposi's
sarcoma (a cancer) and Pneumocystis carinii pneumonia (an infectious
disease) in AIDS patients are examples of opportunistic illnesses. In
this paper, the term is often used synonymously with AIDS-defining
condition.

Oral candidiasis: See <u>candidiasis</u>.

Outpatient care: Care that is provided in a hospital and that does not include an overnight stay.

Pap test: Papanicolaou's test. A cell-staining procedure used for the detection and diagnosis of various conditions, particularly malignant and premalignant conditions of the female genital tract (cancer of the vagina, cervix, and endometrium).

- Pelvic inflammatory disease: A disease among females commonly associated with sexually transmitted pathogens, the symptoms of which include abdominal pain, fever, chills, vomiting, foul-smelling discharge, and postcoital bleeding. Potential complications include sterility, chronic pain, chronic infections, and even death. Methods of prevention include limiting the number of sexual partners, using condoms, and avoiding the use of intrauterine contraceptive devices. Treatment is with antibiotics.
- Pneumocystis pneumonia: See Pneumocystis carinii pneumonia.
- Pneumocystis prophylaxis: The prevention of *Pneumocystis carinii* pneumonia through the use of agents such as trimethoprim sulfamethoxazole or aerosolized pentamadine. Prophylaxis against *Pneumocystis carinii* pneumonia is recommended for all HIV-infected persons with CD4[†] lymphocyte counts below 200 cells/mm³ of blood.
- Pneumonia: A disease of the lungs characterized by inflammation and consolidation, which is usually caused by infection or irritation. See also *Pneumocystis carinii* pneumonia, bacterial pneumonia.
- Presumptive diagnosis: A diagnosis of a disease that is presumed to be correct but is not certainly known because it is not based on conclusive indicators (e.g., histology, biopsy, culture, antigen detection, or stool microscopy, as appropriate). Compare definitive diagnosis.
- Presumptive disability under the Supplemental Security Income (SSI) program:

 The Social Security Administration (SSA) is mandated by Congress to provide claimants who are "presumptively disabled or blind" with SSI disability benefits during the time that their application is being reviewed. Presumptive disability can be awarded by the field offices or by the State Disability Determination Services (DDS). Field office determinations of presumptive disability are usually restricted to impairment categories that can be easily identified by a trained lay person or can be easily confirmed with a single call to a physician or other health care provider (e.g., the amputation of two limbs, allegation of total blindness); in 1985, AIDS became part of the presumptive disability process at the field office level.

 Determinations of presumptive disability that require more medical knowledge are made by the State DDS, which has medically trained personnel.

- Prevalence: In epidemiology, the number of cases of disease, infected persons, or persons with disabilities or some other condition, present at a particular time and in relation to the size of the population. Also called "prevalence rate." Compare <u>incidence</u>.
- Prevalent cases: Total number of cases of a disease present in a defined population at a particular time.
- Privacy rights: According to Black's Law Dictionary, the term "right of privacy" is a generic term encompassing various rights recognized to be inherent in ordered liberty and such rights prevent governmental interference in intimate personal relationships or activities, freedom of the individual to make fundamental choices involving himself, his family, and his relationship with others. It is said to exist only so far as its assertion is consistent with law or public policy. Various Federal and State statutes prohibit an invasion of a person's right to be left alone and also restrict access to personal information (e.g., income tax returns) and overhearing of private communications.
- Program Operations Manual System: An internal Social Security Administration (SSA) manual that instructs all SSA employees and the State Disability Determination Service (DDS) employees on the SSA's operating procedures.
- #Progressive multifocal leukoencephalopathy: Leukoencephalopathy is of a
 group of diseases affecting the white matter of the brain, especially of
 the cerebral hemispheres, thought to be caused by a papovavirus.
 Progressive multifocal leukoencephalopathy is a generally fatal disease
 probably of viral origin. In the CDC's 1987 case definition of AIDS,
 this is considered an AIDS-defining condition.

Prophylaxis: The prevention of disease; preventive treatment.

Psoriasis: A common chronic squamous dermatosis, marked by exacerbations and remissions and having a polygenic inheritance pattern. It is characterized clinically by the presence of rounded, circumscribed, erythematous, dry, scaling patches of various sizes, covered by grayish white or silvery white, umbilicated, and lamellar scales, which have a predilection for the extensor surfaces, nails, scalp, genitalia, and lumbosacral region.

Pulmonary tuberculosis: See <u>tuberculosis</u>.

Regulations: See <u>Federal regulations</u>.

Residual functional capacity: The physical and mental tasks that a person can still perform despite the physical and mental impairments caused by a disease or other medical condition. When a SSA disability examiner determines the applicant's residual physical and mental capacity, he or she focuses on the person's ability to perform in a work environment. The physical evaluation takes into account his or her ability to lift, carry, push, pull, and perform other purely physical functions. The mental evaluation concentrates on the ability to understand, carry out, and remember instructions, and to respond appropriately to supervision, coworkers, and work pressures. The assessment of residual functional

- capacity is used to determine whether a disability claimant can still perform his or her previous job, or can perform any meaningful job in the national economy.
- Retrovirus: Any of a large group of viruses that contain RNA, not DNA, and that produce a DNA analog of their RNA through the production of an enzyme known as 'reverse transcriptase." (The resulting DNA is incorporated into the genetic structure of the cell invaded by the retrovirus.) HIV is a type of retrovirus.
- Ryan White Comprehensive AIDS Resources Emergency Act of 1990 (Public Law 101-381): An act that authorizes Federal funds for treatment, prevention, and other services related to HIV. Funds are administered by the Health Resources and Services Administration and the Centers for Disease Control in the U.S. Department of Health and Human Services.
- #Salmonella septicemia: The presence and persistence of bacteria of the genus Salmonella in the blood. In the CDC's 1987 case definition of AIDS, recurrent Salmonella septicemia is considered an AIDS-defining condition.
- Sarcoma: A cancer made up of cells resembling embryonic connective tissue which normally develops into tissues such as muscle, fat, bone, and blood vessels; sarcomas are often highly malignant.
- Sensitivity (of a test): One measure of the validity (or accuracy) of a diagnostic or screening test: the percentage of all those who actually have the condition being tested for who are correctly identified as positive by the test. Operationally, it is the number of true positive test results divided by the number of patients that actually have the disease (true positives divided by the sum of true positives plus false negatives). Compare specificity.
- Sepsis (bacterial or fungal): The presence in the blood or other tissues of pathogenic micro-organisms or their toxins.
- Septic arthritis: Inflammation of the joints caused by microbial infection.
- Septicemia: Systemic disease associated with the presence and persistence of pathogenic micro-organisms or their toxins in the blood.
- Serology: The study of in vitro reactions of immune sera; or the use of such reactions to measure serum antibody titers to infectious disease.
- Sinusitis: Inflammation of a sinus. The condition may be purulent or nonpurulent, acute or chronic.
- Social Security Administration's 'HIV Infection Listing for disability determinations: A proposed addition to the "Listing of Impairments," published for review and comment in 1991, that sets forth criteria for determining disability in persons with HIV infection.
- Social Security Administration's 'Listing of Impairmentsⁿ: A list of over 100 physical and mental impairments which the Social Security Administration (SSA) considers to be so severe as to make a person disabled (i.e.,

- unable to engage in any substantial gainful activity). The "Listing of Impairments" is used in making disability determinations under SSA disability programs. Any claimant who has a "listed impairment," or an impairment that is equal in severity to a listed impairment, is to be considered disabled. The "Listing of Impairments" is published in the Code of Federal Regulations (20 C.F.R., Part 404, Subpt P, Appendix 1).
- Social Security Disability Insurance (DI): A Federal disability social insurance program, administered at the Federal level by the Social Security Administration within the U.S. Department of Health and Human Services, for workers who have contributed to the Social Security retirement program and have become disabled before retirement age. Beneficiaries receive monthly cash payments.
- Social Security Rulings: Statements by the Social Security Administration (SSA) that draw upon and codify the policies and criteria used at all levels of the administrative adjudication process (in administrative law judge and Appeals Council decisions, in decisions by SSA disability examiners, etc.). The rulings are binding on all components of the SSA, including State disability examiners, administrative law judges, and the SSA Appeals Council. Unlike SSA regulations, however, they are not binding on Federal or State courts.
- Soundex codes: Alpha-numeric codes used by the State or local health department as a substitute for individuals' names on AIDS case reporting forms sent to the Centers for Disease Control (CDC) in the U.S. Public Health Service. The CDC does not receive the names of persons with AIDS; names are retained by the State or local health department.
- Specificity (of a test): One measure of the validity (or accuracy) of a diagnostic or screening test: the percentage of all those who do not "have the condition being tested and who are correctly identified as negative by the test. Operationally, it is the number of true test negatives (all those with a negative test result who actually do not have the condition being tested for) divided by the sum of true negatives plus false positives (i.e., all those who do not have the condition). Compare sensitivity.
- Strongyloidiasis: Infection with S. stercoralis, a species of Strongyloides.

 S. stercoralis (S. intestinalis) is a roundworm occurring widely in tropical and subtropical countries. The female worm and her larvae inhabit the mucosa and submucosa of the small intestine, where they cause diarrhea and ulceration. The larvae expelled from an infected person with his or her feces develop in the soil and penetrate the human skin on contact. They eventually are carried in the bloodstream to the lungs, where they cause hemorrhage (pulmonary strongyloidiasis); from the lungs, they reach the intestine via the trachea and esophagus.

 Massive infections may be seen in patients with depressed immune systems.
- Strongyloides: A genus of plasmids belonging to the superfamily Rhabditoidea, widely distributed as intestinal parasites of mammals.

Supplemental Security Income (SSI): A Federal income support program for low-income disabled, aged, and blind persons. Eligibility for the monthly cash payments is based on the individual's current status without regard to previous work or contributions to a trust fund. Some States supplement the Federal benefit.

Surveillance: See AIDS surveillance.

"Symptomatic HIV Infection Not Indicative of AIDS": A category of disability adopted by the Social Security Administration for use in disability determinations under the DI and SSI programs that was equivalent to a Listing.

Syndrome: The aggregate of symptoms considered to constitute the characteristics of a morbid entity; used especially when the cause of the condition is unknown.

T-cells (or T-lymphocytes): Specialized lymphocytes (white blood cells involved in the body's, immune response) that are produced in the bone marrow and mature in the thymus gland and engage in a type of defense that does not depend directly on antibody attack (cell-mediated immunity). T-helper lymphocytes are known as CD4 lymphocytes. T-suppressor/cytotoxic lymphocytes are known as CD8 cells. Normally, about 2/3 of the T-cells are CD4 lymphocytes, and about 1/3 are CD8 lymphocytes.

Third-party payment: Payment by a private insurer or government program to a medical provider for care given to a patient.

Thrombocytopenia: Decrease in the number of blood platelets.

#Toxoplasmosis: An acute or chronic widespread disease of animals and humans caused by the protozoan *Toxoplasma gondii*, transmitted by oocysts containing the pathogen in the feces of cats, usually by contaminated soil or direct exposure to infected feces. Most human infections are asymptomatic, but when symptoms occur, they may range from a mild, self-limited disease clinically resembling mononucleosis to a fulminating, disseminated disease that may cause extensive damage to the brain, eyes, skeletal and cardiac muscles, liver, and lungs. Severe manifestations are seen principally in immunocompromised patients. In the CDC's 1987 case definition of AIDS, toxoplasmosis of the brain is considered an AIDS-defining condition.

Tuberculosis: A chronic infectious disease of humans and animals caused by any of several species of mycobacteria. Tuberculosis usually begins with lesions in the lung but can metastasize (spread) to other parts of the body. Tuberculosis in the lung is known as pulmonary tuberculosis.

Vaginal candidiasis: See <u>candidiasis</u>.

Virology: The branch of microbiology that specializes in viruses.

- virus: Any of a large group of submicroscopic agents infecting plants, animals, and bacteria and characterized by a total dependence on living cells for reproduction and by a lack of independent metabolism. A fully formed virus consists of nucleic acid (DNA or RNA) surrounded by a protein or protein and lipid coat.
- Wasting syndrome due to HIV: See <u>HIV wasting syndrome</u>.
- Western blot: A method of separating proteins, such as antibodies, by electrophoresis. The Western blot for HIV has become the most commonly used confirmatory test for HIV.
- Zidovudine (Retrovir): A drug used to reduce symptoms prolonging the lives of persons infected with human immunodeficiency virus (HIV). This drug was formerly called azidothymidine (AZT).