Journal of Gender, Social Policy & the Law

Volume 22 | Issue 3 Article 2

2014

The More Things Change, the More They Stay the Same: A Section 504 Examination of the Social Security Administration's Use of 1993 Medical Criteria to Determine Disability in 2014

Adrienne Jones

THE MORE THINGS CHANGE, THE MORE THEY STAY THE SAME: A SECTION 504 EXAMINATION OF THE SOCIAL SECURITY ADMINISTRATION'S USE OF 1993 MEDICAL CRITERIA TO DETERMINE DISABILITY IN 2014

ADRIENNE JONES*

* Clinical Instructor and 2014 LL.M Candidate, University of the District of Columbia, David A. Clarke School of Law. 2006 J.D. University of the District of Columbia, David A. Clarke School of Law. With thanks and appreciation to LaShanda Adams, Vanita "Saleema" Snow, and Matthew Fraidin for reading drafts, providing feedback, and encouraging my progress. Also thanks to Bethany Shechtel and Anna Massoglia for their assistance in the beginning stages of legal research. Lastly, thanks to my fellow LL.M's, and UDC-DACSL faculty and staff for all of the support.

INTRODUCTION

Access to social security disability benefits for individuals asserting HIV infection-related claims has decreased considerably in recent years. The Social Security Act defines "disability" as the "inability to engage in any substantial gainful activity . . . ."[1] An individual is found to be under a disability only if his physical or mental impairment or impairments are of such severity that he is not only unable to do his previous work but cannot, considering his age, education, and work experience, engage in any other kind of work that exists in the national economy.[2] This narrow definition of disability under the Social Security Act is further narrowed, and in my view, discriminatorily so, in the Social Security Administration's current HIV Infection Listing. The HIV Infection Listing is an essential function of the disability determination process and its establishment has been the subject of a class action against the Social Security Administration (SSA) alleging violation of Section 504 of the Rehabilitation Act of 1973.

In 1991, a federal district court heard *Rosetti v. Sullivan*, a case involving an allegation of discrimination under Section 504 of the Rehabilitation Act.[3] The plaintiff class of HIV-infected people alleged that the SSA, in its internal guidance for evaluating HIV infection-related claims, relied upon the Center for Disease Control (CDC) surveillance definition of AIDS, which did not account for the manifestations experienced by women, people of color, the indigent, and users of illicit drugs.[4] The plaintiff class

1. 42 U.S.C. § 423(d)(1)(A) (2012).
2. 42 U.S.C. § 423 (2006); 42 U.S.C. § 1382c (2006).
3. Rosetti v. Sullivan, 788 F. Supp. 1380 (E.D. Pa. 1992).
4. *Id*. at 1385. Plaintiffs also alleged that the internal guidance, in the form of the

characterized the evaluation process of HIV infection-related claims as using "overly narrow criteria that fail[ed] to recognize some of the ways in which the virus can cause disabling impairments."[5] The class concluded that individuals making HIV infection-related claims who were "disabled, but who suffer from symptoms of the virus that the SSA's rules and policies have overlooked, [we]re not awarded benefits to which they should be entitled."[6] Prompted by *Rosetti* and after much delay, the SSA finally promulgated an HIV Infection Listing on July 2, 1993, establishing formalized medical criteria upon which it would make disability determinations for HIV infection-related claims.

More than twenty years after *Rosetti v*. *Sullivan*, the SSA has not substantively updated the HIV Infection Listing to reflect the current manifestations of HIV/AIDS.[7] The SSA's reasoning for its inaction is that "there has not been significant progress in the treatment and control of [the] HIV infection to warrant any change in the rules." This assessment is wholly without merit. The advent of life-prolonging medication therapy, such as Highly Active AIDS Retroviral Treatment (HAART) has changed the course of HIV infection from a "death sentence" to a manageable disease; however, many people living with HIV/AIDS suffer long-term, debilitating illnesses and conditions that negatively impact their functioning and ability to work. Such debilitating ailments are exacerbated by poverty, which has a specific and profound impact on individuals with HIV/AIDS. While not a stated purpose of the Social Security Act, disability benefits are a tool to lessen poverty. The medical criteria of the HIV Infection Listing, if satisfied, would expedite the disability determination process, and successful recipients would receive cash assistance, medical insurance coverage, and access to employment and vocational opportunities. Those "benefits" are crucial for impoverished individuals who are infected with HIV/AIDS and act to stabilize, through healthy medical status, potential re-entry into the workforce and productivity as any other member of society.

SSA's Program Operations Manual System and Social Security Rulings, did not comply with the Administrative Procedural Act (APA) requirement for notice and public comment although, as the plaintiffs alleged, they were *de facto* substantive rules.

5. Rosetti v. Shalala, 12 F.3d 1216, 1217 (3d Cir. 1993).

6. *Id*.

7. As of this writing, the SSA published its Notice of Proposed Rulemaking for Revised Medical Criteria for Evaluating Human Immunodeficiency Virus (HIV) Infection and for Evaluating Functional Limitations in Immune System Disorders. However, the current HIV Infection Listing is still in effect until the Final Rules are issued. It is unknown when Final Rules revising the HIV Infection Listing will be published. *See* 79 Fed. Reg. 10,730 (Feb. 26, 2014).

Section 504 of the Rehabilitation Act of 1973, is the vehicle for the enforcement of "civil rights for the handicapped." The Rehabilitation Act of 1973—promulgated to provide evenhanded treatment to the disabled relating to benefits, services, and employment—has yielded an expansive view of "discrimination" under Section 504. The Supreme Court has recognized that disabled "otherwise qualified" individuals are entitled to "meaningful access" to a service, benefit or aid afforded to the non-disabled. However, some lower courts have extended Section 504 to prohibit discrimination vis-à-vis the same protected class and for failure to reasonably accommodate. Moreover, lower courts have also held that preferential treatment of a comparison class or disparate treatment is not always required.[8] The SSA's failure to revise the HIV Infection Listing denies "meaningful access" as defined by case law. The lack of revision substantially impairs the objectives of the social security program, and is a failure to reasonably accommodate as established by judicial interpretations of Section 504 and implementing regulations promulgated by the Department of Health and Human Services (DHHS), Department of Justice (DOJ), and Department of Health, Education, and Welfare (HEW). One of the purposes of the Rehabilitation Act is "to ensure that the federal government plays a leadership role in promoting the employment of individuals with disabilities . . . and in assisting States and providers of services in fulfilling the aspirations of such individuals with disabilities for meaningful and gainful employment and independent living."[9] This purpose is undermined by the lack of equity in the determination process for approval of disability benefits for HIV infection-related claims because it fails to account for the current manifestations of the disease. By providing meaningful access to HIV infection-related disability benefit claims, the SSA will create a pathway to employment and self-sufficiency, in compliance with the Rehabilitation Act of 1973.

The SSA's disability determination process as applied to HIV-related claims is not a publicized incidence of discrimination, but "acts of discrimination, whether publicized or not, diminish our society's adherence

8. *See, e.g.*, Martin v. Voinovich, 840 F. Supp. 1175, 1192 (S.D. Ohio 1993) ("[T]he language of [Section] 504 evinces an intent to eliminate handicap-based discrimination and segregation. A strict rule that [Section] 504 can never apply between persons with different disabilities would thwart that goal. The relevant inquiry is whether the application [Section] 504 between persons with different or varying degrees of disability furthers the goal of eliminating disability-based discrimination."); Henrietta D. v. Bloomberg, 331 F.3d 261, 274 (2d Cir. 2003); Messier v. Southbury Training School, 916 F. Supp. 133, 141 (D. Conn. 1996); 45 C.F.R. § 84.4(b)(1)(iv) (2014) (prohibiting the provision of "different or separate aid, benefits or services to handicapped persons *or to any class of handicapped persons*") (emphasis added).

9. 29 U.S.C. § 701(b)(2) (2012).

to the principles of justice and equality."[10] This Article examines whether the SSA's HIV Infection Listing affords "equal treatment as implied by the right to 'meaningful access.'"[11] Section I focuses on the intersection of HIV/AIDS and poverty, and how social security disability benefits are a tool to lessen poverty. Section II describes the Social Security determination process and the history of the HIV Infection Listing. In Section III of this Article, I describe the Rehabilitation Act and apply a Section 504 analytical framework to examine the SSA's use of the outdated HIV Infection Listing. Finally, Section IV describes my recommendations for the SSA.

I. THE INTERSECTION BETWEEN POVERTY AND HIV/AIDS

A. The Particular Needs of People with HIV/AIDS and the "Poverty Effect"

Poverty impacts people living with HIV/AIDS in specific ways and is a determinant of health outcomes. The "poverty effect" on the basic needs of shelter, food, transportation, and medical care can jeopardize the immune system of an individual with HIV/AIDS. Shelter and stable housing are critical to meet the needs of people living with HIV/AIDS.[12] Poor, HIV infected individuals risk their health when relegated to communal living. Shelters with poor or no ventilation subject the HIV infected to the coughing, sneezing, and general illness of other residents, to the detriment of their compromised immune systems. Unstable housing also makes it difficult for a person living with HIV/AIDS to maintain a medication regimen that has a prescribed schedule. An HIV therapy schedule may also include specific food consumption restrictions.[13] Several HIV/AIDS medications must be refrigerated in addition to other storage

10. PRESIDENT'S COMM'N ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC, INTERIM REPORT OF THE PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC (1988) [hereinafter INTERIM REPORT OF THE PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC].

11. Doe v. Astrue, 2009 U.S. Dist. LEXIS 72819, at *41 (N.D. Cal. Aug. 18, 2009).

12. *See generally* C.A. Leaver et al., *The Effects of Housing Status on Health-Related Outcomes in People Living with HIV: A Systematic Review of the Literature*, 11 AIDS BEHAVIORAL SUPPL. 6, 85-100 (2007); Elise D. Riley et al., *Social, Structural, And Behavioral Determinants of Overall Health Status in a Cohort of Homeless and Unstably Housed HIV-Infected Men*, 7 PLOS ONE 1 (2012); Elise D. Riley et al., *Poverty, Unstable Housing and HIV Infection Among Women Living in the United States*, 4 CURRENT HIV/AIDS RPTS 4, 181-86 (2007).

13. *Currently Approved Drugs for HIV: A Comparative Chart*, AIDSMEDS (Nov. 13, 2012), http://www.aidsmeds.com/articles/DrugChart_10632.shtml.

requirements.[14] Transient or temporary housing also has a direct impact on an individual's ability to attend medical appointments regularly. Food insecurity[15] is prevalent among the impoverished and HIV-positive populations[16] and impacts nutritional status. To protect his or her immune system, an individual with HIV/AIDS must have access to a consistent, adequate diet. Insufficient dietary intake of food, mal-absorption, diarrhea, impaired storage of nutrients, and altered metabolism are ways that the HIV infection can escalate malnutrition, which in turn prevents the body from fighting off infection, and increases the risk of further infection.[17] Food insecure individuals were found to be more likely to miss their antiretroviral therapy (ART) doses than individuals who were considered food secure.[18] Transportation is also a basic need for individuals living with HIV/AIDS. To maintain a healthy status, people living with HIV/ AIDS must travel to medical appointments and fill prescriptions for HIV medications. Transportation to such appointments is vital to managing health. For example, in general, HIV-treatment guidelines suggest that once HIV treatment is prescribed, it must be continued indefinitely.[19] An inability to maintain medical appointments or get to the pharmacy because of a lack of transportation could lead to missed medication dosages, and result in compromised viral suppression and CD4 counts.[20] A lack of

14. *Id*.

15. *Definitions of Food Security*, USDA ECONOMIC RESEARCH SERV., http://www.ers.usda.gov (last updated Sept. 4, 2013) (search "food security definition").

16. KHOU XIONG ET AL., REVIEW OF THE EVIDENCE: LINKAGES BETWEEN LIVELIHOOD, FOOD SECURITY, ECONOMIC STRENGTHENING AND HIV-RELATED OUTCOMES 1, 8 (2012) (citing L. Normen et al., *Food Insecurity and Hunger Are Prevalent Among HIV-Positive Individuals in British Columbia*, *Canada*, 135 J. NUTRITION 820 (2005)); J. McMahon et al., *Repeated Assessments of Food Security Predict CD4 Change in the Setting of Antiretroviral Therapy*, 58 J. ACQUIRED IMMUNE DEFICIENCY SYNDROME 60 (2011).

17. XIONG ET AL., *supra* note 16 (citing Alice Tang, *Getting the Knack of NACS: Nutrition Implications of HIV and ART*).

18. *Id*. (citing S.D. Weiser et al., *The Association Between Food Insecurity and Mortality Among HIV-infected Individuals on HAART*, 52 J. AIDS 342 (2009)).

19. Prudencia Mweemba et al., *Quality of Life and Adherence to Antiretroviral Drugs*, 37 MED. J. ZAMBIA 1 (2010).

20. *Id*. ("If patients do not take antiretroviral drugs essentially as prescribed, if doses are missed or taken improperly, resistance is expected, leading to clinical failure."); *CD4 Cell Test*, AIDSMEDS, http://www.aidsmeds.com/articles/ TCellTest_4727.shtml (last revised June 24, 2011); *see also*, *CD4 Count*, AIDS.GOV, http://aids.gov/hiv-aids-basics/just-diagnosed-with-hiv-aids/understand-your-test-results/cd4-count/ (last revised Oct. 11, 2010). CD4 or T-cells are a type of white blood cell that functions to protect the immune system by "signaling other immune

health insurance is also prevalent among the HIV-positive community. According to results from the HIV Cost and Services Utilization Study (HCSUS), one-fifth of individuals with HIV/AIDS are uninsured,[21] thereby effectively foreclosing healthy management of the virus. Healthy outcomes for individuals with HIV/AIDS require consistent access to shelter, food, transportation, and healthcare; the effects of poverty significantly impair those basic needs.

B. A Tool to Lessen the "Poverty Effect"

Social security benefits are a tool to lessen the "poverty effect" and its impact on individuals living with HIV/AIDS by creating access that begins with financial assistance. An integral part of this effort must include the elimination of discrimination in the SSA disability determination process to allow "meaningful access" to the social security disability benefits. The elimination of discrimination and the opportunity to access disability benefits enhances the ability of an individual, who is living with HIV/ AIDS, to receive consistent treatment, care, and employment or vocation.

C. The Benefits of "Benefits"

Housing, food, and transportation—needed for stabilization—are accessible by those in need who are able to take advantage of a monthly subsidy provided through social security benefits. Relating to shelter as a basic need, research has suggested that housing is the top unmet service need for people living with HIV/AIDS.[22] Social security benefits could be used to assist with the accompanying costs of housing, including rent,

---

system cells to fight an infection in the body." HIV attacks CD4 cells, causing the number of cells to decrease. A high CD4 or T-cell count is important to prevent opportunistic infections and other HIV infection-related illnesses. The normal CD4 count is somewhere between 500 and 1500 cells per cubic millimeter of blood (cells/mm^3). When the CD4 count is 350 cells/mm^3 or below, treatment should be started. In general, when a CD4 count drops to 200 cells/mm^3 or below, a diagnosis of AIDS follows.

21. Samuel A. Bozette et al., *The Care of HIV-Infected Adults in the United States*, 339 NEW ENG. J. MED. 1897-904 (1998). *See generally* ARLEEN LEIBOWITZ ET AL., A PORTRAIT OF THE HIV+ POPULATION IN AMERICA INITIAL RESULTS FROM THE HIV COST AND SERVICES UTILIZATION STUDY (1999) (evaluating estimates of health coverage for individuals with HIV using a nationally representative study of people with HIV/AIDS in care, conducted from 1994 to 2000).

22. V. SHUBERT ET AL., MOVING FROM FACT TO POLICY: HOUSING IS HIV PREVENTION AND HEALTH CARE, 11 AIDS AND BEHAVIOR 6 (Supp. 2), 167-71 (2007) T. Bekele et al., *Direct and Indirect Effects of Social Support on Health-Related Quality of Life Among Persons Living with HIV/AIDS: Results from the Positive Spaces Health Places Study*, AIDS CARE: PSYCHOLOGICAL AND SOCIO-MEDICAL ASPECTS OF AIDS/HIV (2013).

security deposit, and furniture.[23] Access to Medicaid insurance is also a benefit of social security disability benefits.[24] Medicaid insurance could cover the costs of necessary medication treatment. In a 2010 study, Antiretroviral (ARV) combination medication therapy accounted for sixty-one to seventy-four percent of costs for those with CD4 counts >200 cells/ mm^3, forty-five percent of costs for those with CD4 counts between 51 and 200 cells/mm^3, and twenty-three percent of costs for those with CD4 counts $\leq$ 50 cells/mm^3.[25] The cost of ARVs can be exorbitant.[26] Uninsured or underinsured people living with HIV/AIDS may access the AIDS Drug Assistance Program (ADAP) to subsidize the costs of prescribed HIV/ AIDS medications. ADAP is authorized under Title II of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.[27] However, ADAP has struggled with underfunding in recent years and a funding crisis in 2010 left many low-income people, with HIV/AIDS, on waiting lists for medication.[28] All states cover prescription drugs as "optional benefits" under the Medicaid program.[29] The unpredictability of ADAP funding makes the need for Medicaid insurance coverage provided to recipients of security disability benefits indispensable. Recipients of disability benefits

23. Housing Opportunities for People Living with AIDS (HOPWA), a federal program designed to assist states with meeting the housing needs of people living with HIV/AIDS, is an invaluable housing resource. However, several states and cities have waiting lists. *See HOPWA 2013 Budget Request: NAHC Recommends $380 million*, NAT'L AIDS HOUSING COALITION (2013), *available at* http://nationalaidshousing.org/PDF/2013HOPWANeedPaper.pdf.

24. Medicaid is available to recipients of Supplemental Security Income (SSI). Receipt of disability benefits is one of the eligibility requirements for Medicaid, so access is virtually automatic upon approval for benefits.

25. Kelly A. Gebo et al., *Contemporary Costs of HIV Health Care in the HAART Era*, 24 J. AIDS 17 (2010).

26. *Id*. The mean ARV costs for those taking medications were $10,775 for patients with CD4 counts $\leq$ 50 cells/mm^3 and were $13,140, $13,783, $14,437, and $14,430 for the other respective CD4 categories; only the difference between the two lowest CD4 categories was significant. In absolute terms, antiretroviral medication costs remained substantial for all patients, regardless of CD4 count.

27. Ryan White Comprehensive AIDS Resources Emergency Act, 42 U.S.C. § 300ff-26 (2012).

28. *See generally* Press Release, Nat'l Alliance of State and Territorial AIDS Dirs., After Five Years, ADAP Waiting Lists Have Been Eliminated; Unmet Need and Funding Uncertainties Require Continued Commitment (Nov. 15, 2013) (on file with NASTAD).

29. HIV/AIDS POLICY FACT SHEET, HENRY J. KAISER FAMILY FOUND. (2014), *available at* http://kff.org/hivaids/fact-sheet/the-hivaids-epidemic-in-the-united-states. Several states, however, limit the number of prescriptions per month or year. The expansion of Medicaid under the Affordable Care Act (ACA) may address these limitations.

are afforded access to vocational resources. The purpose of SSA's "Ticket to Work Program" is to expand employment opportunities for individuals receiving social security disability benefits that will increase the likelihood that these individuals will reduce their dependency on Social Security and SSI cash benefits.[30] As recipients in the Ticket to Work Program, successful claimants work with "employment networks" that assist claimants in finding employment or vocational programs that are based upon the particular, stated need of each recipient. The SSA also has several work incentive programs that serve to bridge the gap between receipt of disability benefits and eventual financial independence.[31] In addition to increasing stabilization, employment is a "normalizing" feature for people living with HIV/AIDS. Employment has a direct positive effect on self-esteem, self-worth, and connection to society. In turn, those positive self-values can lead to positive health outcomes and overall quality of life.

Social Security disability benefits are an effective tool for impoverished people with HIV/AIDS to achieve stabilization by receipt of cash assistance, medical insurance coverage, and employment/vocation opportunities. As a result of stabilization, individuals with HIV/AIDS are in a position to fully re-enter the work force, maintain employment, and thereafter no longer require the financial assistance of social security disability benefits. This is an ideal but attainable goal. It is shared to demonstrate that the desire to obtain disability benefits is not contradictory to employment or self-sufficiency. Instead, social security benefits are a means to lessen poverty and attain self-sufficiency.

Currently, access to social security benefits is impeded because the rules that the SSA uses to determine disability for HIV infection-related claims do not consider the particular needs and impairments experienced by people infected with HIV/AIDS. This is a denial of "meaningful access" under Section 504. Meaningful access to the disability determination process, and by extension, social security benefits, affords people living with HIV/AIDS not only access to social security benefits, but also participation in mainstream society, a goal of the Rehabilitation Act of 1973. The following section describes the social security disability determination process and the HIV Infection Listing, an integral aspect of

30. 20 C.F.R. § 411.105 (2014).

31. U.S. Soc. Sec. Admin., *Welcome to the Work Site*, SOC. SECURITY: OFFICIAL SOC. SECURITY WEBSITE, http://www.socialsecurity.gov/work/index.html (last visited Feb. 20, 2014). Recipients may receive benefits until they begin earning income above the applicable earnings limit for Supplemental Security Income (SSI). *See* U.S. Soc. Sec. Admin., *Frequently Asked Questions, Ticket to Work*, http://choosework.net/about/frequently-asked-questions/index.html (search "About Ticket to Work," Frequently Asked Questions).

determining disability for HIV infection-related claims.

II. DISABILITY APPROVAL AND THE SIGNIFICANCE OF "STEP THREE"

A. Social Security Disability Determination Process

The Social Security Act defines "disabled" as the inability to engage in substantial gainful activity by reason of any medically determinable physical or mental impairment that can be expected to result in death or that has lasted, or is expected to last, for a continuous period of not less than six months.[32] The SSA administers, among other services, two federal programs under the Act that provide disability benefits to individuals who are unable to work: Social Security, otherwise known as Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).[33] Although SSDI and SSI determination processes have similar features, they are distinct. SSDI is an insurance program. Benefits are provided to disabled individuals who have been employed, and have paid social security taxes for the requisite number of work quarters. SSI is a needs-based program. Benefits are provided to disabled individuals who do not have the requisite employment history but are in financial need. Both programs require the applicant to be "medically disabled." The process that the SSA uses to determine if an applicant is "medically disabled," and therefore eligible for disability benefits, is called the "six-step evaluation" process.[34] Each step of the sequential evaluation process must be satisfied in turn before a claim is approved or denied.[35]

---

32. 42 U.S.C. § 423(d)(1)(A) (2012); 42 U.S.C. § 1382c(a)(3)(A) (2012); 42 U.S.C. § 423(d)(2)(A) (2012); 42 U.S.C. § 1382c(a)(3)(B) (2012).

33. This article will focus on SSI.

34. 20 C.F.R. § 416.920 (2014).

35. Step One: First, an applicant may not be engaged in "substantial gainful activity." Substantial gainful activity is work that is for pay, that does not exceed $1,040 per month, and that requires mental and physical activities. Step Two: An applicant must show that they have a severe medical impairment or severe medical impairments. Step Three: An applicant whose particular ailment(s) or impairment(s) is so severe that it is presumed that they are unable to engage in substantial gainful activity and are therefore disabled and entitled to benefits. If an applicant has a condition(s) or impairment(s) that meets or equals the medical criteria required at this step, the sequential evaluation process ends, and the applicant is eligible for disability benefits. It is at this step where the SSA utilizes its "Listings of Impairments." If an applicant's disability "meets" or "equals" the Listing-level medical criteria, Steps Four and Five are "skipped." If an applicant's impairments, conditions, and symptoms do not "meet" or "equal" the criteria set forth in the Listings, the applicant's case must be evaluated under the remaining steps in the sequential evaluation. Step Four: At this step, SSA evaluates an applicant's ability to do his or her past relevant work in spite of his or her physical or mental health impairments. SSA assesses an applicant's

At "Step Three" of the six-step sequential evaluation process, the SSA utilizes the medical criteria in its "Listing of Impairments" (Listings),[36] which describe fourteen body systems[37] and impairments considered severe enough to prevent an individual from doing any substantial, gainful activity.[38] Since its inception in 1954, the Listings have been revised extensively and are "less dependent on diagnosis and more dependent on function."[39] In 1967, the Listings were revised and further reflected fewer disease specifications and more highly-specific criteria involving signs, symptoms, and laboratory findings.[40] Beginning in 1968, the Listings have been revised in response to changes in disease patterns and the advent of new technology.[41] The SSA comprehensively updated and revised all of the adult Listings in 1979.[42] In 1985, the SSA updated most of the body system Listings and added expiration dates for the adult Listings. [43] At that time, the SSA noted that it would periodically review and update the Listings based on medical advancements in disability evaluation and treatment, and program experience.[44] In 2011, the SSA Commissioner set a

---

"residual functional capacity." Step Five: SSA evaluates an applicant's age, education, and work experience to determine if he or she is able to perform other work in the national economy. Step Six: At this step, the SSA proscribes receipt of disability benefits for applicants whose disability is a result of a substance or alcohol addiction. Step Six was added in 1996. *Id*.

36. 20 C.F.R. § 404.1525 (2014). The Listing of Impairments are organized into Part A for Adults and Part B for children.

37. 20 C.F.R. § 404, app. 1 (2014). The fourteen major body systems, categorized in the adult "Listings" are: Musculoskeletal, Special Senses and Speech, Respiratory, Immune system, Cardiovascular system, Digestive system, Skin Disorders, Neurological, Endocrine Disorders, Mental Disorders, Malignant Neoplastic Diseases, Congenital Disorders that affect multiple body systems, Hematological Disorders, and Genitourinary Impairments.

38. *See* 20 C.F.R. § 404.1510 (meaning of substantial gainful activity); ALAN L. COWLES, A HISTORY OF THE DISABILITY LISTINGS (2005).

39. COWLES, *supra* note 38.

40. *Id*.

41. *Id*.

42. 44 Fed. Reg. 18,170 (proposed Mar. 27, 1979) (to be codified at 20 C.F.R. pt. 404); 20 C.F.R. § 404.1525.

43. JOHN D. STOBO ET AL., SSA'S LISTING OF IMPAIRMENTS AND AGENCY ACCESS TO MEDICAL EXPERTISE BOARD ON MILITARY AND VETERAN HEALTH, INSTITUTE OF MEDICINE, IMPROVING THE SOCIAL SECURITY DISABILITY PROCESS, COMM. ON IMPROVING THE SOC. SEC. DISABILITY DECISION PROCESS (2007).

44. Federal Old-Age, Survivors, and Disability Insurance; Revised Medical Criteria for the Determination of Disability, 50 Fed. Reg. 50,068 (proposed Dec. 6, 1985) (to be codified at 20 C.F.R. pt. 404).

five-year cycle for updating Listings for each body system,[45] replacing the agency's prior practice of setting expiration dates for listings that ranged from three to eight years and then frequently extending them.[46] The HIV Infection Listing was promulgated in 1993 and has not been substantively revised since that time.

B. History of the HIV Infection Listing

The SSA has a significant history relating to HIV/AIDS and the disability determination process. On September 24, 1982, the Center for Disease Control (CDC) published its first case definition of AIDS in its Morbidity and Mortality Weekly Report.[47] The CDC acquired its understanding of AIDS and HIV from studies of white, affluent, homosexual males. Other individuals—people of color, women, and the less affluent—were not studied and therefore the symptoms exhibited by those individuals were not considered or included in the CDC definition. The SSA began receiving claims for disability benefits filed by people with AIDS in late 1982.[48] In April 1983, the SSA developed an emergency teletype that contained the first instructions for adjudicators to evaluate AIDS-related claims.[49] In 1985, the SSA issued an interim regulation, relying on the CDC's definition of AIDS for its presumptive disability determinations.[50] By 1987, the Secretary of the SSA expressed his intention in the Federal Register to promulgate a regulation addressing AIDS-related claims.[51] The SSA acknowledged that the CDC surveillance definition of AIDS did not have utility in presumptive disability determinations in 1988.[52] On December 17, 1991, the SSA issued its

45. Revised Medical Criteria for Evaluating Endocrine Disorders, 76 Fed. Reg. 19,692 (proposed Apr. 8, 2011) (to be codified at 20 C.F.R. pts. 404, 416).

46. U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-12-511T, MODERNIZING SSA DISABILITY PROGRAMS, PRELIMINARY OBSERVATIONS OF UPDATES OF MED. AND OCCUPATIONAL CRITERIA (2012) (statement of Daniel Bertoni, Director of Education, Workforce and Income Security, GAO).

47. CTR. FOR DISEASE CONTROL, MORBIDITY AND MORTALITY WEEKLY REPORT, CURRENT TRENDS UPDATE ON ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) 31 (1982).

48. Federal Old-Age, Survivors, and Disability Insurance; Determining Disability and Blindness; Revision of Part A and Part B of the Listing of Impairments; Endocrine, and Multiple Body Systems; Immune Systems, 56 Fed. Reg. 65,702 (proposed Dec.18, 1991) (to be codified at 20 C.F.R. pt. 404).

49. Rosetti v. Shalala, 12 F.3d 1216, 1219 (3d Cir. 1993).

50. Presumptive Blindness; Categories of Impairments—AIDS, 50 Fed. Reg. 5573 (proposed Feb. 11, 1985) (to be codified at 20 C.F.R. pt. 416).

51. 56 Fed. Reg. 65,702-04.

52. 53 Fed. Reg. 3739 (Feb. 9, 1988) (to be codified at 20 C.F.R. pt. 416) ("We

Notice of Social Security Ruling (SSR), a policy interpretation for evaluating HIV-related claims.[53] The following day, the SSA issued its Notice of Proposed Rule-Making (NPRM).[54] The HIV Infection Listing, included as a part of the new Immune System Disorder Listing, was published in the Federal Register on July 2, 1993.[55]

Since 1993, federal activity regarding the HIV Infection Listing has been limited. On May 9, 2003, the SSA issued an Advanced Notice of Proposed Rule Making (ANPRM) of its intent to revise and update the rules used to evaluate Immune System disorders.[56] Three years later, in August 2006, the SSA proposed its Revised Medical Criteria for Evaluating Immune System Disorders.[57] On March 18, 2008, the SSA issued its Final Rules, revising medical criteria for evaluating immune system disorders.[58] The Final Rules included organizational changes to the Immune System Listing as a whole, but no substantive change to the HIV Infection Listing. On that same date, SSA issued an ANPRM announcing its intention to update and revise the medical criteria for the HIV Infection Listing.[59] To date, revision has not occurred. On July 13, 2010, the Obama Administration released its National HIV/AIDS Strategy, a comprehensive plan for responding to the HIV epidemic in the United States.[60] To meet the Strategy's goal of increasing access to care and improving health outcomes for people living with HIV, an operational plan directed support for people living with HIV,

---

agree that the CDC definition of AIDS should not be directly linked to Social Security presumptive disability determinations. The CDC and SSA view AIDS from different perspectives. The CDC defines AIDS for public health and other purposes that are not necessarily intended to have prognostic significance nor to designate the severity of the illness. By contrast, the SSA must determine if the presumptive disability requirements of the law are met.").

53. 56 Fed. Reg. 65,498 (proposed Dec. 17, 1991).

54. 56 Fed. Reg. 65,702. The Administrative Procedures Act (APA) governs the way federal agencies establish regulations. It requires public notice and comment period. *See* 5 U.S.C. § 551 (2012).

55. 58 Fed. Reg. 36,008 (proposed July 2, 1993) (to be codified at 20 C.F.R. pt. 404).

56. 68 Fed. Reg. 24,896 (proposed May 9, 2003) (to be codified at 20 C.F.R. pt. 404).

57. 71 Fed. Reg. 44,432 (proposed Aug. 4, 2006) (to be codified at 20 C.F.R. pts. 404, 416).

58. 73 Fed. Reg. 14,570 (proposed Mar. 18, 2008) (to be codified at 20 C.F.R. pt. 404).

59. 73 Fed. Reg. 14,409 (proposed Mar. 18, 2008) (to be codified at 20 C.F.R. pt. 404).

60. OFFICE OF NAT'L AIDS POLICY, EXEC. OFFICE OF THE PRESIDENT, NATIONAL HIV/AIDS STRATEGY FOR THE UNITED STATES (2010) [hereinafter NATIONAL HIV/AIDS STRATEGY].

who have challenges meeting their basic needs, and for those with co-occurring conditions.[61] Six lead agencies, including the SSA, were directed to submit a report to the Office of National AIDS Policy (ONAP) and the Office of Management and Budget on the agency's operational plans for implementing the Strategy.[62] As directed, the SSA published its report in December 2010. At that time, the SSA noted that it expected to publish a Notice of Proposed Rulemaking (NPRM) for evaluating HIV infection in the Federal Register within about eighteen months, followed by the publication of Final Rules after all of the public comments on the NPRM were considered.[63] By February 2011, the SSA was specifically directed by ONAP to update its medical criteria for HIV Infection "based on an Institute of Medicine[64] review. Listings for HIV infection, as with other conditions, are intended to be updated periodically to ensure that disability determinations are made in accordance with clinical advances."[65] To date, this has not occurred.[66]

Congress perceived discrimination against the handicapped to most often be the product of thoughtlessness, indifference, and benign neglect, rather than animus against the disabled.[67] The SSA's indifference to the specific issues facing individuals living with HIV/AIDS is reflected in its HIV Infection Listing. The HIV Infection Listing needs redress to comply with Section 504 of the Rehabilitation Act of 1973 and the implementing regulations.

---

61. OFFICE OF NAT'L AIDS POLICY, EXEC. OFFICE OF THE PRESIDENT, IMPLEMENTING THE NATIONAL HIV/AIDS STRATEGY: OVERVIEW OF AGENCY OPERATIONAL PLANS (2011) [hereinafter IMPLEMENTING THE NATIONAL HIV/AIDS STRATEGY].

62. 75 Fed. Reg. 41,687 (July 16, 2010).

63. Memorandum from Soc. Sec. Admin., to Office of Nat'l AIDS Policy & Office of Mgmt. & Budget (Dec. 8, 2010) (on file with Office of National AIDS Policy).

64. IMPLEMENTING THE NATIONAL HIV/AIDS STRATEGY, *supra* note 61, at 18. In 2009, the SSA commissioned the Institute of Medicine (IOM) to evaluate its HIV Infection Listing and provide comment recommendations. The substance of the IOM's recommendations is discussed below. At the time of the Obama Administration's strategy directive, the IOM evaluation had been completed but results were not published until September 2010. *See id*.

65. *Id*.

66. Letter from Dawn S. Wiggins, Freedom of Information Officer, Soc. Sec. Admin., to author (June 20, 2013) (on file with author). The SSA noted that it was on track to propose comprehensive revisions in the Federal Register for all listings by the end of 2014. *See id*.

67. *See* Alexander v. Choate, 469 U.S. 287, 295 (1985).

III. DISABILITY LAW FOR THE FEDERALLY-FUNDED

A. The Rehabilitation Act of 1973: History, Purpose, and Implementation

The Rehabilitation Act of 1973, codified at 29 U.S.C. § 701 replaced the Vocational Rehabilitation Act "to extend and revise the authorization of grants to States for vocational and comprehensive rehabilitation services, to authorize supplementary funds for vocational and comprehensive rehabilitation services to severely handicapped individuals, to expand special Federal responsibilities and research and training with respect to handicapped individuals, to establish an Office for the Handicapped within the Department of Health, Education, and Welfare, and for *other purposes*."[68] At the time of its introduction to Congress, the Act was intended to ensure that individuals with disabilities were incorporated into the mainstream of society, and that they were no longer "shunted aside, hidden and ignored."[69]

Section 504 and its prohibition of discrimination against individuals with disabilities by entities receiving Federal financial assistance is the "other purposes" for which the Rehabilitation Act of 1973 was enacted. Several proposed bills in the House and Senate sought to extend the prohibition of discrimination due to race, gender, or religion, to individuals with disabilities. As a result, Section 504 of the Rehabilitation Act was modeled, at least in part, after the prohibitions of discrimination in Section 601 of the Civil Rights Act of 1964 (relating to race, color, or national origin) and Section 901 of the Education Amendments of 1972 (relating to gender).[70]

---

68. 118 CONG. REC. 30,680 (1972) (emphasis added).

69. 117 CONG. REC. 45,974 (1971).

70. S. REP. NO. 93-1297, at 6390 (1974). The Civil Rights Act of 1964, as amended by proposed House and Senate bills would have read as follows: No person in the United States shall, on the ground of race, color, *physical or mental handicap*, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance, "*unless lack of such physical or mental handicap is a bona fide qualification reasonably necessary to the normal operation of such program or activity*." 118 CONG. REC. 526 (emphasis added); S. 3044, 92d Cong., 2d Sess., 118 CONG. REC. 525-26 (1972); *see also* S. 3987, 92d Cong., 2d Sess., 118 CONG. REC. 30,680 (1972); H.R. 12154, 92d Cong., 1st Sess., 117 CONG. REC. 45,945 (1971); H.R. 14,033, 92d Cong., 2d Sess., 118 CONG. REC. 9712 (1972); 118 CONG REC. 525 (1972). Senator Percy, a drafter of the predecessor to Section 504 introduced the bill as an amendment to the Civil Rights Act of 1964. "It had been my hope that the Concurrent Resolution would begin a national commitment to eliminate the glaring neglect of our handicapped citizens. The amendment we are introducing today would realize this commitment, guaranteeing the handicapped equal opportunity to education, job training, productive work, due process of law, a decent standard of living, and

As codified, Section 504 provides that

> [n]o otherwise qualified individual with a disability in the United States, as defined in section 7(20) [29 U.S.C. § 705(20)], shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving [f]ederal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.[71]

On April 28, 1977, the Secretary of the Department of Health, Education, and Welfare (HEW) issued regulations implementing Section 504 mandating that individuals with disabilities have access to programs and activities receiving federal funding.[72] When the regulations were issued, Section 504's application was focused on eliminating discrimination against or exclusion of the disabled by removal of architectural and communication barriers. The reach of Section 504, however, was not intended to be so limited.[73] Following the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, each federal agency receiving federal assistance was required to establish its own Section 504 regulations that would apply to its program and activities.[74] The Department of Justice (DOJ) established its own Section 504 regulations in 1984.[75] The regulations are an important source

---

protection from exploitation, abuse, and degradation. In essence, our amendment will give the handicapped their rightful place in society." 118 Cong. Rec. 526 (daily ed. Jan. 20, 1972) (statement of Senator Percy) (describing intent and purpose of proposed bill).

71. 29 U.S.C. § 794 (2012).

72. 45 C.F.R. § 84 (2014); *Implementation of Section 504 Rehabilitation Act of 1973: Hearings before the Subcomm. on Select Education of the House Comm. On Education and Labor*, 95th Cong., 1st Sess. (1977) [hereinafter *The 1977 Section 504 Implementation Hearings*]. At first, HEW did not promulgate implementing regulations, relying solely on the language of the Act. In Cherry v. Matthews, 419 F. Supp. 922 (1976), a lawsuit against HEW, the District Court of the District of Columbia held that Congress had intended regulations to be issued and ordered HEW to do so.

73. 124 CONG. REC. 38, 550 (1978) ("As a result of Section 504 it has become clear to many that 504 means more than just removing architectural barriers for the physically handicapped. While this is certainly a priority goal, there are many other types of disabilities to which 504 applies and to which attention must be paid.") (statement of Rep. Jeffords). *See generally The 1977 Section 504 Implementation Hearings*, *supra* note 72; Timothy M. Cook, *The Scope of the Right to Meaningful Access and the Defense of Undue Burdens Under Disability Civil Rights Laws*, 20 LOY. L.A. L. Rev. 1471 (1987).

74. Pub. L. No. 95-602, § 92 Stat. 2955 (1978).

75. Exec. Order No. 12,250, 45 Fed. Reg. 72,995 (Nov. 4, 1980). HEW's

of guidance on the meaning of Section 504.[76] Case law has further developed the scope and interpretation of Section 504.

B. Case Law Attempts to Address the Ambiguity of "Discrimination" Under Section 504 of the Rehabilitation Act of 1973

The language of the Rehabilitation Act of 1973 focused on ensuring that individuals with disabilities received equal access to services, benefits, and opportunities that were afforded to the non-handicapped. However, analysis of "discrimination" under Section 504 of the Rehabilitation Act has resulted in varied judicial determinations.[77] The case law encompasses a broad view of the Act,[78] viewing intentional discrimination, disparate impact, and failure to reasonably accommodate as all falling within the concept of "discrimination" under Section 504.

The Court in *Alexander v. Choate* interpreted the scope of Section 504.[79] *Alexander* involved a plaintiff class, who alleged that a fourteen-day Medicaid coverage limitation on inpatient care had a discriminatory effect

---

coordination authority and the coordination regulation that was issued pursuant to Exec. Order No. 11914, were transferred to the DOJ in 1980. Pursuant to Exec. Order No. 12,250, the Department of Justice developed a prototype regulation to implement the 1978 amendment for federally conducted programs and activities.

76. Alexander v. Choate, 469 U.S. 287, 304 n.24 (1985); Nelson v. Thornbough, 567 F. Supp. 369, 379 (E.D. Pa. 1983), *aff'd*, 732 F.3d 147 (3d Cir. 1984), *cert. denied*, 469 U.S. 1189 (1985).

77. Regents of the Univ. of Cal. v. Bakke, 438 U.S. 265, 284 (1978) (describing that the concept of discrimination "is susceptible of varying interpretations").

78. *See e.g.*, Sch. Bd. of Nassau Cnty. v. Arline, 480 U.S. 273, 273-74 (1987); *Alexander*, 469 U.S. at 294, n.11 (discussing whether case law, legislative history, and congressional action intended Title VI to reach both intentional and disparate-impact discrimination, and, if so, whether the intent/effect issue is patterned similarly in the application of Section 504 of the Rehabilitation Act); Consol. Rail Corp. v. Darrone, 465 U.S. 624, 632-33, n.13 (1984); Lau v. Nichols, 414 U.S. 563, 569-70 (1974); *see also* Henrietta D. v. Giuliani, 119 F. Supp. 2d 181, 205 (E.D.N.Y. 2000) ("As remedial statutes, both the ADA and the Rehabilitation Act must be broadly construed to effectuate their anti-discriminatory purpose."); Niece v. Fitzner, 941 F. Supp. 1497, 1505 (E.D. Mich. 1996) ("It is a familiar canon of statutory construction that remedial legislation should be construed broadly to effectuate its purposes. This broad construction is also applied to civil rights statutes. Accordingly, a broad construction is given to both the Rehabilitation Act and the ADA.") (citations and internal quotations omitted); Civic Ass'n of the Deaf v. Giuliani, 915 F. Supp. 622, 634 (S.D.N.Y. 1996); 1974 U.S. SUBCOMMISSION ON THE HANDICAPPED HEARINGS, ("Section 504 . . . enumerates a broad government policy . . . this department fully intends to treat Section 504 as civil rights legislation that is remedial in design and to construe the legislation broadly to effectuate its purposes, to correct and alleviate conditions adversely affected handicapped individuals in federally-assisted programs.").

79. *Alexander*, 469 U.S. at 287-88.

on the handicapped. In its discussion, the Court assessed whether federal law reached action by a recipient of federal funding that discriminated against the handicapped by effect rather than by design.[80] The Court decided that Section 504 did not reach only claims of intentional, purposeful discrimination.[81] The Court, however, also declined the blanket assertion by the plaintiffs that disparate treatment cases would always invoke Section 504's protection. The Court instead "assume[d] without deciding that Section 504 reaches at least some conduct that has an unjustifiable disparate impact upon the handicapped."[82] Under the facts, the Court held, however, that the fourteen day limitation on Medicaid coverage for inpatient hospitalization was not rested upon a discriminatory motive, was equally accessible for the disabled and non-disabled, and therefore was not the kind of disparate impact recognized under Section 504.[83] As guidance for determining whether a disabled person has been discriminated against, the Court directed that "rather than attempt to classify a type of discrimination as 'deliberate' or as 'disparate impact,' it [is] more useful to assess whether disabled persons were denied 'meaningful access.'"[84] Few courts have defined "meaningful access." Without uniformity, some courts however have concluded that:

> Where the plaintiffs identify an obstacle that impedes their access to a government program or benefit, they likely have established that they lack meaningful access to the program or benefit. By contrast, where the plaintiffs seek to expand the substantive scope of a program or benefit, they likely seek a fundamental alteration to the existing program or benefits and have not been denied meaningful access.[85]

When applying the standard of discrimination under Section 504, a court must balance the need to give effect to the statutory objectives and the desire to keep Section 504 within manageable bounds.[86] Recent case law examining the reach of Section 504 reveals that an otherwise qualified individual is entitled to meaningful access to a benefit, aid, or service

---

80. *Id*. at 292.

81. *Id*. at 294 n.11, 296-97 ("In addition, much of the conduct that Congress sought to alter in passing the Rehabilitation Act would be difficult if not impossible to reach were the Act construed to proscribe only conduct fueled by a discriminatory intent.").

82. *Id*. at 299.

83. *Id*. at 309.

84. Crowder v. Kitagawa, 81 F.3d 1480, 1484 (9th Cir. 1996) (citing *Alexander*, 469 U.S. at 302).

85. Am. Council of the Blind v. Paulson, 525 F.3d 1256, 1267 (D.C. Cir. 2008); Keitt v. New York City, 882 F. Supp. 2d 412, 453 (S.D.N.Y. 2011); Am. Council of the Blind v. Astrue, 2009 U.S. Dist. LEXIS 97599, at *55 (N.D. Cal. 2009).

86. *Alexander*, 469 U.S. at 301.

"regardless of whether other individuals are granted access," and is not "conditioned on the ability of the otherwise qualified . . . applicant to show that other applicants receive more favorable treatment."[87] In *Henrietta v. Bloomberg*, in determining whether the plaintiff had meaningful access to the services, benefit or aid, the Second Circuit held that demonstration that a disability makes it difficult for a plaintiff to access benefits is enough; they need not always show that a comparison class had preferential treatment or more access to the benefit.[88] In asserting its holding, the court relied upon *Olmstead v. L.C. ex rel. Zimring*.[89] That case involved an alleged violation of the Americans with Disabilities Act (ADA), but has implications with respect to Section 504. Justice Ginsburg, announcing the plurality opinion, rejected the defendant's contention that discrimination had not occurred because the plaintiffs did not identify a comparison class. The Court was "satisfied that Congress had a more comprehensive view of the concept of discrimination advanced [in the ADA]."[90] In his dissent, Justice Thomas chastised the majority for interpreting discrimination as including disparate treatment among members of the *same* protected class and warned that the majority's opinion contravened the Supreme Court's previous judicial interpretations.[91] However, nothing in the language of the statute proscribes a claim of discrimination upon failure of a federal agency to provide for a handicapped individual's needs vis-à-vis the needs of other handicapped individuals. Some lower courts have interpreted Section 504 to prohibit discrimination vis-à-vis other disabled groups or upon the severity of a disability.[92] While "Section 504's discrimination proscription

87. Henrietta D. v. Bloomberg, 331 F.3d 261, 274 (2d Cir. 2003).

88. *Id*. at 275.

89. 527 U.S. 581 (1999).

90. *Henrietta D*., 331 F.3d at 276 (quoting Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581, 598 (1999)).

91. *Olmstead*, 527 U.S. at 622 (Thomas, J., dissenting) ("Under this view, discrimination occurs when some members of a protected group are treated differently from other members of the same group.").

92. *See*, *e.g*., Helen L. v. DiDario, 46 F.3d 325, 335 (3d Cir. 1995); Martin v. Voinovich, 840 F. Supp. 1175, 1191 (S.D. Ohio 1993) (rejecting the argument that Section 504 can never apply between persons with different disabilities); McGuire v. Switzer, 734 F. Supp. 99, 114 n.16 (S.D.N.Y. 1990) (asserting that "discrimination vis-à-vis other disabled person is cognizable under the bulk of the authority"). *But see* Traynor v. Turnage, 485 U.S. 535, 549 (1988) ("There is nothing in the Rehabilitation Act that requires that any benefit extended to one category of handicapped persons also be extended to all other categories of handicapped persons."); Parker v. Metro. Life Ins. Co., 107 F.3d 359 (6th Cir. 1997); Flight v. Gloeckler, 68 F.3d 61, 63-64 (2d Cir. 1995) (finding that the Rehabilitation Act does not "clearly establish an obligation to meet a disabled person's particular needs vis-à-vis the needs of other handicapped individuals, but mandates only that the services provided non-handicapped individuals not be

. . . has yielded divergent court interpretations,"[93] the case law has consistently construed that a "reasonable accommodation"[94] shall be provided to an otherwise qualified individual. That proposition is consistent with the Section 504 implementing regulations.

Following *Alexander*, "to ensure meaningful access[,] reasonable accommodations in the grantee's program or benefit may have to be made."[95] A federal grantee's modification[96] to its program need not be "fundamental" or "substantial" to accommodate the handicapped.[97] The extent of an accommodation's reasonableness is guided by the DOJ regulations implementing Section 504. The regulations require a federally funded recipient to make a reasonable accommodation to the known physical or mental limitation of an applicant unless the recipient can show that the accommodation would cause the program undue hardship.[98] The Section 504 regulations may be read together with the regulations implementing the ADA.[99] The DOJ's ADA regulations require reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the

---

denied to a disabled person because he is handicapped").

93. *Olmstead*, 527 U.S. at 600 n.11.

94. Am. Council of the Blind v. Paulson, 525 F.3d 1256, 1266 n.14 (D.C. Cir. 2008) (The term "reasonable accommodation" is not referred to in the text of the Rehabilitation Act, but the Supreme Court has used the term in its interpretations of Section 504).

95. Alexander v. Choate, 469 U.S. 287, 301, 302 n.21 (1985) ("The regulations implementing § 504 are consistent with the view that reasonable adjustments in the nature of the benefit offered must at time be made to assure meaningful access.").

96. *See generally* ROBERT L. BURGDORF, DISABILITY DISCRIMINATION IN EMPLOYMENT LAW (1995) (recognizing that the U.S. Supreme Court has used the terms "reasonable accommodations," "reasonable modifications," and "reasonable adjustments" interchangeably) (citing *Alexander*, 469 U.S. at 299-301).

97. *Alexander*, 469 U.S. at 300, n.20; Se. Cmty. Coll. v. Davis, 442 U.S 397, 410, 411, 413 (1979).

98. 28 C.F.R. § 41.53 (2014).

99. Rodriguez by Rodriguez v. City of New York, 197 F.3d 611 (2d Cir. 1999) ("Because Section 504 of the Rehabilitation Act and the ADA impose identical requirements, we consider these claims in tandem."); Lincoln CERCPAC v. Health & Hosps. Corp., 147 F.3d 165 (2d Cir. 1998) ("Apart from the Rehabilitation Act's limitation to denials of benefits 'solely' by reason of disability and its reach of only federally funded—as opposed to 'public'—entities, these provisions purport to impose precisely the same requirements."); Henrietta D. v. Giuliani, 119 F. Supp. 2d 181, 206 (E.D.N.Y. 2000) ("[A]lthough there are subtle differences between these disability acts, the standards adopted by Title II of the ADA for State and local government services are generally the same as those required under Section 504 for federally assisted programs and activities.").

public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.[100] The Supreme Court in *Southeastern Community College v. Davis* held that the line between a lawful refusal to extend "affirmative action" and illegal discrimination against a person with a handicap will not always be clear.[101] The analytical framework below will make clear that the SSA's inaction is discriminatory and prohibited by Section 504 of the Rehabilitation Act of 1973 and the implementing regulations.

IV. ANALYZING THE HIV INFECTION LISTING: A SECTION 504 PERSPECTIVE

The elements of a claim under Section 504 of the Rehabilitation Act establish that the SSA, overseeing the HIV Infection Listing in its disability determination process, denies meaningful access to individuals making HIV infection-related claims. To assert a claim under Section 504 of the Rehabilitation Act of 1973, (1) the program or activity must receive federal financial assistance, (2) the individual must have or be perceived as having a disability, (3) must be otherwise qualified, but (4) excluded from the participation in, denied the benefits of, or subjected to discrimination, (5) solely by reason of his or her disability.[102]

The SSA is a federal agency that is subject to compliance with Section 504. Individuals with HIV/AIDS are "disabled" under the Act. Whether they are "otherwise qualified" for the sought benefit first requires redress of the criteria upon which that determination is made—the HIV Infection Listing. The HIV Infection Listing has not been substantively revised since 1993 and does not consider the particular needs of the HIV-infected. Therefore, claimants with HIV infection-related claims are denied "meaningful access" as interpreted by case law.[103] Moreover, the SSA's inaction substantially impairs the objectives of the social security program and is therefore in violation of the regulations established by HEW, as well as the regulations promulgated by the Department of Health and Human Services (DHHS). The SSA's failure to revise the Listing as a reasonable accommodation is in contravention to the implementing regulations established by the Department of Justice (DOJ). Lastly, an inference that

100. 28 C.F.R. § 35.130(b)(7) (2014).

101. *Se. Cmty. Coll.*, 442 U.S. at 412; Crowder v. Kitagawa, 81 F.3d 1480, 1486 (9th Cir. 1996); Chalk v. United States Dist. Ct., 840 F.2d 701, 705 (9th Cir. 1988).

102. 29 U.S.C. § 794 (2006).

103. *Alexander*, 469 U.S. at 287; Am. Council of the Blind v. Paulson, 525 F.3d. 1256, 1267 (D.C. Cir. 2008); Keitt v New York City, 882 F. Supp. 2d 412, 453 (S.D.N.Y. 2011); Am. Council of the Blind v. Astrue, 2009 U.S. Dist. LEXIS 97599, at *55 (N.D. Cal. 2009).

the SSA's adverse inaction is solely by reason of HIV infection is suggested by the political climate prior to the HIV Infection Listing, the stagnant federal action since 1993, and the SSA's rationale that, in spite of overwhelming evidence to the contrary, significant progress in the treatment of the HIV infection had not occurred to warrant changes to the rules. An in-depth discussion of each element follows below, establishing the SSA's violation of Section 504 of the Rehabilitation Act of 1973.

A. Program or Activity Carried Out with Federal Funds

The SSA is a federal agency and its programs and activities are carried out with federal funds. Section 504 of the Rehabilitation Act is applicable if an Agency's action violates the prohibition against nondiscrimination. Section 504 of the Rehabilitation Act is therefore extended to the programs and activities of the SSA.[104]

B. Disabled

The terms "disabled" or "disability"[105] have different meanings in varying contexts. The relevant inquiry is whether an individual with HIV/AIDS is an "individual with a disability" under the Rehabilitation Act. In its original text, Section 504 of the Rehabilitation Act prohibited discrimination against a "handicapped individual."[106] The term "individual with a handicap" included only those individuals whose disability limited their employability and those who could be expected to benefit from vocational rehabilitation. In 1974, this definition was expanded to include persons with physical or mental impairments, which substantially limit one or more major life activities, or who have a record of or are regarded as having such an impairment.[107] In 1994, Congress further amended the definition and replaced "handicap" with "disability."[108] As defined under 29 U.S.C. § 705(20), an "individual with a disability" is "any individual who (1) has a physical or mental impairment which for such individual constitutes or results in a substantial impediment to employment; and (2) can benefit in terms of an employment outcome from vocational rehabilitation services provided pursuant to Title I, III, or VI."[109] Pursuant

104. *See, e.g.*, Ransom v. Sullivan, 1991 U.S. Dist. LEXIS 8181, at *17 (N.D. Ill. June 13, 1991).

105. For the purposes of this article the terms "disabled" and "disability" are used interchangeably.

106. Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 355.

107. Rehabilitation Act of 1973, Pub. L. No. 93-112, 88 Stat. 1617.

108. Rehabilitation Act of 1973, Pub. L. 102-569, § 102(f)(1)(A), 106 Stat. 4344 (amended 1992).

109. 29 U.S.C. § 705(20) (internal citations omitted).

to the case law and regulations,[110] people with HIV/AIDS are "individuals with a disability" as defined in the Act.

The case law interpreting HIV/AIDS as a "disability" under the Rehabilitation Act has been consistent.

> Every reported decision construing the protection of the Rehabilitation Act of 1973 up to the passage of the Americans with Disabilities Act (ADA) in 1990 found the HIV-infection, whether it resulted in an AIDS diagnosis or was asymptomatic, to meet the criteria for establishing that HIV-infected individuals were "persons with handicaps.[111]

In 1988, the Court of Appeals for the Ninth Circuit addressed the treatment of AIDS as a handicap under the Rehabilitation Act in *Chalk v. United States District Court*.[112] The plaintiff, a schoolteacher diagnosed with AIDS, sought preliminary and permanent injunction barring his employer, the Department of Education, from excluding him from the classroom. Applying the Supreme Court's four-part analysis in *School Board of Nassau County, Florida v. Arline*, the district court denied the injunctive relief and determined that discriminatory exclusion was permitted because the plaintiff was not "otherwise qualified" due to uncertain risk of contagion.[113] The Ninth Circuit Court of Appeals reversed.[114] In its analysis, the circuit court assumed that an individual who was diagnosed with AIDS met the definition of "individual with a handicap" under the Act, and instead focused its attention on whether there was a "significant risk of contagion" under *Arline* to justify discriminatory exclusion.[115] The court concluded that given the medical and scientific evidence available, no apparent risk of contagion was present to warrant the plaintiff teacher's exclusion from the classroom.[116] The parameters of "individual with a handicap" were further expanded in *Doe v. Centinel Hospital*.[117] The plaintiff in *Doe*, an asymptomatic individual, alleged discriminatory discharge from a federally funded hospital's drug treatment program.[118]

---

110. 45 C.F.R. § 84.3 (2014).

111. Donald H.J. Hermann, *The Development of AIDS Federal Civil Rights Law: Anti-Discrimination Law Protection of Persons Infected with Human Immunodeficiency Virus*, 33 IND. L. REV. 783, 802 (2000) (discussing the evolution of federal disability law applied to persons infected with HIV).

112. Chalk v. United States Dist. Ct., 840 F.2d 701, 704-05 (9th Cir. 1988).

113. *Id*. at 704, 707-08.

114. *Id*. at 710.

115. *Id*. at 711.

116. *Id*. at 705-09.

117. Doe v. Centinel Hosp., 1988 U.S. Dist. LEXIS 8401, at *22 (C.D. Cal. June 30, 1998).

118. *Id*. at 9.

The court did not reach the broader question of whether asymptomatic HIV infected individuals are in all cases protected by Section 504. Instead, by way of peripheral analysis, the court

> broadened the basis for establishment of whether a person with an impairment is handicapped by allowing a showing that discrimination that followed from a perception that the person is handicapped resulted in interference with a major life activity, rather than requiring that the impairment directly result in a substantial limitation of a major life activity.[119]

In 1986, a California federal district court heard *Thomas v. Atascadero Unified School District*.[120] The court, relying on CDC classifications,[121] found that "individuals in all four of the CDC classifications suffer from impairments to their physical systems . . . [and] persons infected with the AIDS virus suffer significant impairments of their major life activities."[122] As a result, though the plaintiff's health had improved since diagnosis, the court found that the plaintiff "suffered from impairments to major life activities" as required by the Act to qualify as an "individual with handicap."[123]

Taking these court decisions into consideration, individuals with HIV/ AIDS, whether symptomatic or asymptomatic, meet the definition of "individuals with a disability." As the court found in *Thomas*, "people infected with the AIDS virus may have difficulty caring for themselves, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working, among other life functions.[124] Even those who are asymptomatic have abnormalities in their hemic and reproductive systems making procreation and childbirth dangerous to themselves and others."[125] Similarly, "fluctuating symptoms are common among people living with HIV and have the potential to disrupt day-to-day-living, including the ability to work."[126] Applying these factors to the definition, individuals

---

119. Hermann, *supra* note 111, at 807.

120. Thomas v. Atascadero Unified Sch. Dist., 662 F. Supp. 376 (C.D. Cal. 1986).

121. *Id*. at 379. At the time the district court heard *Thomas*, the CDC grouped the range of AIDS-related symptoms into four categories: (1) early acute, though transient, signs of the disease; (2) asymptomatic infection; (3) persistent swollen lymph-nodes; and (4) presence of opportunistic disease and/or rare types of cancer, including one known as Kaposi's Sarcoma. *Id*.

122. *See id*.

123. *Id*.

124. *Id*.

125. *Id*.

126. *U.K. Survey: 'Fluctuating' HIV Symptoms Affect Work Ability and Daily Living*, AIDSMEDS (Sept. 13, 2011), http://www.aidsmeds.com/articles/hiv_symptoms_survey_1667_21121.shtml; *see also*

with HIV/AIDS are "individuals with a disability" under the Rehabilitation Act.

C. Otherwise Qualified

The analysis of whether an individual is "otherwise qualified" for receipt of benefits, aids, or services that would make the authority of Section 504 relevant is unlike the analysis in cases alleging discrimination in access to employment or an educational program.[127] In such cases, the plaintiffs were not able show that they were "otherwise qualified" to participate in a program *in spite of* their disability.[128] *Southeastern Community College v. Davis*,[129] the first case where the Supreme Court interpreted Section 504, involved a student with a severe hearing impairment seeking entry into a graduate nursing program. The school denied the application and the prospective student thereafter alleged discrimination under Section 504.[130] The District Court concluded that "otherwise qualified can only be read to mean otherwise able to function sufficiently in the position sought in spite of the handicap, if proper training and facilities are suitable and available."[131] Therefore the prospective student was not otherwise qualified because her "handicap actually prevent[ed] her from safely performing in both her training program and her profession."[132] The Fourth Circuit disagreed, relying on the HEW regulations promulgated while the appeal was pending, holding that a determination of whether the plaintiff was "otherwise qualified" should be limited to whether the plaintiff met the

---

NAT'L AIDS TRUST, FLUCTUATING SYMPTOMS OF HIV 18 (2011) (statement from Deborah Jack, Chief Executive of NAT, commenting on findings of survey) ("The fluctuating symptoms experienced by people living with HIV are not fully understood or recognized and it is vital that further research be done in this area. Symptoms such as fatigue, nausea or insomnia are frequently experienced and can be unpredictable; causing real distress and having a debilitating mental and emotional effect on people living with HIV. One of the biggest issues for people living with HIV who experience fluctuating symptoms is the barrier it places on work and daily life. NAT is calling for disability and illness related benefits assessments, as well as social care assessments, to fully take into account the range of barriers fluctuating symptoms can present when working and going about other daily activities.").

127. *See, e.g.*, Se. Cmty. Coll. v. Davis, 442 U.S. 397 (1979); Falcone v. Univ. of Minn., 388 F.3d 656, 659 (8th Cir. 2004); Woolfolk v. Duncan, 872 F. Supp. 1381, 1387 (E.D. Pa. 1995) ("The Rehabilitation Act has been applied predominantly to challenge allegedly discriminatory denials of employment or admission to educational programs.").

128. *Se. Cmty. Coll.*, 442 U.S. at 405-06.

129. *Id.*

130. *Id.* at 401-02.

131. *Id.* at 403.

132. *Id.*

academic and technical qualifications only; the disability should not be considered.[133] Additionally, the Fourth Circuit suggested that the school had an "affirmative duty" to accommodate the disabilities of its applicants.[134] The Supreme Court reversed. Looking at the plain language of the statute, the Court affirmed the District Court definition of "otherwise qualified."[135] The Court held that the statute did not impose "affirmative action" on all recipients of federal funds.[136] However, if the HEW regulations required modification to the program the plaintiff would not likely benefit and the specific modifications that the plaintiff requested would have been a "fundamental alteration in the nature of the program far more than the reasonable modification the regulations required."[137]

The regulations implementing Section 504 provide guidance in understanding "otherwise qualified." A "qualified individual with handicaps" is defined as an individual with handicaps who meets the *essential eligibility requirements* for participation in, or receipt of benefits from, that program or activity.[138] Under this definition, a "qualified individual with handicaps" would need to meet the six-step sequential evaluation process for receipt of disability benefits from the social security program. Whether an individual is "otherwise qualified" or is a "qualified individual with handicaps" presumes fair "essential eligibility requirements" by which the SSA determines approval for benefits. The benefits of the supplemental security income program[139] are intertwined with the disability determination process such that any assessment of whether an individual is "otherwise qualified" is not possible without redress of the disability determination process in whole.

133. *Id*. at 404.

134. *Id*.

135. *Id*. at 406.

136. *Id*. at 411. The *Alexander* Court, in clarifying its holding that federally-funded programs do not have an "affirmative action obligation" in *Davis* noted that the term "affirmative action" referred to those "changes," "adjustments," or "modifications" to existing programs that would be "substantial," or that would constitute fundamental alterations in the nature of the program rather than those that would be reasonable accommodations. Alexander v. Choate, 469 U.S. 287, 301 (1985).

137. *Se*. *Cmty*. *Coll*., 442 U.S. at 410.

138. 45 C.F.R. §§ 85.3, 84.3 (2014); 28 C.F.R. § 41.32(b) (2014).

139. *See supra* Section I.C, The Benefit of "Benefits."

D. HIV Infected Claimants Are Subject to Discrimination by Denial of "Meaningful Access" to Social Security Benefits by Way of the SSA's Medical Criteria in Its HIV Infection Listing

A facial challenge to the validity of the SSA's policies and procedures was examined in *Davis v. Astrue*.[140] The plaintiff, an individual suffering from schizophrenia, and similarly situated individuals, filed a class action lawsuit alleging that the SSA denied the plaintiff and others with mental disabilities treatment equal to those with physical disabilities, in violation of Section 504.[141] Specifically, the plaintiff alleged that he was wrongfully denied benefits and was made to suffer additional injuries even after his benefits were restored, due to the SSA's failure to adequately evaluate the needs of mentally disabled persons in its work reviews.[142] To bolster the claim, the plaintiff relied on statistics showing that mentally disabled individuals had benefits terminated based on work reviews at a higher rate than physically disabled recipients.[143] The plaintiff argued that he and similarly situated persons were entitled to additional protections to equalize treatment amongst all disability recipients.[144] The Ninth Circuit, following *Alexander*, rejected the argument for additional protections.[145] Nonetheless, the court held that meaningful access under the Rehabilitation Act required an agency to "consider the particular needs of disabled" persons seeking benefits.[146]

The SSA's HIV/AIDS-related policies can be challenged in a way similar to that in *Davis v. Astrue*. The criteria used in Step Three of the disability determination process for HIV infection-related claims does not reflect the current medical manifestations and functional limitations of HIV/AIDS. By failing to consider the particular needs of individuals with HIV infection, the SSA has deprived claimants of meaningful access to benefits provided by the supplemental security income program.

---

140. Davis v. Astrue, 513 F. Supp. 2d 1137, 1145 (N.D. Cal. 2007). This matter was consolidated on March 6, 2009 with Doe v. Astrue, 2009 U.S. Dist. LEXIS 72819 (N.D. Cal. Aug. 18, 2009). *Id*.

141. *Id*. at 1149.

142. *Id*. at 1140, 1149.

143. *Id*. at 1149.

144. *Id*. (emphasis added).

145. *Id*.

146. Davis v. Astrue, No. C 06-6108 MHP, 2007 U.S. Dist. LEXIS 52188, at *11 (N.D. Cal. July 17, 2007) (citing Armstrong v. Davis, 275 F.3d 849, 862 (9th Cir. 2001)).

1. Current Medical Knowledge that Is Particular to the Needs of Individuals with HIV/AIDS

In the Final Rules published in 2008, the SSA concluded that "sufficient progress in the treatment and control of HIV infection had not occurred to warrant change in the rules."[147] According to current medical knowledge, sufficient progress in the treatment and control of HIV/AIDS has been made. Advances in treatment have reduced the frequency of many opportunistic infections and manifestations referred to in the current HIV Infection Listing.[148] Since 1996, a combination of these treatments, known as Highly Active Antiretroviral Treatment (HAART), has led to the steep decline in the AIDS mortality rate.[149] HAART is a potent combination of at least three active ARVs from two different classes.[150] The advent of HAART has drastically changed the nature, course, and treatment of the HIV infection. The disease is no longer deemed immediately fatal and is instead characterized as chronic and manageable.[151] However, many people suffer from long-term debilitating ailments. Moreover, HAART is not a cure, and the prescribed medication regimen can have serious side effects that may impact functional capacity.[152] "Many patients with HIV/

147. 73 Fed. Reg. 14,570 (Mar. 18, 2008) (to be codified at 20 C.F.R. pt. 404).

148. In 1987, mono-therapy with the nucleoside analogue zidovudine (ZDV), also known as azidothymidine (AZT) became the first licensed treatment for patients with AIDS. Since then, over thirty antiretroviral (ARVs) have been introduced and are separated by "classes:" Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs), Nonnucleoside Reverse Transcriptase Inhibitors (NNRTIs), Protease Inhibitors (PIs), Fusion inhibitors, Entry inhibitors and Integrase inhibitors. *See generally* INST. OF MED., IOM REPORT, APPENDIX C, TABLE C-2 (2012); CTRS. FOR DISEASE CONTROL & PREVENTION, *1994 Revised Classification System for HIV Infection in Children Less Than 13 Years of Age*, MORBIDITY & MORTALITY WKLY. REP., Sept. 30, 1994, at 1-10 [hereinafter CDC].

149. CTRS. FOR DISEASE CONTROL & PREVENTION, DEP'T. OF HEALTH AND HUMAN SERVS., *Deaths among persons with AIDS Through December 2006*, HIV/ AIDS SURVEILLANCE SUPPLEMENTAL REPORT (2009), *available at* http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2009supp_vol14no3/pdf/HIVAIDS_SSR_Vol14_No3.pdf; INST. OF MED., IOM REPORT Figure 2-2 (2012).

150. *Clinical Guidelines Portal*, AIDSINFO, (Feb. 12, 2013), http://aidsinfo.nih.gov/guidelines/html/1/adult-and-adolescent-arv-guidelines.

151. C. P. Hoy-Ellis & K. I. Fredriksen-Goldsen, *Is AIDS Chronic or Terminal? The Perceptions of Persons Living with AIDS and Their Informal Support Partners*, 19 AIDS CARE, PSYCHOLOGICAL & SOCIO-MEDICAL ASPECTS AIDS/HIV 835, 836 (2007).

152. NAT'L INST. OF HEALTH, DEP'T. OF HEALTH AND HUMAN SERVS., GUIDELINES FOR THE USE OF ANTIRETROVIRAL AGENTS IN HIV-1-INFECTED ADULTS AND ADOLESCENTS (2014) *available at* http://aidsinfo.nih.gov/contentfiles/lvguidelines/AdultandAdolescentGL.pdf; INST. OF MED., HIV AND DISABILITY UPDATING THE SOCIAL SECURITY LISTINGS 38-39, 65-73 (2010); *Updated: Revise Social Security HIV Disability Requirements Says Institute of*

AIDS show a decline in functional abilities after diagnosis and as their disease progresses. Additionally, co-morbid conditions often lead to a more disabling condition than would be predicted from the sum of their individual effects."[153]

In response to public comment[154] the SSA issued an Advanced Notice of Proposed Rule Making (ANPRM) announcing its intent to revise the HIV Infection Listing.[155] Thereafter, the SSA requested that the Institute of Medicine (IOM) review the current medical criteria for disability resulting from the HIV infection in the SSA's Listing of Impairments, and identify areas in which the HIV Infection Listing should be revised and updated based on current medical knowledge and practice.[156] By September 2010, the IOM completed its assessment and made several recommendations.[157] The IOM Committee described the SSA's HIV Infection Listing as "represent[ing] a time prior to the availability of effective antiretroviral therapy when HIV/AIDS was defined largely by having an opportunistic infection or malignancy resulting in a fatal outcome in a short period of time,"[158] and that the infections and manifestations in the HIV Listings are

---

Medicine, POZ, HEALTH LIFE & HIV (Sept. 28, 2010), http://www.poz.com/printView.php?page=/articles/hiv_disability_ssa_1667_19133.shtml&domain=www.aidsmeds.com (statement by Paul Volberding) ("HAART is not the panacea everyone thinks it is. Fatigue, diarrhea, sleeplessness, depression, weakness, lipodystrophy are real issues, and the medical establishment doesn't listen.").

153. COMM. ON SOC. SEC. HIV DISABILITY CRITERIA, INST. OF MED., HIV AND DISABILITY, UPDATING THE SOCIAL SECURITY LISTINGS 26 (2010) [hereinafter INST. OF MED.].

154. At that time, as well as in response to the previous ANPRM and NPRM, LAMBDA Legal as well as several other HIV/AIDS advocates submitted comment letters specifying how individuals with HIV infection experience the disease and advocated for appropriate revision of the HIV Infection Listing. *See Revised Medical Criteria for Evaluation of HIV Infection*, REGULATIONS.GOV, YOUR VOICE IN FEDERAL DECISION-MAKING, http://www.regulations.gov/#!docketDetail;D=SSA-2007-0082 (search "SSA-2007-0082") (last visited Feb. 23, 2014).

155. Revised Medical Criteria for Evaluating HIV Infection, 73 Fed. Reg. 14,409 (Mar. 18, 2008).

156. Letter from Dawn S. Wiggins, Freedom of Information Officer, Soc. Sec. Admin., to author (June 20, 2013) (on file with the author); *see generally* INST. OF MED., *supra* note 152.

157. INST. OF MED., *supra* note 152, at 6. In addition to specific recommendations, the Committee identified four categories, according to which they suggested claimants should be considered disabled: those with CD4≤ 50 cells/mm^3; those with imminently fatal or severely disabling HIV-associated conditions; those with HIV-associated conditions without listings elsewhere in the Listing of Impairments; and those with HIV-associated conditions with listing elsewhere in the Listing of Impairments. *Id*.

158. INST. OF MED., *supra* note 152, at 13; *Updated: Revise Social Security HIV Disability Requirements Says Institute of Medicine*, AIDSMEDS (Sept. 28, 2010),

"generally less common, no longer necessarily permanently debilitating or less predictive of disability than they were in 1993 when the HIV Infection Listing was developed.[159] The Committee next stressed the importance of incorporating a measure of work-related functional capacity in individuals infected with HIV to determine their ability to participate in employment. Indeed, functional capacity plays an essential role in the Listing of Impairments. In 2005, the SSA acknowledged that functional listings criteria more realistically represented the definition of disability, permitted more allowances to be screened in at the Listings step, permitted greater parity among different listings, made it possible to give meaningful consideration to an individual's symptoms and to the medical opinions of their medical treatment sources, and allowed better evaluations of combinations of impairments.[160] The IOM Committee recommended specific assessment tools that could be utilized by the SSA for evaluating the functioning of individuals with HIV/AIDS in the physical, mental, and neuro-cognitive domains.[161] Notably, these measurement tools were well received because they are not cost prohibitive.[162] Finally, the Committee's report contravened the SSA's contention that sufficient progress in the treatment and control of HIV had not been made to warrant change in the rules, noting that "despite the remarkable advances in HIV/AIDS management resulting from the availability of potent antiretroviral therapy in 1996, the HIV Infection Listings have not been substantially revised."[163] As in the case of *Rosetti v*. *Sullivan* in 1991, the current HIV Infection Listing's medical criteria is "overly narrow criteria and it fails to recognize some of the ways in which the virus can cause disabling impairments"[164]

---

http://www.poz.com/printView.php?page=/articles/hiv_disability_ssa_1667_19133.shtml&domain=www.aidsmeds.com ("Now, one has to get an OI for easy access. The revisions we suggest would allow the many who are diagnosed with advanced stage disease but without an OI to gain access.") (statement by Paul Volberding, a lead author of the IOM report).

159. *Id*.

160. B. Eigen, *Listings Issues*, Oral presentation to the IOM Committee on Improving the Social Security Disability Decision Process (2005).

161. INST. OF MED., *supra* note 152, at 28. The SSA currently measures functioning in these three domains.

162. INST. OF MED., *supra* note 152 (citing I. Grant, *Neurocognitive Disturbances in HIV*, 20 INT'L REVIEW PSYCHIATRY 15 (2008)).

163. *Id*.

164. Rosetti v. Shalala, 12 F.3d 1216, 1217 (3d Cir. 1993).

2. Use of Outdated Medical Criteria Impairs the Objectives of the Program.

DHHS, HEW, and DOJ Section 504 implementing regulations prohibit the SSA's inaction. The relevant provision states in pertinent part:

> The Agency may not, directly or through contractual or other arrangements, utilize criteria or methods of administration the purpose or effect of which would—
> (ii) Defeat or substantially impair accomplishment of the objectives of a program or activity with respect to individuals with handicaps.[165]

When established, the objective of the Listing of Impairments was three-fold: (1) efficiency, (2) equal treatment for all applicants, and (3) adjudicative consistency.[166] Each of these objectives is substantially impaired or defeated as a result of the limited revision or update to the medical criteria encompassed in the current HIV Infection Listing.

An objective of the Listing of Impairments via Step Three of the six-step sequential evaluation process is to ease the administrative burden of determining disability, by establishing a list of impairments deemed to likely result in an inability to engage in substantial gainful activity.[167] Expediency in the processing of claims is a benefit for both the SSA and individual claimants whom meet the criteria. The use of outdated medical criteria undermines the expediency goal, which may result in "a time-consuming and resource-intensive inquiry into all of the case facts."[168] Any unsuccessful claim made upon the current Listing would be especially unfair and frustrating because of the deficiencies in the Listing. This would lead to a "time-consuming" inquiry (Steps 4 and 5) in an already protracted process.[169] In this author's experience, the average processing time for an initial decision is three months or more. A three-month or more wait, especially for a person experiencing a debilitating disease, is unconscionable and substantially impairs the efficiency objective.

Equal treatment is also a goal of the SSA's Step Three process.

> The Listings help to ensure that determinations and decisions regarding disability have a sound medical basis and that claimants receive equal treatment through the use of specific criteria, and that people who are disabled can be readily identified and awarded benefits if all other factors of entitlement or eligibility are met.[170]

---

165. 45 C.F.R. § 85.21 (2014); *see also* 28 C.F.R. § 41.51(b)(3)(ii) (2014); 45 C.F.R. § 84.4(b)(4)(ii) (2014).

166. STOBO, *supra* note 43, at 66-67.

167. *Id*. at 2.

168. *Id*. at 3-4.

169. *See infra* note 35 and accompanying text.

170. Revised Medical Criteria for Determination of Disability, Musculoskeletal

This objective is defeated by the current HIV Infection Listing. HIV claimants are not afforded equal treatment because the "specific criteria" used is not equitable across all of the fourteen body systems. To guarantee equal opportunity, the specific medical criteria used should reflect *current* data and standard of care for HIV infection as indicated in SSA's policy on updating and revising the Listing of Impairments.[171] That is not the case here.

Adjudicative consistency is the third objective of Step Three of the disability determination process. In the early days of the disability program, the Listings accounted for more than ninety percent of the initial allowances.[172] In subsequent years, the Listings have accounted for fewer initial allowances; in the early 1980s, they were the basis for seventy to eighty percent of the initial allowances, and in 2000 they accounted for less than sixty percent of allowances.[173] The Listings accounted for only fifty-two percent of the initial allowances in 2004.[174] These numbers are reflected in allowances at the Listings level for adult HIV claims; between 1999 and 2009, twenty-two percent of the claims met the Listing and seven percent medically equaled the listing.[175] The total allowance rate for all adult HIV infection claims fell from thirty-nine percent in 1999 to thirty percent in 2009.[176] There is no indication that the decline in allowances is consistent with decline in impact of ailments, conditions, and impairments endured by people living with HIV/AIDS. It is logical that the discrepancy is due to medical criteria encompassed in the HIV Infection Listing that does not comport with current data about the disease. Updated medical criteria that accurately reflects the course and manifestations of the HIV infection would allow the SSA to accomplish its goal to "screen in" claimants with impairments so severe they are not likely to be able to engage in substantial gainful activity. Without doing so, each of the stated objectives of the social security program are substantially impaired or defeated and, therefore, in violation of the Section 504 regulations.

System and Related Criteria, 66 Fed. Reg. 58,010 (Nov. 19, 2001).

171. 73 Fed. Reg. 14,570 (Mar. 18, 2008) (to be codified at 20 C.F.R. § pt. 404) (emphasis added).

172. SOC. SEC. ADVISORY BD., THE SOCIAL SECURITY DEFINITION OF DISABILITY (2003), *available at* http://www.ssab.gov/documents/SocialSecurityDefinitionOfDisability_002.pdf.

173. SOC. SEC. ADVISORY BD., CHARTING THE FUTURE OF SOCIAL SECURITY'S DISABILITY PROGRAMS: THE NEED FOR FUNDAMENTAL CHANGE (2001), *available at* http://www.ssab.gov/publications/disability/disabilitywhitepap.pdf.

174. STOBO, *supra* note 43.

175. INST. OF MED., *supra* note 152, at 26.

176. *Id*. at 24.

3. A "Reasonable" Revision to HIV Infection Listing

The SSA has not modified the HIV Infection Listing, as a reasonable accommodation to the known physical and mental limitations of the HIV infection, in violation of the DOJ implementing regulations and *Alexander*.[177] Disability benefits are for individuals who are unable to work *because of* their disability. *Perdue v. Gargano* discussed when a reasonable accommodation should be provided. In that case, the plaintiff alleged that the state's Family and Social Services Administration (FSSA) decision to not assign specific caseworkers to assist applicants with the application and recertification process for benefits disproportionately impacted individuals with a disability and was a failure to accommodate the plaintiff's hearing disability. The trial court followed *Alexander's* holding that an agency should not define the benefit for which a disabled individual must show they are otherwise qualified in a manner that "effectively denies otherwise qualified handicapped individuals the meaningful access to which they are entitled."[178] The trial court held that "were we to define the benefit so narrowly as to encompass only the individual's actual entitlement . . . the FSSA would only be required to reasonably accommodate disabled applicants who could demonstrate that they are eligible for benefits *before* applying for benefits."[179] As held in *Perdue*, because the SSA does not know whether an individual is legally entitled to benefits *before* an applicant's eligibility is determined, "it must reasonably accommodate all individuals during the application process so as not to inadvertently burden qualified disabled applicants."[180]

A modification to the HIV Infection Listing is not a "fundamental alteration in the nature of the program,"[181] but an adjustment to the determination process that would ensure meaningful access to the benefit sought. The Listing of Impairments is an essential, routine aspect of the disability determination process. The inclusion of updated medical criteria and specific measures for evaluating functional capacity in individuals that are HIV infected will only modify how adjudicators make their assessments. This will increase the accuracy of determinations and allow for increased "screen in" claimants with impairments so severe they are not likely to be able to engage in substantial gainful activity, consistent with the goals of the SSA. A reasonable accommodation would not require the

177. 28 C.F.R. § 41.53 (2014); Alexander v. Choate, 469 U.S. 287, 301-02 n.21 (1985).

178. *Alexander*, 469 U.S. at 301.

179. Perdue v. Gargano, 964 N.E.2d 825, 844 (Ind. 2012).

180. *Id*.

181. Se. Cmty. Coll. v. Davis, 442 U.S. 397, 410 (1979).

SSA to extend the substantive scope of the HIV Infection Listing, social security disability determination process, or the social security program. The six-step sequential evaluation process would stay the same. The monthly monetary benefit and other benefits of the program would remain unchanged. A reasonable modification to the HIV Infection Listing would not result in the provision of additional or "new" benefits.[182]

A reasonable accommodation is not required if the SSA is able to demonstrate that the accommodation would impose an "undue hardship on the operation of its program."[183] This is unlikely. It is clear by the March 18, 2008 ANPRM that the SSA intended to update the HIV Infection Listing.[184] This stated intention is not only an acknowledgment of the need to revise the listing, but it also presumes that the SSA has considered the associated costs, if any, and determined that revising the Listing would not impose an undue hardship on the operations of its program. There are no indications that revision to the HIV Infection Listing, as a reasonable accommodation, will result in any hardship.

E. Based Solely on the HIV Infection Disability

Since its promulgation in 1993, there have been three "actions" in the Federal Register relating to the HIV Infection Listing.[185] The limited movement and the SSA reasoning suggest that the adverse action is based solely on the HIV infection disability. HIV/AIDS has long been a stigmatized, divisive, and politicized issue in American society. That context, perhaps, helps us understand the SSA's lack of attention to its Listing for HIV infection. "When deciding whether to revise the Listings, the SSA considers such things as specific litigation, court decisions and congressional interest."[186] Whichever factor influenced SSA's decision to not revise the Listing since promulgation in 1993, the impact is insidious and profound. In its current form the Listing perpetuates a trend of ignoring the specific plight experienced by people living with HIV/AIDS.[187] The SSA's prior history with HIV/AIDS underpins the Agency's

182. *Alexander*, 469 U.S. at 303; Jones v. City of Monroe, 341 F.3d 474 (6th Cir. 2003); Rodriguez v. City of New York, 197 F.3d 611, 619 (2d Cir. 1999); Crawford v. Ind. Dep't of Corr., 115 F.3d 481, 486 (7th Cir. 1997).

183. 28 C.F.R. § 41.53 (2014).

184. 73 Fed. Reg. 14,409 (Mar. 18, 2008) (to be codified at 20 C.F.R. pt. 404).

185. 68 Fed. Reg. 24,896 (May 9, 2003) (to be codified at 20 C.F.R. pts. 404, 416); 71 Fed. Reg. 44,431 (Aug. 4, 2006) (to be codified at 20 C.F.R. pt. 404), 73 Fed. Reg. 14,570 (Mar. 18, 2008) (to be codified at 20 C.F.R. pt. 404).

186. STOBO, *supra* note 43, at 87.

187. John Leland, *People Think It's Over*, N.Y. TIMES, June 1, 2013, http://www.nytimes.com/2013/06/02/nyregion/spared-death-aging-people-with-hiv-

view of HIV/AIDS inherent in its current HIV Infection Listing. The SSA history includes its reliance on a CDC surveillance definition that did not include the HIV infection manifestations experienced by people of color, women, nor illicit drug users.[188] It also includes the use of the CDC surveillance definition as "internal guidance" in its Program Operation Manual System (POMS) and Social Security Ruling (SSR), which was not subjected to the Administrative Procedures Act (APA) rules, requiring public notice and comment. The political climate during the time when the SSA began receiving HIV-related claims until present day provides background for understanding the HIV Infection Listings as a "mirror" of the overall perception of the disease and those whom are infected.[189]

The political climate since 1981, when the first cases of AIDS were recognized, likely influenced governmental attention and public perception of HIV/AIDS. President Ronald Reagan did not publicly discuss the disease or use the term "AIDS" until well into his second term.[190] However, in June 1987, President Reagan by Executive Order organized the President's Commission on the HIV Epidemic.[191] The Commission's purpose was to report and advise the President on the "public health dangers, including the medical, legal, ethical, social, and economic impacts, of the epidemic."[192] The Commission received immediate criticism due to its appointment of only two medical professionals that had prior experience with the treatment of HIV/AIDS. There was also criticism about the appointment of members whom were known opponents of AIDS education.[193] At the time of the Commission report, discrimination was

---

struggle-to-live.html?_r=0 ("People think it's over, you can just take a pill, there's a cure around the corner. It drives me crazy when people think it's over.") (Osvaldo Perdomo commenting on his plight as an aging person living with HIV/AIDS).

188. AIDS AND THE LAW § 9.15 (David W. Webber ed., 1997) ("This inherent bias was then absorbed into the SSA's disability evaluation, through adoption the CDC's AIDS definition. The result [was that] a number of individuals [who] did not fit squarely into the CDC definition for AIDS were disqualified from receipt of social security benefits, even when they were suffering from ailments, conditions, etc. that were debilitating.").

189. *See generally* Lawrence O. Gostin, *A Decade of a Maturing Epidemic: An Assessment and Directions for Future Public Policy*, 5 NOTRE DAME J.L. ETHICS & PUB. POL'Y 7 (1990) (discussing governmental response to public health policies related to HIV/AIDS).

190. *Id*. at 8.

191. Exec. Order No. 12,601, 52 Fed. Reg. 24,129 (June 24, 1987).

192. INTERIM REPORT OF THE PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC, *supra* note 10.

193. Philip M. Boffey, *Washington Talk: The President's Aids Commission; First Meeting Is Today, but Not the First Criticism*, N.Y. TIMES (Sept. 8, 1987), http://www.nytimes.com/1987/09/09/us/washington-talk-president-s-aids-commission-

discussed largely in the context of the workplace, medical care, education, and access to housing. In its report on June 29, 1988, the Commission made recommendations for a number of specific issues to move towards a comprehensive national strategy to defeat the epidemic.[194] "President Reagan explicitly accepted only a few of the hundreds of recommendations made in the Commission's report."[195]

By 1988, perhaps in response to the Reagan administration's refusal to fully embrace the recommendations made by the President's Commission, Congress passed legislation that created the U.S. National Commission on AIDS with the purpose of "promoting the development of a national consensus on policy concerning acquired immune deficiency syndrome."[196] The composition of this Commission included members that were "especially qualified . . . by reason of their education, training, or experience."[197] The National Commission, however, also had its fair share of controversy, mostly surrounding the Commission's criticism of inadequate federal government attention and specifically George H.W. Bush's lack of supportive response to their recommendations. The Commission's first report was produced in September 1991 and entitled "America Living with AIDS: Transforming Anger, Fear and Indifference into Action."[198] At that time, the Commission highlighted "the waning national interest in AIDS" and warned that "[AIDS] should not be allowed to fall off the list of national priorities because it seems like old news."[199] In discussing the federal government's responsibilities in defeating the HIV epidemic, the Commission stated, "[o]ur nation's leaders have not done well. In the past decade, the White House has rarely broken its silence on the topic of AIDS."[200] The Commission also suggested, "disability issues are all crucial to the care for many people with HIV disease and should be closely linked to research, prevention, and care programs."[201] In its last report, "AIDS: An Expanding Tragedy," the Commission reported that

---

first-meeting-today-but-not-first.html.

194. *Id*.

195. Gostin, *supra* note 189, at 8 (citing IMPLEMENTING RECOMMENDATIONS OF THE PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC: THE 10-POINT PLAN (Aug. 2, 1988)).

196. Act of Nov. 4, 1988, Pub. L. 100-607, 102 Stat. 3048.

197. *Id*.

198. NAT'L COMM'N ON ACQUIRED IMMUNE DEFICIENCY SYNDROME, AMERICA LIVING WITH AIDS: TRANSFORMING ANGER, FEAR, AND INDIFFERENCE INTO ACTION (1991).

199. *Id*.

200. *Id*.

201. *Id*.

"[its] widely heralded recommendations contained in . . . previous reports have been so consistently underfunded or ignored."[202] The National Commission on Acquired Immune Deficiency Syndrome ceased its operations on September 3, 1993 and was succeeded by the Presidential Advisory Council on HIV/AIDS (PACHA) in 1995.[203] The "waning national interest" in 1991 undoubtedly influenced the SSA's slow movement in establishing formal, regulated guidelines to evaluate HIV infection-related disability claims even though the Agency began receiving such claims in 1982. Nonetheless, after class action and much delay, the SSA promulgated its HIV Infection Listing in 1993. Since 1993, the SSA has not taken substantial steps to revise the Listing in spite of data indicating that revision is warranted.

An inference that the SSA's adverse action or inaction is based upon the disability itself is rooted in the flawed rationale in the Federal Register. On August 4, 2006, the SSA published its Notice of Proposed Rule-Making. In its Proposed Rules, the medical criteria of the HIV Infection Listing went unchanged. The SSA opined that sufficient progress in the treatment and control of the HIV infection had not occurred to warrant change in the rules.[204] In an analysis of its decision, the SSA acknowledged the disabling effects of necessary treatment, but ironically characterized advances in treatment of HIV infection treatment as a "problem."

> Moreover, even as some problems of people who have HIV infection appear to be improved, new problems have arisen to take their place. Advances in treatment are case in point. While there have been significant strides in the treatment of HIV infection that improved mortality, *the treatment itself is often disabling both in terms of its side effects and its administration*. Many people must structure their days and nights around their treatment, and any lapse can have dire consequences. Some people respond to treatment initially but become unresponsive without warning. Others have limited success with their treatments. *Relatively few people with HIV infection are considered* '*well*.' [205]

---

202. NAT'L COMM'N ON ACQUIRED IMMUNE DEFICIENCY SYNDROME, AIDS: AN EXPANDING TRAGEDY, THE FINAL REPORT OF THE NATIONAL COMMISSION ON AIDS vii (1993).

203. Exec. Order No. 12,963 (1995), as amended by Exec. Order No. 13,009 (1996). Due to the lack of effectiveness of the National Commission, PACHA was not afforded confidence in its ability to achieve its goal of providing recommendations on the U.S. government's response to the AIDS epidemic. Critics again cited appointment of under qualified members and those that did not support the Council's goals. PACHA, as reorganized under the George W. Bush administration held only two meetings in 2002 and made just five recommendations to the President.

204. 71 Fed. Reg. 44,432, 44,443 (Aug. 4, 2006) (to be codified at 20 C.F.R. pt. 404).

205. *Id*. (emphasis added).

The SSA appears to justify its decision to not propose substantive change to the HIV Infection Listing with illogical reasoning. The agency acknowledges that the required medication regimen has a significant, adverse, and disabling impact on a person's life (and likely their ability to work), but refuses to meaningfully incorporate that as a measure upon which to assess disability. The SSA concluded that "based upon social security disability policy and need for efficient administration of the disability programs," it had not seen sufficient evidence to prompt any change to the listing.[206] This sentiment was repeated in the Final Rules published in 2008.[207] The SSA provided no other reasoning. Given its meritless rationale, it is difficult to imagine that the SSA has failed to substantively revise the HIV Infection Listing for any reason other than the disability itself. There is no doubt that significant progress in the treatment and control of the HIV infection has occurred to warrant a change in the rules. Perhaps prior to the 2010 IOM Committee report, the SSA had not obtained data that revealed this as a reality. An inquiry to determine why the SSA had not gathered such data regarding a disease for which it began receiving claims over twenty years ago leads this author to the same conclusion as to why the SSA has not substantively updated the HIV Infection Listing: it is solely due to the HIV infection disability itself.

The statutory framework tends to establish that the SSA is acting in violation of Section 504 of the Rehabilitation Act of 1973. The SSA is a federal agency subject to scrutiny under Section 504 and individuals with HIV/AIDS are "individuals with handicaps" as defined by the Rehabilitation Act. The requirement that disabled individuals are "otherwise qualified" is so intertwined with the determination process that a fair assessment is not possible without first redress to the determination process as a whole. The SSA's failure to revise the HIV Infection Listing denies meaningful access as defined by case law, contravenes the language of Section 504, and its implementing regulations promulgated by the Department of Health, Education, and Welfare (HEW), Department of Health and Human Services (DHHS), and Department of Justice (DOJ). The SSA's inaction is based solely on the HIV disability itself.

IV. RECOMMENDATIONS TOWARD COMPLIANCE WITH SECTION 504

Given the public comments and the IOM recommendations, the SSA should move forward with the regulatory process to update the HIV Infection Listing expeditiously. The SSA began applying a five year

206. *Id*. at 443-44.

207. 73 Fed. Reg. 14,570, 14,583 (Mar. 18, 2008) (to be codified at 20 C.F.R. pt. 404).

expiration date for its Listing of Impairments in 2011, ending its practice of periodically updating listings according to each body system, ranging from three to eight years, but frequently extending them.[208] Instead, the SSA conducts targeted revisions of a small number of medical diseases or disorders that need to be updated towards revision prior to the five year expiration date.[209] This targeted revision approach will take place only after a comprehensive review of each Listing has been completed. The SSA's five year expiration cycle applied to the HIV Infection Listing is arbitrary and ineffective. It has been five years since the date of its stated intention to revise the listing, and three years since the IOM made its recommendations. In 2013, the SSA indicated that they are "currently revising" the HIV Infection Listing.[210] A public comment period will follow pursuant to the statute.[211] The regulatory practice, while required, will cause further delay in an already protracted process, continue the SSA's use of the outdated HIV Infection Listing, and extend the SSA's non-compliance with Section 504.

Pursuant to 45 C.F.R. § 85.11, the SSA needs to engage in a thorough "self-evaluation" to ensure that its policies and procedures are in compliance with Section 504 of the Rehabilitation Act of 1973.[212] Given the intense scrutiny of the HIV Infection Listing over the past ten years, the SSA is on notice that its current policies with respect to the HIV Infection Listing "do not or may not meet the requirements" of the prohibition against discrimination. In 2010, the SSA initiated an action in the Federal Register, requesting public comments and suggestions on how it should conduct a "self-evaluation" of its program policies and procedures under Section 504.[213]

A part of SSA's self-evaluation should include promulgation of its own Section 504 regulations. Currently, SSA uses the Section 504 regulations promulgated by DHHS. The SSA is in the best position to assess its

208. U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-12-420, MODERNIZING SSA DISABILITY PROGRAMS: PROGRESS MADE, BUT KEY EFFORTS WARRANT MORE MANAGEMENT FOCUS 8 (2012).

209. *Id*.

210. Letter from Dawn S. Wiggins, Freedom of Information Officer, Soc. Sec. Admin., to author (June 20, 2013) (on file with the author).

211. 5 U.S.C. § 552 et seq. (2000).

212. 45 C.F.R. § 85.11 (2014).

213. Agency Self-Evaluation Under Section 504 of the Rehabilitation Act of 1973, 75 Fed. Reg. 68,395 (Nov. 5, 2010). As of this writing, SSA has re-initiated its regulatory process for engaging in a "self-evaluation." *See* Agency Proposed Business Process Vision Under the Rehabilitation Act of 1973, 78 Fed. Reg. 70,088 (Nov. 22, 2013).

policies and procedures to ensure they are in compliance with Section 504. Reliance on the DHHS regulations, while sufficient for guidance, does not account for the issues relevant to the programming of the SSA. The SSA is currently conducting a review of all adopted DHHS regulations, with the goal of establishing new SSA-specific regulations in all areas currently covered by adopted regulations.[214]

The SSA must stay up-to-date with current medical knowledge about HIV/AIDS. Additionally, the SSA needs to direct more attention and understanding about how a lack of access to medical care affects the efficacy of the HIV Infection Listing. In 2001, the SSA initiated a research effort with the Disability Research Institute (DRI) at the University of Illinois at Urbana-Champaign to investigate how the Listing of Impairments might be "validated."[215] This research was not specific to the HIV Infection Listing, but is entirely applicable because many people living with HIV/AIDS do not have access to healthcare[216] and therefore are at a disadvantage when applying for disability benefits under the current Step Three Listing. Unfortunately, the research effort was not continued past the initial report.[217] Disability status and access to medical care are inextricably intertwined. A person's disability status is primarily determined by medical evidence and is of critical importance at Step Three of the disability determination process. In 2007, the IOM Committee tasked with examining the SSA Listings and Agency Access to Medical Expertise to improve the disability determination process acknowledged that many individuals with remediable work limitations are not eligible for medical care or vocational rehabilitation until after they have completed the process of qualifying for cash disability benefits. This seems to disadvantage people with inadequate or no health care coverage. Some have criticized the current HIV Infection Listing as not taking into account the discrepancy between those with access to medical care and those without, noting "[a]s a practical matter, [the listing] still tends to disserve lower income claimants who may have little medical documentation of their repeated manifestations of HIV disease."[218] The IOM Committee,

214. SOC. SEC. ADMIN., ACCESSIBILITY HELP, http://www.ssa.gov/accessibility/504_faq.html (last visited Feb. 23, 2014).

215. Disability Research Institute, *Research Approaches to Validation of SSA'S Medical Listings: Medical Listings Validation Criteria* (Aug. 16, 2001), *available at* www.dri.uiuc.edu/research/p01-02c/related_project_validation_p01-02c.doc.

216. LEIBOWITZ ET AL., *supra* note 21 (detailing a nationally representative study of people with HIV/AIDS in care, conducted from 1994 to 2000, evaluating estimates of health coverage for individuals with HIV); Samuel A. Bozette et al., *The Care of HIV-Infected Adults in the United States*, 339 NEW ENG. J. MED., 1897-1904 (1998).

217. STOBO, *supra* note 43, at 82.

218. DAVID W. WEBBER, AIDS AND THE LAW § 9.15 (3d ed. 1997)

however, dismissed reliance upon the Listings as a "remedy" to the disparity, commenting that "any unfairness is the result of the social and political system that created these inequities, not the Listings."[219] The SSA, a federal agency, is a part of the social and political system and, indeed, created the inequities in the Listings.[220] In 2010, Paul Volberding, a lead author of the IOM Committee reviewing the HIV Infection Listing, took a more progressive view of the link between medical care access and disability status, acknowledging that "the issues of . . . access to care [are] critical in the discussion of Social Security disability benefits . . . ."[221] Nonetheless, Mr. Volberding, representing the Committee, did not make any specific recommendations relating to the incorporation of that factor in the Listing. Instead, he reiterated focus on the SSA's outdated HIV medical criteria, remarking that "trying to ignore the difference between AIDS in 1993 and the situation today seems hard to hold too seriously."[222] A lack of access to medical care acts as a barrier for HIV-infected claimants to submit medical evidence of their impairments that is too serious to ignore. The HIV Infection Listing must be administered in a way that acknowledges lack of medical access as a factor that limits receipt of disability benefits.

CONCLUSION

HIV/AIDS discrimination is a civil rights issue occurring twenty years after the first cases of the epidemic were recognized. The SSA's failure to revise and update the medical criteria encompassed in the HIV Infection Listing is a violation of Section 504 of the Rehabilitation Act of 1973. Dubious governmental interest in HIV/AIDS likely influenced the SSA's decision-making. This led to a ten year gap between when the SSA first began receiving HIV infection-related claims in late 1982 and its promulgation of the HIV Infection Listing in 1993. Since then, there has been limited action to advance the HIV Infection Listing and ensure that it comports with medical data, and reflects the current manifestations,

219. STOBO, *supra* note 43, at 9.

220. SOC. SEC. ADVISORY BD., SOCIAL SECURITY ADMINISTRATION'S PERFORMANCE AND ACCOUNTABILITY REPORT FOR FISCAL YEAR 2006, *available at* http://www.socialsecurity.gov/finance/2006/FY06_PAR.pdf (indicating that the Social Security Board also acknowledged that differences in health status and access to care impact consistency in disability decision-making).

221. *Updated: Revise Social Security HIV Disability Requirements Says Institute of Medicine*, POZ, HEALTH LIFE AND HIV (Sept. 28, 2010), http://www.poz.com/printView.php?page=/articles/hiv_disability_ssa_1667_19133.shtml&domain=www.aidsmeds.com (statement by Paul Volberding).

222. *Id*.

treatment, and control of the disease. The SSA's inaction denies meaningful access to the disability determination process and disability benefits, which negatively impacts the most impoverished individuals with HIV/AIDS. The "poverty effect" on basic needs, such as shelter, food, transportation, and medical care, has a specific effect on individuals with HIV/AIDS and determines health outcomes. The Rehabilitation Act of 1973, by its terms, underpins the federal Government's role in the prohibition against discrimination. The SSA, while not required under the Social Security Act to lessen poverty, is a federal agency that must make efforts to comply with the purposes of the Rehabilitation Act of 1973 to "empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, [] inclusion, and integration into society, through . . . the guarantee of equal opportunity."[223] By updating the HIV Infection Listing, the SSA will eliminate discrimination, lessen poverty, and promote the self-empowerment of individuals with HIV/AIDS by helping individuals become self-sufficient.

223. 29 U.S.C. § 701(b)(1)(F) (2012).