

The Use of the CDC Definition of AIDS in Social Security Disability
Determinations

INTRODUCTION

The controversy over the Centers for Disease Control (CDC) definition of acquired immune deficiency syndrome (AIDS) did not primarily arise among epidemiologists and public health professionals concerned about proper tracking of the AIDS epidemical. The issue was brought to the public's attention by AIDS activists and lawyers who represent HIV-infected women and injection drug users. These advocates were seeking to obtain access to Federal disability and medical insurance programs because their clients were no longer able to work. In particular, they were seeking financial assistance and medical care under the following Federal programs:

- the Social Security Supplemental Security Income (SSI) program;
- m the Social Security Disability Insurance (DI) program; and
- 8 the Medicaid program.

SSI and DI are administered at the Federal level by the Social Security Administration (SSA) in the U.S. Department of Health and Human Services (DHHS). Medicaid is administered at the Federal level by the Health Care Financing Administration in the DHHS.

1 The CDC has been exploring ways to simplify its definition of AIDS since 1989; however, this is not what sparked the public debate (16).

The SSI and DI programs are Federal entitlement programs designed to provide income support for persons who are aged, disabled, or blind.

Individuals under 65 years of age are eligible for SSI or DI only if they are blind or disabled. In almost all States and the District of Columbia, qualification for SSI benefits, and to a lesser extent qualification for DI benefits, provides an individual with the opportunity to receive health insurance under Medicaid, which is a Federal/State jointly financed health care program for low-income individuals who are aged, blind, or disabled, members of families with dependent children, and certain other pregnant women and children (189).

The SSA began using the CDC definition of AIDS in evaluating disability under its DI and SSI programs in 1983, although it did not issue a ruling acknowledging its use until 1984. The SSA's initial decision to use the CDC definition in disability determinations for HIV-infected individuals was not objectionable. The agency's continued reliance on the CDC definition and its failure to develop specific disability criteria for other HIV-infected persons who were seriously ill but did not have AIDS brought the SSA under considerable criticism from AIDS activists, disability attorneys, and certain members of Congress (113,147).

AIDS activists and legal service attorneys asserted that, while persons with AIDS were almost always awarded disability, the SSA failed to award disability benefits to other seriously ill HIV-infected women and men, many of whom are minorities. They argued that the SSA's instruction that all persons with AIDS are disabled created a perception that symptomatic HIV-infected individuals who did not have AIDS were not disabled. This contradicts the SSA's written instructions to its disability adjudicators and, to some degree, the SSA's own statistics which demonstrate that a number of HIV-infected individuals who did not have AIDS were awarded disability benefits.

This debate is difficult to sort out because there has not been an objective, comprehensive examination of the disposition of disability claims made by symptomatic HIV-infected persons who do not have AIDS. Most of the evidence that deserving claimants with HIV infection are not being awarded disability comes from examples provided by legal services attorneys. Although these examples are quite compelling (see app. I), they may represent only the most egregious cases. Nonetheless, this does not discount the fact that a number of HIV-infected persons who appear to be very ill were unable to get disability benefits.

The SSA, however, has recently revised its criteria for evaluating disability of persons with HIV infection, and this revision changes the nature of the debate. First, it demonstrates that the SSA will not tie its disability determinations to the CDC's new definition of AIDS. HIV-infected individuals who have one of the 1987 AIDS-defining conditions (except Kaposi's sarcoma) will continue to be considered disabled on the basis of their medical conditions alone. HIV-infected persons with CD4⁺ lymphocyte counts below 200 cells per cubic millimeter (/mm³), however, will be evaluated in the same manner as HIV-infected individuals with pulmonary tuberculosis, recurrent vaginal candidiasis, endocarditis, and a list of other HIV-associated conditions. The new disability criteria includes a number of HIV-associated conditions that are frequently seen in HIV-infected women and injection drug users. However, as discussed below, the new criteria are not without its critics. Indeed, the SSA has received approximately 3000 comments on their proposed regulations, an unprecedented number (95) .

The following sections present an overview of the SSA's disability programs and the debate over disability determinations for persons with HIV infection. This background enables one to better evaluate the SSA's new disability criteria for HIV infection.

THE SSA DISABILITY PROGRAM--GENERAL PROCEDURES AND STANDARDS

The DI program is a publicly funded disability insurance system. In order to qualify for DI benefits, a person must have worked for a certain number of years, and thus have paid into the Federal Social Security program. The SSI program, on the other hand, is an income-assistance program for financially needy persons who are disabled, blind, or 65 years of age or older. The SSA uses the same definition for disability for both DI and SSI-- *an inability to engage in any substantial gainful activity (defined as earning more than \$500 per month) by reason of any physical or mental impairment which can be expected to result in death or which lasts for a continuous period of not less than 12 months (42 U.S.C. § 423(d)(1)(A) (DI); s 1382(a)(3)(A) (SSI)).* Applicants with medical conditions that prevent them from performing their previous work or any job that would qualify as substantial gainful activity will be awarded disability benefits, assuming they meet the program's financial requirements and other criteria (e.g., the citizenship requirements) .

Applying for Disability Benefits

Applications for SSI or DI disability benefits are filed at one of the SSA's approximately 1,300 field offices. Each field office is staffed by trained clerical personnel who help initiate a claim and determine whether an applicant meets the financial, age, and citizenship requirements. In some cases (described below), field office personnel can determine that a claimant is presumptively disabled and award interim benefits. In all cases, however,

the ultimate determination that a claimant is disabled is made by one of the 54 State and territorial Disability Determination Service (DDS) offices (42 U.S.C. § 421(a))(188).²The disability determinations are made by a team of disability adjudicators, which includes a physician, a trained disability examiner, and, if needed, one or more vocational experts.

If the State DDS denies an application for disability benefits, the applicant has the right to have the disability determination reconsidered by another DDS adjudicator who was not involved in making the initial decision; this is known as a "reconsideration" (20 C.F.R. §§ 404.907-404.922, 416.1407-416.1413(c)) (see app. H). If the application is denied upon reconsideration, the applicant has the right to a *de novo* hearing before an administrative law judge (20 C.F.R. §§ 404.929-404.965, 416.1429-416.1461). If this decision is also adverse to the claimant, he or she can appeal to SSA's Appeals Council, which reviews the decisions of administrative law judges (20 C.F.R. §§ 404.967-404.979, 416.1468-416.1484). The final stage of review is in the Federal court system (42 U.S.C. §§ 405(g), 1383(c)(3); 20 C.F.R. §§ 404.981, 404.1482).

The SSA's Sequential Disability Process

SSA regulations set forth a five-part sequential procedure that is used by SSA's disability examiners and administrative law judges to determine disability for DI or SSI (see app. G). The disability adjudicator must first determine the following: 1) whether the claimant is working, and 2) whether the claimant has a disabling condition that significantly limits his or her ability to work (20 C.F.R. §§ 416.920(a)(c), 404.1520(b)(c)). If the claimant

² The State offices only focus on medical disability; the examiners in the State offices do not see the financial information (146).

is not working because of a disabling condition that significantly limits his or her ability to work, the disability adjudicator proceeds to the third step in the disability process.

The third step is to compare the applicant's alleged disability with the SSA's "Listing of Impairments," a list of medical conditions that SSA has designated as being so severe as to "prevent a person from doing any gainful employment" (20 C.F.R. § 416.925). The SSA has designated over 100 medical conditions in its "Listing of Impairments" in the Code of Federal Regulations (20 C.F.R. Part 404, Subpt P, Appendix 1). (The medical conditions in the "Listing of Impairments" are often referred to by the SSA as a "Listing," a "listed impairment," or a "listing-level impairment.") The SSA's State disability adjudicators are instructed that if an applicant for SSI or DI presents medical evidence establishing that he or she has one of the listed impairments, that person is disabled and will be awarded disability benefits if he or she meets the financial and other program requirements. In addition, a person will be awarded disability benefits if the evidence demonstrates that his or her medical condition equals, in terms of severity, one of the Listings. Approximately 75 percent of favorable disability decisions are made at this step in the process (189).

If an applicant for disability benefits does not have a medical condition that meets or equals one of the Listings, the SSA disability adjudicator must evaluate the applicant's residual physical and mental capacity to perform in a work environment. In the fourth step of the sequential disability process, the SSA disability adjudicator determines, on the basis of the person's residual capacity, whether the applicant can still perform his or her previous job. If the applicant can perform his or her previous job, the application for disability benefits is denied (20 C.F.R. §§

416.920(e), 404.1520(e)). If the applicant cannot perform his or her previous job, the SSA will determine, taking into account education, age, and prior work experience, whether the applicant can perform any full-time job in the national economy (20 C.F.R. §§ 416.920(f), 404.1520(f)). This is the final step in the disability process.

Presumptive Disability Benefits

Under the SSI program, claimants who have medical impairments that are highly predictive of disability can be awarded presumptive disability benefits during the time their claim is being evaluated under the five-step disability process. Presumptive disability benefits continue for 6 months while the SSA disability adjudicators gather necessary medical evidence to confirm that the person is disabled (42 U.S.C. § 1383(a)(4)(B)) . Presumptive disability benefits can be awarded at any point in the disability process when a disability examiner from one of the 54 State and territorial DDS offices has sufficient medical evidence to conclude that a person is disabled.

The SSA also permits the field offices to award presumptive disability benefits to certain claimants. The medical conditions for which the field offices can award presumptive disability are specified in the SSA's regulations (21 C.F.R. § 416.936), and are usually restricted to conditions that are either easily identified by a trained lay person or can be easily confirmed with a single call to a medical practitioner (e.g., the amputation of two limbs, amputation of a leg at the hip, or allegation of total deafness). By permitting the field office to award presumptive disability benefits, the SSA enables applicants for SSI who are clearly disabled to receive their benefits promptly.

THE LINK BETWEEN SOCIAL SECURITY DISABILITY PROGRAMS AND MEDICAID

An important consideration in the controversy over the SSA's disability decisions for persons with HIV-associated conditions is that SSA's disability programs serve as an entry to federally funded health insurance, primarily Medicaid.³ Medicaid is a Federal-State funded medical insurance system for low-income individuals who are aged, blind or disabled, and certain other pregnant women and children, or members of families with dependent children. Federal funds account for approximately 57 percent of total funds (192).

The majority of SSI recipients are eligible to receive Medicaid.⁴ DI recipients cannot automatically qualify for Medicaid because DI benefits generally exceed State Medicaid income levels. If DI recipients' medical expenses greatly exceed their income, however, they may qualify for Medicaid under State programs for the "medically needy" (189). As of 1991, 35 States, the District of Columbia, and Puerto Rico had "medically needy" programs (198).

Medicaid is rapidly becoming the primary insurer of persons with AIDS. Researchers have estimated that Medicaid covers approximately 40 percent of individuals with AIDS, private insurance covers 29 percent, Medicare covers 2

3 Medicare is not available to persons receiving 7DI until 24 months after DI benefits are awarded. (42 U.S.C. § 1395e). In the past, most HIV-infected individuals who qualified for DI did not live long enough to qualify for Medicare (12). This may change, however, as treatment extends the life expectancy of persons with HIV infection.

4 All but 12 States automatically allow SSI recipients to receive Medicaid (198). The other 12 States have more restrictive disability or financial requirements (121). In those States that use more restrictive financial requirements, SSI recipients may become eligible for Medicaid if their medical bills greatly exceed their income (189).

percent, and approximately 29 percent of persons with AIDS are without insurance coverage (120). This trend towards the "Medicaidization" of AIDS (69) demonstrates the demand for publicly funded health care for HIV-infected persons. This demand is likely to continue to grow as there appears to be an increasing number of HIV-infected persons who are poor and who do not have adequate health insurance. Even among those with private insurance, there is some evidence that HIV-infected persons may lose their insurance once they can no longer work (92) .

The costs of providing medical care for HIV-infected individuals without Medicaid or other health insurance will probably be borne by the States (167a). In 1991, the States spent approximately \$168 million on medical services for people with AIDS and HIV, excluding State Medicaid funds. The majority of care was provided in outpatient settings (85).

Although many disability claimants may need medical care immediately, they will not be able to get medical care through Medicaid until they are determined to be disabled. The SSA cannot alter the statutory disability definition to make more people eligible for Medicaid; however, if the SSA incorrectly denies a person disability benefits, this decision may also affect the person's ability to obtain federally financed health care.

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DISABILITY DETERMINATIONS AND HIV/AIDS

The debate over disability determinations for HIV-infected claimants has focused on the SSA's decision to use the CDC definition of AIDS as a Listing and in presumptive disability determinations. The decision to use the AIDS case definition in disability determinations did not preclude HIV-infected claimants without AIDS from receiving disability benefits; adjudicators had

the discretion to conclude that HIV-infected claimants without AIDS were disabled because their condition was equal in severity to a Listing. Alternatively, HIV-infected claimants could be found disabled at a later stage in the disability process, based upon their residual functional capacity. By 1990, however, the SSA concluded that it needed a Listing that enumerates specific disability criteria for HIV-infected claimants without AIDS. The development of this Listing is discussed below.

Disability Determinations for Persons With AIDS

Since 1983, the SSA has instructed its disability adjudicators to use the CDC definition of AIDS as a Listing, although it has never published regulations formally incorporating the CDC definition of AIDS into its "Listing of Impairments." The SSA's instruction on AIDS was maintained in an internal policy manual, the Program Operations Manual System (POMS), until 1984, when the SSA outlined this policy in the first of two Social Security Rulings (SSRs) (224a,224b).⁵ (These rulings were not published in the Federal Register.) The SSA used the CDC definition of AIDS as a disability definition and incorporated all of the CDC's subsequent revisions of the case

⁵ Social Security Rulings are not regulations; instead the rulings draw upon and codify the policies and criteria used at all levels of the administrative adjudication process (e.g., administrative law judge and Appeals Council decisions, decisions by SSA disability examiners, opinions of the SSA's Office of Disability or Office of the General Counsel, and other policy interpretations by SSA). These rulings are binding on all components of the SSA, including State DDS examiners, administrative law judges, and the SSA's Appeals Council (20 C.F.R. § 422.406(b)(1)) . Because they do not have the force and effect of law or SSA regulations, however, they are not binding on Federal or State courts (56 FR 65498).

definition into the disability definition. In 1990, however, the SSA added Hodgkin's lymphoma, a condition that is not included in the CDC AIDS definition, to its AIDS disability definition.

In 1985, the SSA published regulations making AIDS one of the conditions for which "presumptive disability" could be awarded at the field office level (50 F.R. 5573). This enabled claimants with AIDS to receive disability benefits quickly⁶, and the decision was generally well received. It was also the first time that the appropriateness of using the CDC definition of AIDS in disability determinations was subject to public debate.'

The SSA recognized that a surveillance definition is designed for a different purpose than a definition for determining disability. Nonetheless, the SSA concluded that it was unlikely that any person with AIDS who had stopped working could engage in substantial gainful activity (53 F.R. 3740). The decision to use the CDC definition of AIDS in field office presumptive disability determinations and as a Listing facilitated the processing of disability claims for persons with AIDS, and almost 100 percent of claimants whom the SSA recognized as having AIDS were awarded disability benefits (225) .

Disability Determinations for Persons with HIV Infection

The SSA also recognized that persons with HIV infection could become ill and disabled prior to developing AIDS. In the 1986 Social Security ruling on AIDS and disability, the SSA instructed its adjudicators that persons with HIV

6 Presumptive disability benefits are often awarded within 3 weeks, while an initial determination by the DDS may take 3 months or longer (49,227).

7 The regulations were issued as interim regulations, effective immediately, but public comments were accepted. These comments were addressed in 1988, when **SSA** renewed the regulations (53 **F.R.** 3740).

infection might suffer from a number of potentially disabling conditions prior to developing AIDS, including recurrent fevers, lymphadenopathy, prolonged diarrhea, fatigue, weight loss, night sweats, and recurrent infections such as oral candidiasis. The SSA wrote that HIV-infected individuals who suffer from one or more of these conditions may be disabled and their degree of disability should be assessed on a case-by-case basis (224b).

By 1987, the SSA announced that it would soon publish regulations creating a Listing for HIV infection and AIDS (56 F.R. 65704). The SSA failed to publish these regulations, and mounting public and Congressional pressure led the SSA to reconsider its instructions on HIV infection and disability.⁸ As a result, in 1988, the SSA decided that it needed more specific criteria for evaluating disability in HIV-infected claimants without AIDS (113).

In February of 1990, the SSA published a new disability definition entitled "Symptomatic HIV Infection Not Indicative of AIDS." This new criteria was published in the POMS, an internal policy manual. The public does not have input into the development of the POMS, and it is only made available by request to the SSA (5 U.S.C. § 552(2)). Moreover, the POMS does not bind the administrative law judges in their decisions.

The POMS disability definition "Symptomatic HIV Infection Not Indicative of AIDS" (henceforth referred to as POMS "Symptomatic HIV Infection") functioned as a Listing for HIV-infected persons who do not have AIDS. In

⁸ In 1988, Congress mandated that the SSA conduct an internal review of disability determinations for persons alleging HIV infection but not AIDS (Public Law 100-647, Sec. 8019). In attempting to complete this report (it has never been completed (115)), the SSA found that close to half of the State DDS offices collected no data separating AIDS and other HIV infection claims, and other DDS offices often inaccurately classified AIDS and HIV infection claims. Among those States with data, SSA found significant variation in allowance and denial rates for HIV infection claims that were not AIDS (147,235).

other words, if an HIV-infected claimant documented that he or she had the combination of medical conditions and symptoms that were included in, or were equal in severity to, the POMS "Symptomatic HIV Infection" criteria, he or she would be awarded disability benefits at step 3 in the disability process.

In order to meet the POMS "Symptomatic HIV Infection" criteria, a claimant needed to document:

- 1) Evidence of HIV infection (e.g., HIV antibody or viral testing); AND
- 2) A CD4⁺ lymphocyte count less than or equal to 200 cells/mm³ (or a CD4⁺ percent of lymphocytes less than or equal to 25); **AND**
- 3) *Two or more of the following persisting over a 2-month period:*
 - a. anemia (hematocrit value below 30 percent)
 - b. granulocytopenia
 - c. thrombocytopenia
 - d. documented fever
 - e. weight loss >/- 10 percent of baseline
 - f. oral candidiasis
 - g. oral hairy leukoplakia
 - h. recurrent herpes zoster
 - i. persistent, unresponsive diarrhea;AND
- 4) Marked restriction of activities of daily living (such that individual needs help with most activity including climbing stairs, shopping, cooking, or housework) **or** Deficiencies of concentration, persistence, or pace, resulting in frequent failure to complete tasks in a timely manner (in work settings or elsewhere) (POMS).

Advocates for people with HIV infection were generally pleased that the SSA created more specific disability criteria for persons with HIV infection, but they claimed that the POMS "Symptomatic HIV Infection" criteria did not go far enough. Most of the HIV-associated conditions included in the POMS "Symptomatic HIV Infection" criteria were derived from the same epidemiologic

studies used to develop the CDC definition of AIDS, in which the cohorts largely consisted of white men who have sex with men (168). The conditions identified by these studies--e.g. , fever, weight loss, fatigue, chronic diarrhea, night sweats, lymphadenopathy, oral thrush, and hairy leukoplakia (241a)--do occur in other HIV-infected populations, including women and injection drug users. There are other disabling conditions, however, that are seen particularly in HIV-infected women and injection drug users--e.g. , endocarditis, pneumonia, sepsis, pelvic inflammatory disease, genital herpes, and persistent vaginal candidiasis--that were not included in the POMS "Symptomatic HIV' Infection" criteria.

CRITICISMS OF THE SSA'S DISABILITY PROCESS

By the late 1980s, as more individuals infected with HIV were identified, it became apparent that some of the serious medical conditions that were seen particularly in HIV-infected women and injection drug users were not included in the CDC definition of AIDS. Legal service attorneys and other advocates for HIV-infected persons charged that the SSA routinely denied disability benefits to HIV-infected women and injection drug users whose HIV-associated conditions were not included in the CDC definition of AIDS or, after 1990, in the SSA's POMS "Symptomatic HIV Infection" criteria. This is the main argument made in the lawsuit S.P. v. Sullivan, discussed below.

The SSA, on the other hand, stated that it had no policy that prevented HIV-infected persons who did not have AIDS or meet the POMS "Symptomatic HIV Infection" criteria from obtaining disability. The SSA specifically instructed its disability adjudicators that HIV-infected persons who did not have AIDS or meet the SSA's POMS "Symptomatic HIV Infection" criteria should

be evaluated under the full sequential disability process. In other words, if HIV-infected claimants were not awarded disability on the basis of a Listing, the DDS adjudicator would determine their residual functional capacity to work and evaluate whether they can perform any full-time work in the national economy. If they were unable to work, they were awarded disability.

Legal service attorneys claim that, while this may be the stated policy, in practice their clients with HIV-associated conditions not included in the POMS "Symptomatic HIV Infection" criteria were not able to receive disability at these last steps in the disability process. In addition, attorneys have challenged the legality of the SSA's decision to use the POMS and SSRs to establish that AIDS and the POMS "Symptomatic HIV Infection" equals a Listing.

The SSA Disability Statistics

The SSA's statistics reveal that, in 1990, almost 100 percent of persons with AIDS who applied for either SSI or DI benefits were awarded these benefits. In addition, approximately 50 percent of claimants who alleged HIV infection on their disability claims, but who did not have AIDS, received disability benefits at the initial or reconsideration stage (225). The statistics do not reveal the condition of the other 50 percent of HIV-infected persons who were denied disability, nor do the statistics reveal the race or socioeconomic class of the persons who were awarded disability benefits versus those who were denied benefits.

The SSA states that, when the analysis is limited to claims made by *symptomatic HIV-infected individuals*, approximately 60 percent or more are awarded disability (49,225). The DDS examiners only classify a person as *symptomatic HIV-infected* if he or she has the symptoms described in the POMS

"Symptomatic HIV Infection" criteria (115) . Therefore, HIV-infected disability applicants who claimed they were disabled on the basis of gynecological conditions, endocarditis, bacterial pneumonia, pulmonary tuberculosis, or sepsis, would not be classified as symptomatic *HIV-infected individuals*.

When one only examines claims made by HIV-infected persons who were not classified by the SSA as having AIDS or *symptomatic HIV-infection*, only 23 percent were awarded disability (49,225). The SSA's position is that the 77 percent of claimants who were not awarded disability did not have disabling symptoms of HIV infection. Legal service attorneys argue that many of these HIV-infected claimants are their clients who were incorrectly denied disability.

Legal Challenges to the SSA's Disability Process

Two lawsuits have been filed against the SSA challenging its disability criteria for persons with HIV infection. The first suit alleges, among other things, that the SSA's use of the CDC definition of AIDS and the POMS "Symptomatic HIV Infection" criteria has resulted in discrimination against women, minorities, and other persons who have HIV-related conditions that are not included in these definitions. The second case alleges that the SSA's decision to develop criteria for listing-level impairments through the POMS and SSRs, rather than through notice and comment rule making, violated the Administrative Procedure Act (5 U.S.C. §§ 551 et. seq.). The suit seeks to have adverse disability decisions that were made using these criteria readjudicated with properly promulgated regulations.

The merits of these cases have not been ruled upon by the respective courts. Both suits, however, have survived requests by the Secretary of Health and Human Services⁹ to have the cases dismissed for failure to state a legal claim (143,169)

S.P. v. Sullivan

In 1990, legal service attorneys in New York filed a lawsuit against the SSA stating that the SSA's disability process discriminated against HIV-infected women and other HIV-infected persons who have disabling medical conditions that are not included in the CDC definition of AIDS or the POMS "Symptomatic HIV Infection" criteria (165). The 19 named plaintiffs¹⁰ were denied disability benefits by the State DDS, and many had been denied disability benefits upon reconsideration or by an administrative law judge. As of April 1992, almost all of the plaintiffs had received their disability benefits, beginning from the date they originally claimed they were disabled; yet, as a result of being initially denied benefits by the State DDS, they often waited 1 to 3 years, and up to 5 years, for their claims to be properly decided. As their attorney explained, this meant they had to make numerous trips to her office and the SSA's offices to fight for benefits (112). The experiences of these plaintiffs (see app. I) do not necessarily prove a pattern and practice by the SSA; they do, however, signal that the system for determining disability has not worked for a number of HIV-infected persons.

9 The suit is brought against the Secretary of Health and Human **Services** rather than the **SSA**. The Secretary is represented by the U.S. Department of Justice.

10 The complaint has been amended three times and additional plaintiffs added (See 165,166,168).

The Secretary of Health and Human Services contends the arguments made in SOP. v. Sullivan are without merit¹¹, citing language in the POMS and Social Security rulings that contradict the plaintiffs' assertion that the SSA considers disabled only HIV-infected persons who have AIDS or meet the POMS "Symptomatic HIV Infection" criteria. Both of these documents instruct disability adjudicators that HIV-infected individuals who do not meet these medical disability definitions should be evaluated on the basis of whether their residual functional capacity allows them to work; if they cannot work, they should be awarded disability benefits (167).

The Secretary also correctly asserts there is no statutory requirement that a particular impairment or disease be treated as a listed impairment. The Secretary, and hence the SSA, has discretion to "establish [its] own procedures and evidentiary requirements with respect to the evaluation of claims for benefits under the Social Security Act's disability programs" (167). Furthermore, as stated above, a Person with an HIV-associated condition that is not included in the POMS "Symptomatic HIV-Infection" criteria is not precluded from being awarded disability.

The plaintiffs in S.P. v. Sullivan concede the SSA is not required to create a Listing for every disabling medical condition, but argue that, once the decision is made to create a Listing for a particular disease like HIV disease, the categories must be created by a rational process that brings forth a reasoned and nondiscriminatory classification. Furthermore, although the Secretary correctly asserts that the SSA's written policies do not

11 The Secretary objected to the suit, in part, because some of the plaintiffs have not exhausted their administrative **remedies--i.e.**, all of the plaintiffs have not had their disability cases adjudicated through to the Appeals Council (see app. H). This procedural issue is not discussed here because it does not relate to the substantive issue.

discriminate against persons with HIV-associated conditions who do not have AIDS or meet the POMS "Symptomatic HIV Infection" criteria, the plaintiffs believe their experiences demonstrate that in practice these policies are not followed.

Rosetti v. Sullivan

In a second lawsuit against the Secretary of Health and Human Services, the plaintiffs argue that the SSA could not make AIDS or the POMS "Symptomatic HIV Infection" equal to a Listing without issuing regulations in accordance with the Administrative Procedure Act (APA) (5 U.S.C. §§ 551 et. seq). The APA requires an executive agency to publish regulations whenever it issues a substantive rule--rules that "grant rights, impose obligations, or produce other significant effects on private interests" (7). The APA regulatory procedures require agencies to publish notice of their intent to develop new regulations and provide interested persons opportunity to participate in developing regulations through submission of data, arguments, and other views (11). An executive agency can only use rulings or internal manuals, such as the POMS, for interpretive rules that "merely clarify or explain existing law or regulations" (132).

Every Listing in the "Listing of Impairments" was promulgated by regulation. AIDS, however, was established as equivalent to a Listing by a SSR, and the POMS "Symptomatic HIV Infection" criteria was only published in the SSA's internal procedures manual. The issuance of both of these documents did not provide for public input (144).

In a preliminary decision,¹² the court in Rosetti v. Sullivan stated that, if the SSA's POMS and SSRs set forth specific disability criteria for AIDS and HIV-associated conditions that function as Listings, these criteria are substantive rules and these policies should have been implemented by notice and comment rulemaking in accordance with the APA (143). The SSA has stated that individuals whose medical conditions meet the CDC definition of AIDS or the POMS "Symptomatic HIV Infection" criteria have met or equaled the "Listing of Impairments" (224b,226a). Therefore, under the test set forth in the court's opinion, the POMS and SSRs concerning HIV infection and disability are substantive rules. The court stated that a failure to follow APA procedures for substantive rules could render these disability criteria void; however, since the SSA recently proposed new regulations governing disability claims by symptomatic HIV-infected persons, it is not clear what relief the court will grant the plaintiffs.

12 This decision primarily addressed whether the court had the legal jurisdiction to hear the claim and a hearing on the merits was scheduled for May 11, 1992.

The SSA's Assessment of Residual Functional Capacity and Vocational Ability

The SSA has maintained that, if an HIV-infected person is disabled but does not have AIDS or meet the POMS "Symptomatic HIV Infection" criteria, the DDS adjudicator will determine whether he or she has sufficient residual functional capacity to continue to work. If the adjudicator determines that the claimant does not have sufficient residual functional capacity to work, the claimant will be awarded disability. The SSA is statutorily mandated to ignore whether suitable job openings are available or whether the claimant will be able to get a particular job (42 U.S.C. §§ 423(d), 1382c(B)).

Advocates claim that disability examiners interpret the evaluation of residual functional capacity and ability to work so strictly that their HIV-infected clients are virtually never found disabled at this final stage of the disability determination evaluation. Advocates do not believe that any single factor can account for all of these adverse decisions; however, they note that the vocational assessment is biased against younger individuals because the SSA assumes that only persons of advanced age (55 years old and older) are significantly restricted in their ability to "adapt and adjust to a new work situation and do work in competition with others" (21 C.F.R. s 404.1563(a)) .13

It is difficult to know whether the evaluation of residual functional capacity and ability to work leads to more denials of benefits to younger HIV-infected individuals than is warranted. It may not be possible to craft a Listing with such specificity that every person who meets the Listing would actually be found disabled if his or her residual functional capacity was

13 The SSA also recognizes that persons approaching advanced age--i.e., 45 years of age to 55 years of age--may have difficulty adjusting to new work situations (20 C.F.R. § 404.1563(b)(c)).

evaluated. In other words, some people who are not yet disabled might fall within the medical criteria of a Listing.¹⁴ Therefore, the disability process may appear less rigorous for people who obtain disability because they meet a Listing.

On the other hand, it is difficult to believe that a number of the HIV-infected claimants who were denied disability benefits were not in fact disabled. Indeed, a number of the plaintiffs in the case S.P. v. Sullivan eventually were awarded disability on appeal, indicating they were improperly denied disability benefits by the State DDS examiners. Several reports and statistics also lend some support to the advocates' claims.

Procedural Issues and Evaluation of Residual Functional Capacity

When HIV-infected claimants establish that they are disabled on the basis of a medical impairment, they only need to present fairly objective medical evidence. There is no subjective evaluation of the degree to which a claimant's medical condition affects his or her ability to concentrate, carry out certain activities of daily living, or work. It is these subjective evaluations that may be influenced by the SSA's procedures and policies.

First, one report concluded that several procedures used by the SSA in making disability determinations appear to reduce DDS disability examiners' ability to evaluate cases on an individual basis. The report noted that SSA's use of the "Listing of Impairments" and the instructions in its POMS "clericalizes the task of disability assessment, reducing it to a series of yes-no questions," rather than focusing on each individual's unique problems

¹⁴ For example, although all persons with AIDS can receive disability, a recent study of over 1000 persons with AIDS found that persons with AIDS exhibit a range of functional abilities depending upon the stage of the disease and other factors (55). This study is discussed in more detail below.

(188). In addition, initial decisions and reconsiderations by the DDS rely extensively on paper evidence that claimants and their physicians submit; there is no face-to-face meeting with claimants.¹⁵ Disability examiners may, however, have difficulty in properly assessing the degree of residual functional capacity by reviewing only the medical records (187).

Second, advocates argue that the extensive DI quality control system imparts excessive rigidity to disability determinations. In 1980, Congress mandated that the SSA review 50 percent of all DI and concurrent DI/SSI allowances prior to awarding benefits (42 U.S.C. § 421(c)). These "pre-effectuation" reviews of DI disability allowances are designed to ensure that the disability adjudicators make decisions that are consistent with SSA's regulations and policies. The review, however, only focuses on allowances, looking for cases in which disability should not be allowed, rather than on incorrect denials (190). Because this quality review focuses on incorrect allowances, it may cause DDS adjudicators to be too conservative in disability decisions.

Differences Between DDS Determinations and Administrative Law Judge Decisions

Evidence that the disability adjudicators might be overly conservative in their determinations also comes from the statistic that initial denials of disability benefits by DDS adjudicators have been reversed by administrative law judges in approximately two out of three cases (42,188). In order to explore the reasons for this disagreement in disability determinations, the

15 The Social Security Reform Act of 1984 requires the **SSA** to conduct demonstration projects in which claimants would be offered the opportunity to have a personal meeting with the disability determination officer prior to an initial unfavorable decision. The **SSA** instituted demonstration projects in 10 States between 1986 and 1988 (188).

General Accounting Office reviewed 242 disability cases in which administrative law judges reversed the SSA's initial disability determinations. The General Accounting Office found that in most cases the reversal stemmed from the fact that the DDS examiner overestimated the claimant's residual functional capacity (42). Whereas SSA disability examiners had determined that 54 percent of claimants could do medium or heavy work, the administrative law judges concluded that only 1 percent of these people could do such work. Conversely, administrative law judges determined that 71 percent of the claimants could do only sedentary work, if that, while the SSA disability examiners concluded only 1 percent of the claimants were so limited in functional capacity (187).

Most of the claimants in the sample suffered from back disorders, lung disease, diabetes, and anxiety--conditions that cause decrements in residual functional capacity that are subjectively measured. Further study is needed to determine whether similar findings would apply specifically to HIV-infected claimants. It is of note that certain common symptoms of HIV-infected patients, such as fatigue, chronic diarrhea, night sweats, gynecological conditions, undefined pain, or early HIV dementia, also cause decrements in residual functional capacity that are subjectively measured (240).

SSA's Implementation of Federal Court of Appeals Decisions

The SSA has also been accused of failing to implement certain decisions of the U.S. Court of Appeals for the Second Circuit (hereinafter Second Circuit), thereby making it more difficult for certain claimants to obtain disability.¹⁶ In Stieberger v. Sullivan (172) the court found the SSA had

¹⁶ The deliberate failure by an executive agency to adopt Appeals Court decisions is known as "non-acquiescence" (172).

failed to issue any SSRs implementing Second Circuit decisions regarding disability determinations, and in at least four areas, there was evidence the SSA's inaction led to a "system-wide pattern of mistaken adjudication."¹⁷ For example, in a series of decisions beginning in 1981, the Second Circuit held that a treating physician's opinion on the diagnosis and nature and degree of disability should be binding on the SSA's disability adjudicators unless contradicted by substantial evidence. The courts reasoned that the treating physician is usually most familiar with the claimant's medical condition (172). The SSA did not, however, explicitly adopt this policy until ordered by the court in 1986, and the final version of the instructions were implemented in 1988 (153). The SSA also failed to implement a Second Circuit decision instructing the SSA that a disability decision could not be based on a report that is issued after the claimant's hearing before an administrative law judge, unless the claimant has the opportunity to cross-examine the authors of the report (172). This decision guaranteed the claimant the opportunity to rebut evidence in the report. In addition, the SSA failed to implement Second Circuit decisions that established claimants with good work records were entitled to substantial credibility when they claimed they were unable to work because of a disability (172).

In those cases where the SSA applied different policies than the Federal courts, claimants who could pursue their claims to the Federal courts were more likely to receive disability (172). Not only would the outcome of certain claimants' disability determinations depend upon their ability to

17 The **SSA** did not formally reject Second Circuit decisions, and therefore in order to prove non-acquiescence the plaintiffs needed to offer evidence of individual disability cases that were adversely affected by the **SSA's** failure to implement a Second Circuit holding (172).

continue to appeal adverse SSA decisions to the Federal courts¹⁸, but the SSA's policy also led to excessive delay in disability determinations as claimants went through lengthy appeals process (see app. H).¹⁹

During the course of the litigation, the SSA issued several policy statements, and finally regulations in 1990, concerning the proper treatment of Federal Court of Appeals decisions.²⁰ The SSA, however, never published opinions explaining to its administrative law judges and State disability examiners why the SSA did not need to adopt certain Second Circuit decisions. The SSA decided that publishing such explanations would:

(2) . . . creat[e] the appearance of "whitewash," i.e. , repeated claim of no real conflict between SSA and the court despite the obvious facts that the conflict was litigated to the circuit court level and produced a decision rejecting the [SSA's] arguments and reversing [SSA's] decision; and

(3) potentially provide evidence for class actions seeking writs of *mandamus*²¹ to compel the [SSA] to follow policies she has adopted. Stieberger v. Sullivan (172)

The court in Stieberger v. Sullivan (172) concluded that the SSA's failure to implement the Second Circuit's rulings may have led to inappropriate denials of disability benefits. In a proposed settlement of the case, the SSA has agreed to distribute Second Circuit disability decisions to

18 By one estimate, only 6 percent of persons who are* initially denied disability appeal to the level of the circuit courts (128).

19 According to the court, a policy of non-acquiescence violated Congressional intent and the Constitution's Equal Protection Clause (172).

20 The court found that these policy statements and regulations left too much "room for non-acquiescence" and further noted that "each significant modification of agency policy came shortly before a major stage of this case" (172).

21 **In a writ** of mandamus, a plaintiff requests a Federal court to **compel** an executive agency to perform a non-discretionary duty owed to the plaintiff (18).

SSA's administrative law judges and State disability examiners and to instruct the administrative law judges and examiners to apply the decisions (173). In addition, a number of adverse disability decisions may be reviewed (44,93,128). The proposed settlement has yet to be approved by the court, and the impact the decision will have in other judicial circuits is not yet known. The case is instructive because it demonstrates how some of SSA's internal procedures and policies, which are not included in regulations and SSRs, may make it more difficult for claimants to obtain disability.

THE SSA'S NEW PROPOSED REGULATIONS FOR HIV INFECTION DISABILITY

In December of 1991, the SSA published a ruling and proposed regulations that create a new Listing for HIV infection (56 FR 65498, 65702). The "HIV Infection Listing" contains medical and functional criteria for determining disability for all persons with HIV infection (see app. J) and these criteria will be subject to public comment before being finally incorporated into the SSA's "Listing of Impairments." Because the SSA issued a ruling as well as proposed regulations, the new "HIV Infection Listing" is presently being used and will be amended if the final regulations differ from the proposed "HIV Infection Listing." The SSA also issued a new ruling and proposed regulations that allow the field offices to award presumptive disability to all persons who meet the new "HIV Infection Listing" (56 FR 65682, 65714). This could increase the number of HIV-infected persons awarded presumptive disability benefits by the field offices; however, according to the SSA, the new "HIV Infection Listing" will not increase the overall number of HIV-infected persons that are awarded disability (56 FR 65702)(126).

The new "HIV Infection Listing" combines the 1987 CDC definition of AIDS and the POMS "Symptomatic HIV Infection" criteria and also adds a number of other HIV-associated conditions, including many of the conditions that are more often found in HIV-infected women and injection drug users. The new "HIV Infection Listing" demonstrates that the SSA will no longer assume that every person who meets the CDC definition of AIDS is disabled. HIV-infected individuals with CD4 lymphocyte counts below 200 cells/mm³ or Kaposi's sarcoma will not be granted disability benefits unless they also document that they have marked functional limitations.

The SSA has received a large number of comments on their new "HIV Infection Listing." A number of commentators are supportive of the SSA's decision to expand the number of HIV-associated conditions that will be considered in determining whether an HIV-infected claimant meets a Listing. The commentators are dismayed, however, by the complexity of the Listing, and more importantly, by the use of the new functional limitation tests. In particular, they question why the SSA is able to develop strictly medical disability criteria for every non-psychiatric Listing in the "Listing of Impairments" except for the new "HIV Infection Listing." Under the "HIV Infection Listing," a number of HIV-infected claimants must document both medical impairments and marked functional limitations.

The HIV Infection Listing

Under the SSA's new "HIV-Infection Listing," all adult claimants²² who have one of the AIDS-defining conditions included in the 1987 CDC definition of AIDS (except Kaposi's sarcoma) will be considered disabled (see app. J). Adult claimants who show evidence of HIV infection and any of the following additional conditions will also be considered disabled:

- Candidiasis, disseminated (beyond the skin, urinary tract, intestinal tract, or oral or vulvovaginal mucous membranes) ;
- Herpes simplex virus infection of the gastrointestinal tract or encephalitis;
- Extraintestinal strongyloidiasis; or
- Nocardiosis;
- Invasive carcinoma of the cervix, International Federation of Gynecology and Obstetrics (FIGO) Stage II and beyond;²³
- Anal squamous cell carcinoma;
- Hodgkin's disease;
- Cardiomyopathy;
- Nephropathy.²⁴

HIV-infected adult claimants with HIV-associated conditions, other than those noted above, can meet the SSA's "HIV Infection Listing" only if they document one of the following medical conditions:

22 The "HIV Infection Listing" contains separate criteria for children; however, these criteria are not discussed herein.

23 Stage II cervical cancer has progressed beyond the **cervix**. This is a different Listing, and arguably easier to meet, than the SSA's current medical Listing for **cervical** cancer, which requires that the cancer be: 1) inoperable and not controlled by existing therapy; 2) recurrent after total hysterectomy; or 3) removed by total pelvic exenteration (20 C.F.R., Part 404, Subpt. P., App. 1, Sec. 13.25).

24 Cardiomyopathy and nephropathy were already included in the SSA's "Listing of Impairments" (20 C.F.R., Part 404, Subpt. P., App. 1, Sees. 4.02, 4.04, 4.05 (cardiomyopathy) and 6.02, and 6.06 (nephropathy), so their inclusion in the SSA's "HIV Infection Listing" is as a cross-reference, not as an addition to the Listings.

- A CD4⁺ lymphocyte count less than or equal to 200 cells/m.m³; □
- Documentation of one or more of the following persistent and/or resistant to therapy:
 - 1) Pneumonia;
 - 2) Pulmonary tuberculosis;
 - 3) Bacterial or fungal sepsis;
 - 4) Meningitis;
 - 5) Septic arthritis;
 - 6) Endocarditis;
 - 7) Peripheral neuropathy;
 - 8) Kaposi's sarcoma; or
- a Two or more of the following persisting over a 2-month period:
 - 1) Anemia (hematocrit value less than 30 percent);
 - 2) Granulocytopenia;
 - 3) Thrombocytopenia;
 - 4) Documented fever;
 - 5) Weight loss \geq 10 percent of baseline;
 - 6) Mucosal (including vulvovaginal) candidiasis;
 - 7) Oral hairy leukoplakia;
 - 8) Recurrent or chronic herpes zoster;
 - 9) Persistent dermatological conditions such as eczema, or psoriasis;
 - 10)** Persistent, unresponsive diarrhea;
 - 11)** Persistent or recurring documented sinusitis.

In addition, the claimant must document two of the following functional impairments:

- 1) Marked restriction of activities of daily living;
- 2) Marked difficulties in maintaining social functioning;
- 3) Marked difficulties completing tasks in a timely manner due to deficiencies in concentration;
- 4) Repeated episodes of decompensation, averaging three times a year or once every 4 months, lasting 2 weeks or more per episode, and which cause deterioration in condition.

The SSA also provided its adjudicators with special instructions for evaluating disability in HIV-infected individuals. The SSA wrote that HIV-infected individuals may suffer from anxiety, depression, apathy, and cognitive impairment, and that these mental impairments should be documented with medical evidence and evaluated under the appropriate Listing in the "Listing of Impairments" and/or be evaluated in determining the individual's

residual functional capacity (56 FR 65708). The SSA also noted that, on occasion, therapy for HIV infection may result in long-term or permanent adverse affects.

General Criticisms of the "HIV Infection Listing"

The inclusion of additional HIV-related illnesses in the "Listing of Impairments" comes at the price of more complexity. Critics have stated that the "HIV Infection Listing" has a "Chinese menu" type layout which requires different combinations of criteria depending upon the claimant's symptoms (30,59) (see app. J). It is arguably one of the most complicated Listings in the "Listing of Impairments." The complexity of the definition, critics argue, may delay processing of claims. Quick processing of claims is important because persons with severe manifestations of HIV infection, especially those persons whose health is already compromised by the effects of injection drug use, may already be close to death.

A number of groups are critical of SSA's decision to use a functional limitations test in a Listing because the test requires additional documentation and subjective assessment. The "Listing of Impairments" is designed to facilitate a finding of disability by allowing a disability determination to be made on the basis of fairly objective medical evidence consisting of: 1) symptoms (claimant's own perception of his or her physical or mental impairments) ; 2) signs (anatomical, physiological, or psychological abnormalities that can be demonstrated by medically acceptable clinical techniques); and 3) laboratory findings (226). The new "HIV Infection Listing" relies heavily on documentation of functional limitations,

essentially merging part of the residual functional capacity analysis into a medical listing²⁵ and thereby diminishing the advantage (to the claimants) of the Listings.

Moreover, the SSA has not explained why certain HIV-related conditions are disabling per se, whereas persons with other HIV-related conditions must also demonstrate functional limitations. An HIV-infected person with *Pneumocystis carinii* pneumonia or another opportunistic infection is considered disabled once he or she documents a single incidence of the disease. HIV-infected persons with serious illnesses, such as bacterial pneumonia, pulmonary tuberculosis, endocarditis, or bacterial sepsis (which often require hospitalization and may be fatal), are only considered disabled if they can also document that their illness is persistent and/or resistant to therapy and that they have marked functional limitations.

The critics contend that the SSA could have developed purely medical criteria to determine when certain HIV-associated conditions are disabling. The American Medical Association has testified that conditions such as endocarditis, pulmonary tuberculosis, Kaposi's sarcoma, and bacterial pneumonia have a high mortality rate in HIV-infected individuals and that HIV-infected persons with these conditions should not also have to prove functional limitations (24). The American Medical Association also argues , that HIV-infected persons with CD4⁺ lymphocyte counts below 200 cells/mm³ should be considered disabled because they are likely to succumb to serious opportunistic illnesses within a short period of time.

25 The residual functional capacity assessment focuses on the activities a person can perform, while the functional limitation assessment examines what activities a person cannot perform. Nonetheless, similar evidence is needed to make each of these assessments.

Advocates and physicians also claim it is possible to develop medical criteria that will be highly predictive of disability, even for HIV-associated conditions that are generally less severe. The National Association of People with AIDS, for example, has proposed that chronic anemia, which is quite prevalent in persons who take AZT, is disabling if an HIV-infected person has any of the following conditions:

- a persistent hemoglobin of less than 10.0 grams per deciliter;
- a hematocrit of less than 30.0 volume percent (regardless of AZT intake);
- the need for blood transfusions due to anemia more often than twice yearly (59) .

HIV-infected persons with chronic anemia who meet these criteria would not have to meet the SSA's functional limitation test.

In sum, the critics argue that HIV-infected individuals could more easily document their disability and obtain benefits if the SSA developed purely medical criteria for most HIV-associated conditions. The alternative the SSA has chosen--i.e. , to require that certain HIV-infected claimants demonstrate medical conditions plus functional limitations--may make it more difficult for certain HIV-infected claimants to document their disabilities.

The need to document functional limitations in two separate areas may be particularly difficult for HIV-infected persons who do not have a regular physician who can attest to their functional limitations on the basis of their treatment history. An official from SSA noted that a physician's opinion about functional limitations under the 'HIV Infection Listing,'"while not definitive, will be given considerable weight (46). Documentation of functional limitations, however, imposes an additional burden on the physician that goes beyond making a medical diagnosis. Many poor claimants receive

their medical care in hospital emergency rooms and busy public clinics and do not have regular physicians who will be able to adequately document their functional limitations (6,91).²⁶

The Functional Limitation Test

The functional limitation tests have been the most strongly criticized part of the SSA's new "HIV Infection Listing" (191). The POMS "Symptomatic HIV Infection" criteria contained a functional limitation test,²⁷ but it was much less stringent than the new SSA functional limitation test, despite the fact that the new "HIV Infection Listing" includes many of the same conditions included in the POMS "Symptomatic HIV Infection" criteria. In other words, the SSA may have made it more difficult for certain individuals with HIV-related conditions to receive disability.²⁸

The functional limitation test of the new "HIV Infection Listing" requires that claimants demonstrate marked limitations in two functional areas. The SSA explains that a claimant has marked restrictions in activities

26 The SSA does provide consultative examinations if a person does not have sufficient medical evidence to document a claim for disability (95) . From this medical evidence the DDS adjudicator might be able to ascertain functional limitations; however, the claimant must wait until the SSA has ascertained that it cannot obtain enough evidence and has scheduled a consultative exam.

27 The functional limitation test under the POMS "Symptomatic HIV Infection Listing" only required that a claimant demonstrate marked restriction in activities of daily living or deficiencies of concentration, persistence, or pace.

28 The new "HIV Infection Listing" has a stricter functional limitation test than the POMS "Symptomatic HIV Infection" criteria. The new "HIV Infection Listing" does not require, however, that an HIV-infected person have both a CD4⁺ lymphocyte count at or below 200 cells/mm³ and one or more HIV-associated conditions. Nonetheless, HIV-infected persons who would have met the "POMS Symptomatic HIV Infection" criteria must now document more extensive functional limitations.

of daily living if *most of the time* the claimant is unable to perform activities of daily living, such as household chores, grooming and hygiene, taking public transportation, or paying bills. The claimant is markedly restricted in social functioning if *most of the time* the claimant cannot interact appropriately and communicate effectively with others. Marked difficulties in completing tasks in a timely manner due to concentration deficiencies means that, *most of the time*, the claimant is unable to sustain concentration, persistence, or pace to permit timely completion of tasks found in work settings. To meet the final functional limitation test--repeated episodes of decompensation--the claimant must document repeated episodes of deterioration or decomposition in work or work-like settings, averaging three times a year, lasting 2 weeks or more per episode, and which cause his or her condition to deteriorate (e.g., repeated hospitalizations) (56 F.R. 65496).

The presence of two or more of these functional limitations establishes that the person cannot perform any substantial gainful activity (46). The functional limitation test is therefore used to establish the claimant's disability status and his or her medical condition is needed to establish that there is an underlying organic cause for the dysfunction (46). This distinguishes the "HIV Infection Listing" from most other medical listings for disability which do not require that claimants extensively document their ability to engage in personal hygiene, interact, or perform in the workplace.²⁹

29 To the extent a Listing contains functional tests, these are usually quite general (e.g., documentation of interference with daily activities caused by neurological impairments or by restrictions in mobility caused by **musculoskeletal** impairments (20 C.F.R. Part 404, Subpt. P, App. 1, Sec. 11.01, 1.01)).

The functional limitation test included in the SSA's "HIV Infection Listing" is derived from the functional limitation test included in the Mental Disorders section of the "Listing of Impairments" (20 C.F.R. Subpt. P, App. 1, Sec. 12.00). A functional limitation test is appropriate for evaluating psychiatric illness because it is often difficult to judge the severity or disabling impact of these conditions using typical medical diagnostic techniques. The functional limitation test used for evaluating the severity of disability due to mental impairments may, however, be ill-suited for evaluating the severity of disability due to physical impairments.

For example, one of the functional limitation tests in the "HIV-Infection Listing" requires that the claimant demonstrate repeated episodes of decompensation or deterioration in work or work-like settings. Decompensation is a psychological term which means "progressive loss of normal functioning in favor of psychotic behavior" or "disorganization of the personality under stress" (31a). For the "Mental Disorders Listing," a person can establish decompensation by documenting repeated failure to adapt to stressful circumstances that cause the person to withdraw from the situation, coupled with a difficulty in maintaining activities of daily living or maintaining concentration, persistence, or pace (20 C.F.R. Part 404, Subpt. P, App. 1, Sec. 1200(C)). It is unclear how a person with a physical impairment would demonstrate decompensation.

The SSA has responded to this problem by establishing different criteria for decompensation for the "HIV Infection Listing." Repeated episodes of decompensation can be demonstrated by at least three hospitalizations or absences from work per year lasting at least 14 days each. The decompensation test used in the "HIV Infection Listing" is, therefore, much less flexible than the decompensation test used in the "Mental Disorders Listing."

In the 'Mental Disorders Listing," impairment of social functioning is demonstrated by a history of altercations, fear of strangers, avoidance of interpersonal relationships, social isolation, and a lack of awareness of others' feelings (20 C.F.R. Subpt. P., App. 1 Sec. 1200 (C)). For the "HIV Infection Listing," impairment of social functioning is indicated by an inability to communicate and interact with people. This may not be a very sensitive test for determining disability in HIV-infected individuals. As noted by attorneys for HIV-infected clients, many very ill people with HIV infection are able to maintain close contacts with family and friends; indeed, social interaction may be an 'important and life-sustaining activity" (170).

Advocates for persons with HIV infection argue that having different definitions for the same functional limitation test may cause confusion. They are also critical of the fact that a person must document functional limitations in two separate areas. They argue that many HIV-infected people will be unable to work if they show a marked functional limitation in just one area. For example, to demonstrate marked restrictions in activities of daily living, one must show that most of the time he or she can't groom or perform personal hygiene, pay bills, or perform other household chores. State DDS disability examiners in New York interpret 'marked" to mean that the person is unable to perform the activity approximately 80 percent of the time (111) . This level of disability has been characterized by advocates and physicians' groups as being close to a nursing home level of functioning (111). A person is likely to lose his or her job prior to reaching this level of restriction in activities of daily living (6).

Similarly, to demonstrate marked difficulties in completing tasks, one must document that most of the time he or she cannot complete work tasks. One would not expect a person who is unable to complete work tasks more than 50

percent of the time to be able to perform in the workplace, and it therefore seems unnecessary to require that person to document another functional limitation (170). One must remember that these claimants will already have documented that they are HIV-infected and that they are either severely immunocompromised (i.e. , they have a CD4⁺ lymphocyte count at or below 200 cells/mm³) or suffer from one or more HIV-associated conditions that are persistent and/or resistant to therapy.

One study has indicated that the ability to perform activities of daily living may not be the best predictor of disability in persons with AIDS and, presumably, in other persons with symptomatic HIV-infection. A recent assessment of disability in 1024 persons with AIDS from various areas-- Atlanta; New Jersey; Seattle; Miami; Ft. Lauderdale; New Orleans; Dallas; and Nassau County, New York³⁰--found that, despite the fact that approximately 50 percent of the sample could not work and a quarter needed some assistance, only 2.6 percent had a very difficult time bathing or dressing, and that close to 60 percent could do heavy housework and walk up 10 steps. Even among respondents who had been hospitalized within 3 months of the interview, only 4.5 percent said they could not bathe or dress themselves and 40 percent could do heavy housework and walk up 10 steps (55).³¹

30 The authors caution that the sample was not randomly selected and that participants tended to be those persons who were more connected to the medical service delivery system and may have included a disproportionate number of persons who were less physically or mentally impaired. In addition, the study consisted of a majority of "white" males, a significant number identifying themselves as homosexuals (55).

31 The overwhelming majority of AIDS patients who had significant difficulty in bathing, washing, and doing heavy household chores, however, died within 11 months (55).

The authors' analysis of the data led them to conclude that the ability to engage in activities of daily living is not necessarily the best measure of the degree of impairment, which they defined as limitations in functioning of bodily organs or systems. The authors concluded that the ability to do strenuous activities may be a better measure of the degree of physical impairment and that the degree of physical impairment was strongly related to ability to work. In addition, they found that when one controlled for physical impairment, HIV-related symptoms and depression "had consistent effects on disability,"³² and in particular, persistent symptoms such as diarrhea or losing sleep due to night sweats may limit one's ability to carry out daily activity roles, such as employment (55). In other words, the authors imply that disability determinations for HIV-infected persons should focus primarily on the nature of conditions and symptoms related to HIV infection and the impact these conditions and symptoms have on a person's ability to consistently perform daily life roles, such as occupational roles.

The Impact of the SSA's New "HIV Infection Listing" on Women

The SSA added cervical cancer to the "HIV Infection Listing" so that HIV-infected women with Stage II cervical cancer--cancer that has progressed beyond the cervix--need not document functional limitations in order to receive disability. Gynecologists and other groups contend that a woman may be disabled before her cancer progresses to Stage II, and recommend that disability not be limited to Stage II (6,170).

32 Disability was defined as limitations in performing important social roles, such as occupational roles (55).

The SSA also added vulvovaginal candidiasis and genital herpes to the "HIV Infection Listing"; however, to meet the Listing an HIV-infected woman must document that these conditions persist *continuously* over a 2-month period and that she has marked functional limitations.

Pelvic inflammatory disease (PID) is not included in the "HIV Infection Listing," nor are two other serious gynecological diseases that the American Medical Association claims may occur more frequently in HIV-infected women: chronic genital ulcers and recurrent herpes (24). With respect to PID, the SSA did instruct its adjudicators that this condition, in combination with other HIV-associated conditions, may be disabling and that the adjudicators should determine whether the conditions of a claimant with pelvic inflammatory disease *equals* the "HIV Infection Listing," even though the condition is not included in the Listing.³³

Advocates argue that HIV-infected women who document recurrent episodes of these gynecological conditions should be awarded "disability without having to also document marked functional limitations. They argue that an HIV-infected woman is disabled if she has had three or more episodes of PID, or one episode of PID that is resistant to therapy and requires hospitalization and/or surgery (59). Similarly, they contend that recurrent herpes lesions are disabling if the lesions recur more often than once every 8 weeks and if the lesions are incompletely suppressed despite continuous therapy (112). Finally, they question why SSA excluded PID and genital ulcers from the "HIV Infection Listing," since HIV-infected women with these conditions would also need to document functional limitations in order to meet the Listing.

33 These instructions are similar to the instructions given in the March 1991 program circular that the SSA issued on evaluating disability in women (228).

The SSA would likely respond that the DDS adjudicators have the discretion to award a woman disability if her gynecological conditions are equally severe to the conditions contained in the "HIV Infection Listing." Moreover, if a disabled woman does not meet the "HIV Infection Listing," she can still receive disability at a later step in the disability determination process. At the heart of the controversy over SSA's disability evaluations, however, is the question of whether the DDS examiners exercise this discretion or whether they primarily rely on stated disability criteria. With respect to SSA's second point, advocates argue that because HIV infection is ultimately fatal, the disability process should be simplified so that benefits are awarded at the earliest stage possible.

Presumptive Disability and HIV Infection

On December 18, 1991, the SSA also issued a notice of proposed rulemaking and a final rule to revise its regulations governing presumptive disability under SSI (56 F.R. 65682, 65714). Under the final rule, field offices will no longer be limited to awarding presumptive disability to persons with CDC-defined AIDS (56 F.R. 65682). Instead, the field offices will be able to award presumptive disability benefits to all HIV-infected claimants who meet the SSA's new "HIV Infection Listing." The personnel in the field offices are not trained to evaluate medical evidence, so they will send checklists to the treating physicians of SSI claimants who allege HIV infection. The checklist itemizes the HIV-associated conditions and functional limitations that meet the SSA's new "HIV Infection Listing" (see app. K). If the claimant's physician verifies that the claimant meets the "HIV Infection Listing," the field office will award the claimant presumptive

disability benefits (56 F.R. 65714). In the event that the field office does not award presumptive disability benefits, the DDS offices may award presumptive disability benefits when they find sufficient evidence to conclude that the person is likely to be disabled (56 F.R. 65714).

When the CDC definition of AIDS was used for presumptive disability determinations, the field office could confirm the case with a phone call to a physician or other health care provider because the medical community also uses the CDC definition of AIDS. In contrast, health care providers may not be familiar with the "HIV Infection Listing" because it will not be used in clinical care. The SSA has responded to this problem by devising a checklist that will be sent to physicians who will verify that their patients meet the "HIV Infection Listing." This procedure should enable the field offices to continue to award presumptive disability to a larger group of HIV-infected individuals. In addition, by using a standard form for all HIV-infected claimants, the SSA hopes to simplify presumptive disability determinations.

However, there is some concern that the confusion caused by the new procedure will outweigh its benefits. The physician is expected to fill out the presumptive disability form and mail it back to the field office; yet, many State DDS offices also send forms to physicians in order to gather information on specific impairments, such as AIDS.³⁴ If a physician first receives the field office presumptive disability form and then several days later receives a more detailed medical form from the State DDS, the physician may only fill out one form because he or she believes this is sufficient, or because of time constraints (182a). It may be unreasonable to expect

34 Although the SSA did not know how many State DDS offices have such a system, an official said this system is not unusual, especially in States with major metropolitan areas (46).

physicians who are treating a large number of HIV-infected patients to fill out two similar forms on the same patient, possibly requiring the physician to review the patient's record twice (29).

If the treating physician only fills out the field office form, believing this to be sufficient, then the State DDS either will be left with little information or will have to go back to the physician to remind him or her to fill out the DDS form. One State DDS has suggested that the physician should only be expected to fill out the State DDS form. The DDS can then award presumptive disability benefits if warranted and proceed with the final disability determination (182a). This alternative would ensure that the one document received from the physician would provide all the information that is needed.

SUMMARY

The debate over the CDC definition of AIDS arose in large part because the case definition was being used in Social Security disability determinations. Advocates for HIV-infected women and injection drug users have presented numerous examples of their very ill clients who were denied disability by SSA. Some of these clients were often awarded disability on appeal, providing support for the advocates' position that the clients were wrongly denied disability. The advocates claim that the use of the CDC definition of AIDS in disability determinations biased the DDS adjudicators against HIV-infected individuals who did not have an AIDS-defining illness, a claim the SSA strongly denied. One court has indicated, however, that SSA's failure to issue regulations making AIDS and the POMS "Symptomatic HIV Infection" criteria equal to a Listing may have violated the Administrative Procedure Act.

It is difficult to sort out why seemingly deserving HIV-infected claimants were being denied disability. They may have been the most egregious cases, or they may be indicative of a larger problem warranting further investigation. One cannot discern the way in which claims were decided from SSA statistics on allowances and denials. However, the statistics do indicate that persons who had AIDS or who met the POMS "Symptomatic HIV Infection" criteria were significantly more likely to receive disability benefits. Moreover, several reports about the SSA's procedures for determining residual functional capacity, including concern about the quality control system and the differing assessments of residual functional capacity among DDS examiners and administrative law judges, may warrant further investigation. Finally, it is of note that the Second Circuit court opinions that the SSA failed to incorporate into its disability process were decisions that appeared to facilitate a finding of disability for certain claimants.

With the new "HIV Infection Listing," the SSA has clearly demonstrated that changes in the CDC definition of AIDS will not necessarily be incorporated into the disability process and that all persons who meet the proposed CDC definition of AIDS will not automatically receive disability. Nonetheless, people with the AIDS-defining conditions included in the 1987 case definition (except Kaposi's sarcoma) will continue to be judged disabled on the basis of their medical condition alone, whereas HIV-infected individuals with other serious diseases, including conditions that may result in hospitalization and death, will also need to prove that they have functional limitations in two of the following areas: activities of daily living, social functioning, difficulties in completing tasks, and repeated episodes of deterioration or decompensation in work or work-like settings.

The new debate over SSA's disability determinations now centers on whether the functional limitation test included in the new "HIV Infection Listing" is reasonable. Critics contend that the SSA should have developed strictly medical criteria for determining disability for persons with any one of the HIV-associated conditions included in the Listing. A number of medical experts and persons who are knowledgeable about HIV infection insist that the functional limitation test is too stringent, especially the requirement that an HIV-infected claimant must document two out of four possible functional limitations. HIV-infected persons may be unfairly barred from obtaining disability because they are unable to document functional limitations to this degree. It may be especially difficult for poor and uninsured HIV-infected claimants to document marked functional limitations in two separate areas because they do not have a continuing relationship with a single physician. The functional limitation tests appear to demand detailed documentation involving physician input.

The debate over the SSA's disability determinations for people with HIV infection is probably not over, as the overwhelming number of public comments on the SSA's new "HIV Infection Listing" demonstrate. The impact that the new "HIV Infection Listing" will have on HIV-infected women and injection drug users is not yet known. The SSA claims, however, that the new "HIV Infection Listing" will not increase the overall number of HIV-infected individuals who obtain disability.

The new "HIV Infection Listing" does separate the debate on the SSA's disability determinations for persons with HIV from the debate about the appropriate surveillance case definition of AIDS. The CDC's definition of AIDS cannot be expected to adequately serve both the purposes of surveillance and disability.