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Considering Innovative Alternatives to Handling Cases of Adults with Special Conditions Under the Social Security Act

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Considering Innovative Alternatives to Handling Cases of Adults with Special Conditions Under the Social Security Act

By Sarah Robichaud *

ABSTRACT:

Title II and Title XVI of the Social Security Act provide critical support to individuals with disabilities. However, until recently, the way that the Social Security Administration processed medical information to make disability determinations had not changed in any fundamental way since the inception of the Act.

The disability determination process is logical for many frequently handled, well-known conditions, yet there are a significant number of cases regarding special conditions that are not as well-known or as frequently considered by the Office of Disability Adjudication and Review, which administers hearings and appeals for the Social Security Administration.

The Social Security Administration is currently updating its business model to ensure that people with special conditions receive effective treatment during the disability hearing process. As a step toward reaching this goal, the Social Security Administration recently enacted Compassionate Allowances, a list of conclusively presumptive disabilities.

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This paper advocates several additional alternatives to further improve the process for cases with special conditions. Using HIV infection as an example of a special condition, this paper recommends (1) using electronic screening tools to efficiently identify cases for adjudication at the earliest opportunity; (2) using specialized medical source statements in combination with Social Security Administration forms to improve the probability of accurately assessing individuals with special conditions; and (3) reviewing cases with special conditions regionally or nationally in order to focus resources to enhance the assessment of such cases.

These improvements will help adjudicators in the Office of Disability Adjudication and Review to efficiently handle the backlog of cases dealing with varied and complex conditions and to more effectively serve individuals who have filed for disability.

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I. INTRODUCTION

The Social Security Act (Act), as initially enacted, was fairly limited in scope. From its modest beginnings, the Social Security program has evolved to become a major aspect of modern life. The Act currently offers two separate types of benefit programs. The Social Security disability insurance program under Title II of the Act pays benefits to individuals who have worked long enough and paid Social Security taxes. Certain family members may also qualify for benefits under this part of the Act. The supplemental security income program under Title XVI of the Act pays benefits to disabled adults and children who have limited income and resources. While Title II and Title XVI of the Act are critical to many people, until recently, the way that the Social Security Administration (SSA) processed medical information to determine disability had not changed in any fundamental way since the inception of the Act.

Individuals seeking benefits initially apply by submitting information about their condition and how it affects their ability to work. In making disability decisions, adjudicators consider objective medical evidence; other evidence from medical sources, including opinions; statements by the individual and others about the impairment and how it affects the individual's functioning;

^{1.} The Social Security Administration paid benefits to about 54.7 million people in 2007, and about 4.7 million people were awarded benefits in 2007. SOCIAL SECURITY ADMINISTRATION, FAST FACTS & FIGURES ABOUT SOCIAL 2008. SECURITY. available http://www.ssa.gov/policy/docs/chartbooks/fast_facts/2008/fast_facts08. On April 28, 2009, Sylvester J. Schieber, Chairman of the Social Security Advisory Board. reported that in Fiscal Year 2008, 41.2 million people were receiving retirement and survivor benefits and 15.1 million people were receiving disability benefits. He noted that, in that same fiscal year, the Social Security Administration processed nearly 4.1 million retirement and survivor claims, 2.3 million initial disability claims, and 559,000 disability hearings. Oversight Hearing on the Progress made by the Social Security Administration in Implementing the American Recovery and Reinvestment Act of 2009: Before the Subcomm. on Social Security of the Comm. on Ways and Means, 111th Cong. (2009) (statement of Sylvester J. Schieber, Chairman, the Social Security Advisory Board), available at http://www.ssab.gov/documents/Schieber_SocialSecuritySubcommitte0409final.pd f. While benefits are available to adults and children, the focus of this paper is adult disability under the Act.

^{2. 42} U.S.C. § 1381 (2006).

information from other sources; and decisions by other governmental and non-governmental agencies.³

Individuals are "disabled" under the Act if they are "unable to engage in any 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 can be expected to last, for a continuous period of not less than twelve months."

The SSA uses a five-step process to determine if an individual is disabled within the meaning of the Social Security Act.⁵ First, an individual who is working and engaged in substantial gainful activity is not disabled.⁶ If an individual is not engaged in substantial gainful activity the SSA will consider, as the second step in the process, the medical severity of an individual's physical or mental impairment-or impairments, and whether the impairment has lasted or is expected to last for a continuous period of at least twelve months.⁷ At this second step of the evaluation process, an individual must have a "severe impairment" to proceed through the disability evaluation process. "Severe impairment" is a term of art that is defined in the regulations: the evidence must establish a medically determinable impairment that is more than a slight abnormality and that has more than a minimal effect on the ability to do basic physical or mental Third, the SSA considers whether the medical work activities.8

^{3. 20} C.F.R. § 404.1512 (2009); 20 C.F.R. § 416.912 (2009).

^{4. 42} U.S.C. § 423(d)(1)(A) (2006).

^{5. 20} C.F.R. § 404.1520 (2009); 20 C.F.R. § 416.920 (2009).

^{6. 20} C.F.R. § 404.1520(b); 20 C.F.R. § 416.920(b).

^{7. 20} C.F.R. § 404.1509 (2009), § 404.1520(a)(4)(ii); 20 C.F.R. § 416.909 (2009), § 416.920(a)(4)(ii).

^{8. 20} C.F.R. § 404.1520(c); 20 C.F.R. § 404.1508 (2009); 20 C.F.R. § 416.920(c); 20 C.F.R. § 416.908 (2009). To establish the existence of a medically determinable impairment there must be evidence from an "acceptable medical source." 20 C.F.R. § 404.1513 (2009); 20 C.F.R. § 416.913 (2009); Titles II and XVI: Considering Opinions and Other Evidence from Sources Who Are Not "Acceptable Medical Sources" in Disability Claims; Considering Decisions on Disability by Other Governmental and Nongovernmental Agencies, Social Security Ruling 06-3p (2006),available http://www.socialsecurity.gov/OP_Home/rulings/di/01/SSR2006-03-di-01.html. Adjudicators determining whether a severe impairment exists must analyze an individual's diagnosis or diagnoses, the limitations alleged, the limitations established, and whether the diagnosed impairments significantly limit the ability of the individual to perform basic work activities. Office of Disability and

severity of the impairment meets or equals one of the listing of impairments in the SSA regulations. The listing of impairments describes impairments for each major body system that are considered severe enough to prevent an individual from doing substantial gainful activity. If the individual meets the requirements of a listing-level condition, the individual is found disabled without further inquiry. Fourth, if the individual does not meet a listing, the SSA assesses the residual functional capacity of an individual, and considers whether an individual can perform past work. An individual who can perform past work is not disabled. Residual functional capacity is an administrative assessment of the most an individual can do despite his or her limitations. Fifth, even if an individual's impairment does prevent the performance of past relevant work, if other work exists in the national economy that accommodates the individual's residual functional capacity and

Adjudication Review, Social Security Administration, *Guidelines for Rationale in Title II and Title XIV Initial Entitlement Decisions*, Hearings, Appeals and Litigation Law Manual, *available at* http://www.ssa.gov/OP_Home/hallex/I-03/I-3-8-12.html.

^{9. 20} C.F.R. § 404.1525 (2009); 20 C.F.R. § 416.925 (2009); 20 C.F.R. § 404, Subpart A, Appendix 1 (2009). In the case of documented HIV infection, as described in 14.00E of the preface to the immune system listings, when an individual meets listing-level requirements for HIV under 14.08 a separate finding on the duration of the impairment is not required. Social Policy Interpretation Ruling Titles II and XVI: Evaluation of Human Immunodeficiency Virus Infection. Social Security Ruling 93-2p (1994),available http://www.ssa.gov/OP_Home/rulings/di/01/SSR93-02-di-01.html. An impairment or combination of impairments is medically equal to a listed impairment if the signs, symptoms, and laboratory findings are "at least equal" in severity and duration to those of a listed impairment. 20 C.F.R. § 404.1526 (2009); 20 C.F.R. § 416,926 (2009). The listing of impairments contains two parts: Part A for adults and Part B for children. This article focuses on Part A of the listing of impairments.

^{10. 20} C.F.R. § 404.1520(a)(4)(iii); 20 C.F.R. § 416.920(a)(4)(iii).

^{11. 20} C.F.R. § 404.1520(a)((4)(iv); 20 C.F.R. § 416.920(a)(4)(iv).

^{12. 20} C.F.R. § 404.1545(a)(1) (2009); 20 C.F.R. § 416.945(a)(1) (2009); see Policy Interpretation Ruling Titles II and XVI: Assessing Residual Functional Capacity in Initial Claims, Social Security Ruling 96-8p, available at http://www.ssa.gov/OP_Home/rulings/di/01/SSR96-08-di-01.html.

vocational factors, the individual is not disabled. If the individual cannot do other work, the SSA will find the individual disabled.¹³

If the SSA does not award disability benefits after an initial determination, an individual may appeal that decision. The Office of Disability Adjudication and Review (ODAR) administers hearings and appeals for the SSA. Adjudicators who consider these cases perform the same five-step analysis to determine whether an individual is disabled within the meaning of the Act.¹⁴

Over time, the number of cases considered at the ODAR hearing level has grown. The rising workload and limited resources have resulted in a significant backlog of cases at the hearing level, with significant implications for individuals filing for disability, including a long wait for hearings and disability decisions. The retirement of the "baby boomer" generation beginning in 2008, and the fact that people are living longer, will further impact this trend.

There are also ongoing problems with the evaluation of cases where individuals have special or unusual conditions. Each individual applying for benefits is unique, and provides a particular medical history for SSA adjudicators to assess. Adjudicators evaluating cases with special or unusual conditions must also take into account symptoms that are not always measurable with objective medical testing, the fact that the impact of the condition on function is unique to each individual, and medical advances that may complicate the correlation of existing objective information with a functional capacity determination necessary to make a disability

^{13. 20} C.F.R. § 404.1520(a)(4)(v); 20 C.F.R. § 416.920(a)(4)(v); see also Walters v. Comm'r of Soc. Sec., 127 F.3d 525, 529 (6th Cir. 1997) (citing 20 C.F.R. § 404.1520).

^{14.} There are nearly 1,200 administrative law judges who hold hearings in 141 hearing offices and over 150 remote hearing locations and issue more than 550,000 decisions a year. The SSA has asked the judges to issue 500 to 700 legally-sufficient decisions each year. *Testimony Before the Subcomm. on Social Security of the H. Comm. on Ways and Means*, 110th Cong., (2008) (statement of Frank A. Cristaudo, C.A.L.J., Office of Disability Adjudication and Review, Social Security Administration), *available at* http://waysandmeans.house.gov/hearings.asp?formmode=printfriendly&id=7384. In addition to administrative law judges, in 2007, the SSA modified prehearing procedures to allow attorneys to conduct prehearing proceedings to issue fully favorable decisions under certain circumstances. Social Security Administration, Amendment to the Attorney Advisor Program, Interim Final Rule with Request for Comments, 72 Fed. Reg. 44,763 (Aug. 9, 2007).

determination. Thus, in the case of an individual with a special or unusual condition, the information typically available to SSA adjudicators when making a decision regarding disability might not adequately ensure an accurate picture of the individual's overall condition prior to a determination of disability.

These issues present ongoing challenges to SSA adjudicators, who must provide full and fair hearings in accordance with the Social Security Act, the Administrative Procedure Act, and the Constitution of the United States.¹⁵ The SSA is currently updating its business model with regulatory modifications designed to reduce the backlog of disability cases before adjudicators at the ODAR hearing level. These improvements include accelerating the review of cases likely or certain to be approved, which will improve the process of disability review for individuals with special conditions while ensuring a fair hearing process.

With this goal in mind, the SSA recently implemented a category of conclusively presumptive disabilities called "Compassionate Allowances" where it is known, by definition, that people with certain diseases and conditions will be unable to work for at least 12 months. The conditions on the Compassionate Allowances list include special conditions with unique characteristics that SSA field office employees and hearing office adjudicators may not regularly consider.

Michael J. Astrue, the Commissioner of Social Security, noted that an accelerated review of cases likely to be approved, including the review of cases with special conditions, will help the SSA to reach its goal of reducing the backlog of disability cases at the hearing level. Commissioner Astrue stated specifically that "[g]uidance for one rare disease affecting 50,000 Americans will not be sufficient to improve the process, but if—over time—we can do it for between 100 to 500 rare diseases, we can make a difference." 17

^{15. 5} U.S.C. §§ 554-56 (2006); 42 U.S.C. § 405 (2006).

^{16.} See Social Security Online, Compassionate Allowances, http://www.socialsecurity.gov/compassionateallowances/. For the initial list of compassionate allowance conditions, see http://www.ssa.gov/compassionateallowances/conditions.htm.

^{17.} Compassionate Allowance Outreach Hearing on Rare Diseases: Hearing Before the Social Security Administration, 110th Cong. (2007) (opening Remarks,

Recognizing this challenge, the SSA is looking ahead to make these changes for a greater number of conditions, especially with cases where adjudicators might be uncertain as to what to do. In this way, the SSA will improve its ability to make a real difference in the lives of Americans.

The implementation of the Compassionate Allowance initiative is a strong sign that the SSA is committed to significantly improving the process of disability review for Americans. This paper evaluates one condition, human immunodeficiency virus (HIV) infection, which is not on the initial list of compassionate allowance conditions. The listing for HIV, under which an individual can be found disabled, however, was recently updated. 18 Despite updates to the listing for HIV, individuals with HIV infection face ongoing problematic delays while awaiting hearings due to the unique and varied symptoms of their condition, the inconsistent rate of deterioration from one individual to the next, and the diverse effect of the symptoms on functional abilities. The condition is, thus, an excellent example of how SSA adjudicators evaluate a special condition, and whether, with further updates, the SSA adjudicatory standards and process can be improved for individuals with special conditions.

This paper encourages ongoing empathy and creativity in the handling of cases regarding special conditions that may not be well-known or regularly seen during routine disability determination proceedings by SSA adjudicators. Using HIV infection as an example, the paper considers innovative alternatives to handling cases with special conditions. The methods that may improve the way that the SSA handles one condition, in this case HIV infection, may be applied to other diseases and conditions. This paper suggests that, if the SSA can further improve the ability of adjudicators to consider the cases of individuals with HIV infection, such improvements may affect further positive changes to the SSA business process and improve the disability determination process for people with many different types of conditions.

Michael J. Astrue, Comm'r of Social Security), available at http://www.socialsecurity.gov/compassionateallowances/agenda1204.htm.

^{18. 20} C.F.R. § 404, Subpart A, Appendix 1, 14.08, available at http://www.ssa.gov/disability/professionals/bluebook/14.00-Immune-Adult.htm#14 08.

II. A Brief History of the Social Security Act

On June 8, 1934, President Franklin D. Roosevelt announced his intention to provide a program for Social Security. Following a committee study and report, President Roosevelt signed the Social Security Act into law on August 14, 1935. The law created a social insurance program to pay retired workers, age sixty-five or older, a continuing income after retirement, and provided unemployment insurance, old-age assistance, aid to dependent children, and grants to the states to provide various forms of medical care.

Congress amended the Act in 1939 to pay benefits to the spouse and minor children of a retired worker and survivor benefits to the family in the event of the premature death of the worker. President Truman signed further amendments in 1950 that increased benefits for beneficiaries. In 1954, President Eisenhower signed amendments that initiated a disability insurance program; changes in 1956 provided cash benefits to disabled workers who were fifty to sixtyfive years of age and to disabled adult children. Congress further broadened the program by permitting both disabled workers and their dependants to qualify for benefits. Changes in the 1960s and 1970s included the passage of Medicare, which extended health coverage to beneficiaries; adjustments to benefits to compensate for wage and price inflation; and the creation of the supplemental security income program, a needs-based program for the elderly, blind, and disabled. Changes in 1972 added automatic cost-of-living adjustments based on the annual increase in consumer prices.

Amendments to the Act in the 1980s included work incentive provisions and the implementation of periodic reviews of current disability beneficiaries to certify continuing eligibility for disability. As a result of financing problems, President Ronald Reagan appointed the Greenspan Commission to recommend legislative changes. President Reagan signed amendments in 1983 that included the partial taxation of Social Security benefits; the coverage of federal employees; raising the retirement age gradually starting in 2000; and increasing the reserves in the Social Security trust fund.

^{19.} Franklin D. Roosevelt, United States President, Message to Congress Reviewing the Broad Objective and Accomplishments of the Administration (June 8, 1934), http://www.ssa.gov/history/fdrstmts.html#message1.

The SSA became an independent agency in 1995. Thus, the Commissioner of Social Security reports directly to the President. In 1994 legislation mandated the formation of a permanent, sevenmember, bipartisan Social Security Advisory Board to provide independent advice and counsel to the President, Congress, and Commissioner of Social Security on Social Security supplemental security income policy. The Act was amended in the 1990s to address issues such as the eligibility of noncitizens, disability benefits to children, work incentives, and beneficiary safeguards. In 2001, the President's Commission to Strengthen Social Security-with members appointed by President George W. Bush-attempted to ensure the future stability of the Social Security program by recommended options to address long-range financing shortfalls of the program. By 2006, the Social Security program had grown to include 49,122,831 disability beneficiaries and 7,235,565 supplemental security income beneficiaries.²¹

III. CURRENT DEVELOPMENTS

With advances in science and medicine, the trend away from physically exertive work, and an aging population, the impact on the SSA is, and will continue to be, tremendous. Non-traditional workloads, including immigration enforcement, require a substantial commitment of resources, and cases regarding complex or special conditions lead to time-consuming and expensive consultations often performed by doctors who are unfamiliar with SSA rules and regulations. Costs are projected to rise steeply between 2010 and 2030 for reasons that include an increase in the number of people receiving benefits and an anticipated increase in the complexity of services.²² Ongoing studies show that the payroll tax that finances

^{20.} For more information on the Social Security Advisory Board, see http://www.ssab.gov/index.html.

^{21.} Social Security: A Brief History, SSA Publication No. 21-059, October 2007, www.socialsecurity.gov. See also David H. Autor & Mark G. Duggan, The Growth in the Social Security Disability Rolls: A Fiscal Crisis Unfolding, 20 J. ECON. PERSP., Summer 2006, at 71, 74.

^{22.} Social Security and Medicare Boards of Trustees, Status of the Social Security and Medicare Programs, A Summary of the 2009 Annual Reports, http://www.ssa.gov/OACT/TRSUM/index.html.

Social Security will not raise enough money to cover anticipated future benefits.²³

The growing number of cases in the system has resulted in a current backlog of cases at the ODAR hearing level, where individuals appeal initial disability determinations before Administrative Law Judges.²⁴ In order to ensure continued success in the basic mission of reducing poverty in old age and insuring Americans against losses due to disability or the death of a working spouse or parent, the SSA must continue to address this pressing issue.

The elimination of the ODAR hearing backlog is a high priority for the SSA. A year-end report for fiscal year 2008 from the SSA summarizes progress on its plan to eliminate the hearing backlog and prevent its recurrence by (1) focusing on compassionate allowances, (2) improving hearing office procedures, (3) increasing adjudicatory capacity, and (4) increasing efficiency with automation and improved business processes. An aggressive effort, during fiscal years 2007 and 2008, towards reaching goals for all of these initiatives resulted in a significant reduction in the backlog of the aged cases in ODAR offices nationwide.²⁵ Notably, changes have included the implementation of a medical expert screening process, the opening of a National Hearing Center, the transition to processing files

^{23.} Id.; see also Will Marshall, Social Security and Medicare Reform for the Twenty-First Century, in Uniting America: Restoring the Vital Center to American Democracy, Yale University Press (2005); Autor, supra note 22, at 71-96; The 2007 Annual Report of the Board of Trustees of the Federal Old-Age and Survivors Insurance and Federal Disability Insurance Trust Funds: Transmitted to the Committee on Ways and Means, 110th Cong. 23-25 (2002), available at http://www.ssa.gov/OACT/TR/TR07/tr07.pdf.

^{24.} Erik Eckholm, Disability Cases Last Longer as Backlog Rises, N.Y. Times, Dec. 10, 2007, at A1; see also Social Security Backlog Grows from Lack of Cash, The Oregonian, Aug. 4, 2008, at a01. On January 16, 2008, the Association of Administrative Law Judges sponsored a roundtable discussion, "Challenges Facing the Social Security Disability Program." Speakers emphasized the need to address systemic SSA problems to ensure the sustainability of the program. The program is available at http://www.aalj.org/09c01.html.

^{25.} OFFICE OF DISABILITY ADJUDICATION AND REVIEW, SOCIAL SECURITY ADMINISTRATION, PLAN TO ELIMINATE THE HEARING BACKLOG and PREVENT ITS RECURRENCE, 1 (Fiscal Year 2008), available at http://www.ssa.gov/disability/Semiannual_Report_FY08.pdf.

electronically, and the effectuation of temporary service area realignments and interregional case transfers.

IV. COMPASSIONATE ALLOWANCES

The Compassionate Allowance initiative is a new effort by the SSA that allows the agency to quickly provide benefits to applicants with special medical conditions whose conditions are so serious that they obviously meet the disability listing standards. The initial list of fifty compassionate allowance conditions, announced in October of 2008,²⁶ allows the SSA to identify diseases and conditions that invariably qualify for disability under the SSA's listing of impairments based on minimal, but sufficient, objective medical information.

The SSA's Listing of Impairments is one of the key elements used in determining whether or not someone qualifies for disability benefits.²⁷ The Listing of Impairments describes, for each major body system, impairments that are severe enough to prevent an individual from doing any substantial gainful activity. Most of the listed impairments are permanent, expected to result in death, or note a durational requirement. The "criteria in the Listing of Impairments are applicable to evaluation of claims for disability benefits under the Social Security disability insurance program" and the supplemental security program.²⁸

The initial list of compassionate allowance conditions was developed as a result of information received at public outreach hearings and from public comment on an Advance Notice of Proposed Rulemaking, comments received from the SSA and Disability Determination Service communities, and medical and

^{26.} News Release, Social Security Administration, Social Security Announces Nationwide Launch of Compassionate Allowances, Process Will Fast Track Applications For People With Cancers and Rare Diseases (Oct. 27, 2008) available at http://www.ssa.gov/pressoffice/pr/compassionate-allowances-1008-pr.htm. The initial list of compassionate allowances is available at http://www.socialsecurity.gov/compassionateallowances/conditions.htm.

^{27. 20} C.F.R. § 404.1525, 404.1526, Subpart P, Appendix 1 available at http://www.ssa.gov/disability/professionals/bluebook/listing-impairments.htm.

^{28. 20} C.F.R. § 404.1525, available at http://www.ssa.gov/disability/professionals/bluebook/listing-impairments.htm.

scientific experts.²⁹ The SSA also considered which conditions are most likely to meet the current definition of disability, and noted that, after the initiative's initial rollout, the list may expand over time.³⁰

The SSA's most recent hearing for Compassionate Allowances focused on early-onset Alzheimer's disease and related dementias; other hearings focused on rare diseases, cancers, and traumatic brain injuries and stroke.³¹ Early-onset Alzheimer's disease was chosen for further study because it is a rapidly progressing and debilitating disease of the brain that affects individuals between fifty and sixty-five years of age, and with better diagnostic tools and the aging of the baby boomers, there is an increasing number of individuals diagnosed with this disease.

SSA Commissioner Michael J. Astrue confirmed, at the hearing for early-onset Alzheimer's disease, that the top priority of the SSA is to improve service to disabled Americans by reducing the hearing backlog and improving accuracy of the decisions and the speed with which they are issued. He also confirmed that the SSA has been making steady progress, even with an unprecedented increase in applications, and that the Compassionate Allowance initiative helps people with devastating conditions receive decisions as quickly as possible. Commissioner Astrue noted that the SSA is working to continually expand the list of compassionate allowances and ensure that Social Security Administration employees are able to expedite cases by providing them with the resources to identify conditions; understand diagnostic testing, coding, disease progression, and

^{29.} The SSA held initial Compassionate Allowance hearings on the following dates: December 4-5, 2007, for rare diseases; April 7, 2008, for cancers; November 18, 2008, for brain injuries and stroke; and July 29, 2009, for early onset Alzheimer's disease and related dementia, in order to obtain the public's views about how to implement Compassionate Allowances for children and adults. For detailed information on these hearings, see http://www.socialsecurity.gov/compassionateallowances.

^{30.} For a list of conditions selected for the initiative's rollout, see Social Security Administration, List of Conditions, http://www.ssa.gov/compassionateallowances/conditions.htm (last visited Sept. 30, 2009).

^{31.} Announcement of Public Hearing, Compassionate Allowances for Early-Onset Alzheimer's Disease and Related Dementias, 74 Fed. Reg. 32,817 (July 9, 2009); see also Social Security Administration, Compassionate Allowances available at http://www.ssa.gov/compassionateallowances/.

treatment of the conditions; and consider other medical criteria necessary to evaluate disability applications. Commissioner Astrue also noted that the SSA must expand the compassionate allowance list, shift its focus to a broader category of conditions, and allow claims based on gradation of severity and symptoms or subsets of medical conditions that clearly do meet SSA disability standards. Testimony of experts at these hearings has allowed the SSA to gather as much information as possible to help identify potential rules to apply to the most severe cases that meet disability standards, whether it is in the Compassionate Allowance initiative or some other area in the disability determination process.

V. HIV INFECTION

HIV infection is an example of a special condition that might benefit from the efforts of the SSA to improve its processing of cases at the ODAR hearing level. Under the five-step sequential evaluation process for disability determination, if an individual with HIV is not working, the SSA will consider the severity of the individual's impairment, and whether the medical severity of the individual's impairment meets or equals the listing for HIV. HIV infection can be considered a special condition for several reasons. Individuals with HIV do not need to meet the twelve month durational requirement of the regulations.³² The condition has varied effects on individuals. and individuals react differently to the spectrum of treatment methods available and that are currently used to treat the condition. Further, medical technology is resulting in ongoing improvements to treatment modalities for HIV. Finally, the condition is not often considered on a daily basis by ODAR adjudicators. Thus, adapting the way adjudicators consider such cases could allow adjudicators to

^{32. 20} C.F.R. § 404.1509, § 404.1520(a)(4)(ii)-(iii); 20 C.F.R. § 416.909, § 416.920(a)(4)(ii)-(iii); 20 C.F.R. § 404, Subpart A, Appendix 1. In the case of documented HIV infection, as described in 14.00E of the preface to the Immune System listings, when an individual meets listing-level requirements for HIV under 14.08, a separate finding on the duration of the impairment is not required. Policy Interpretation Ruling Titles II and XVI: Evaluation of Human Immunodeficiency Virus Infection, Social Security Ruling 93-2p (1994), available at http://www.ssa.gov/OP Home/rulings/di/01/SSR93-02-di-01.html.

more effectively consider whether an individual with HIV meets the requirements of a listing under the sequential evaluation process.

HIV, or human immunodeficiency virus, is the virus that causes acquired immunodeficiency syndrome (AIDS). AIDS is the final stage of HIV infection. The first cases of AIDS were identified in the United States in 1981, and in 1984 scientists proved that HIV causes AIDS.³³

HIV infects cells in the immune system and the central nervous system. Once it has found its way into a cell, HIV produces new copies of itself, which can then go on to infect other cells. Over time, HIV infection leads to a severe reduction in the number of cells available to help fight disease. The process usually takes several years, and infection may go unnoticed, sometimes for years.

HIV infection can generally be broken down into four distinct stages:

- Primary infection,
- clinically asymptomatic stage,
- symptomatic HIV infection, and
- progression from HIV to AIDS.

Having AIDS means that the virus may have weakened the immune system to the point to at which an individual's body has trouble fighting infections.³⁴

If an individual has HIV infection, as the immune system fails, the individual develops symptoms. Initially, the symptoms may be mild. However, as the immune system deteriorates, the symptoms may worsen. Symptomatic HIV infection is mainly caused by the emergence of opportunistic infections and cancers that the immune system would normally prevent. These can occur in almost all the body systems. Symptomatic HIV infection is often characterized by multi-system disease. Treatment for the specific infection or cancer is often carried out, but the underlying cause is the action of HIV as it erodes the immune system. Unless HIV itself can be slowed down,

^{33.} CENTER FOR DISEASE CONTROL AND PREVENTION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, LIVING WITH HIV/AIDS, available at http://www.cdc.gov/hiv/resources/brochures/livingwithhiv.htm (last visited Sept. 28, 2009).

^{34.} CENTER FOR DISEASE CONTROL AND PREVENTION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, BASIC INFORMATION: HIV/AIDS, http://www.cdc.gov/hiv/topics/basic/index.htm (last visited Sept. 28, 2009).

the symptoms of immune suppression will not just continue but will worsen. As the immune system becomes more and more damaged, the illnesses that occur become more and more severe, eventually leading to an AIDS diagnosis.³⁵

In the United States, someone may be diagnosed with AIDS if they have certain signs or symptoms defined by the United States Centers for Disease Control and Prevention (CDC). This includes a very low count of a certain type of cells in the blood.³⁶ Immune cells called "CD4 cells" are disabled and killed during a typical course of Thus, these cells are evaluated by CD4 count. uninfected person usually has 800 to 1200 CD4 T cells per cubic millimeter (mm³) of blood. HIV infection typically involves a decrease in the number of CD4 cells, with a resulting decrease in the effectiveness of the immune system. Antiretroviral therapy is often recommended for individuals with a history of AIDS-defining illness or severe symptoms of HIV, regardless of CD4 cell count. The CDC regularly publishes treatment guidelines for the use of antiretroviral therapy for individuals infected with HIV.³⁷ However, when an individual's CD4 T cell count falls below 200, the individual can become particularly vulnerable to opportunistic infections and cancers that typify AIDS. It is possible for someone to be very ill with HIV but not have an AIDS diagnosis. In comparison, at present in the United Kingdom, an AIDS diagnosis is confirmed if a person with HIV develops one or more of a specific number of severe opportunistic infections or cancers.³⁸

^{35.} Avert.org, The Different Stages of HIV Infection. http://www.avert.org/stages-hiv-aids.htm (last visited Sept. 29, 2009); NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES, DEPARTMENT OF HEALTH AND SERVICES. How HUMAN HIV CAUSES http://www3.njaid.nih.gov/topics/HIVAIDS/Understanding/How+HIV+Causes+AI DS/ (last visited Sept. 30, 2009).

^{36.} CENTER FOR DISEASE CONTROL AND PREVENTION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, BASIC INFORMATION: HIV/AIDS http://www.cdc.gov/hiv/topics/basic/index.htm (last visited Sept. 28, 2009).

^{37.} AIDS Info, U.S. Department of Health and Human Services, http://www.aidsinfo.nih.gov/Guidelines/ (last visited Sept. 30, 2009).

^{38.} NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES, DEPARTMENT OF HEALTH AND HUMAN SERVICES, HOW HIV CAUSES AIDS, http://www3.niaid.nih.gov/topics/HIVAIDS/Understanding/How+HIV+Causes+AI DS/ (last visited Sept. 30, 2009).

The CDC estimates that about 1,106,400 people are living with HIV in the United States, indicating a prevalence rate of 447.8 cases per 100,000 persons. The CDC further estimates that of those individuals, approximately one in five, or twenty-one percent, do not know they are infected. Men who have sex with men of all races, African Americans, and Hispanics/Latinos are disproportionately affected by HIV.³⁹ Today, more people are living with HIV because of better treatments and because, while the number of new HIV infections per year has remained stable in recent years, more people become infected with the disease than die from the disease each year. Data shows that seventy percent of individuals living with HIV in the United States are between the ages of twenty-five and forty-nine.⁴⁰

Jeffrey P. Nadler, M.D., Acting Director of the Therapeutics Research Program, Division of AIDS, National Institute of Allergy and Infectious Diseases (NIAID), reported at a September 10, 2008 conference on HIV sponsored by the SSA that medical advances have substantially improved the treatment of opportunistic infections that previously limited the survival rate for people with HIV. As a result, statistics show more people living with HIV but a decrease in the number of AIDS cases and deaths in the United States between 1985 and 2006.⁴¹ Dr. Nadler suggested that ongoing disease issues related to HIV include viral resistance; demographic changes that increasingly include infected women; and the treatment of HIV in an aging population with secondary physical and mental conditions such

^{39.} Liz Highleyman, CDC Updates Estimates of HIV Prevalence in the United States, Oct. 7, 2008, http://www.hivandhepatitis.com/recent/2008/100708_a.html; CENTER FOR DISEASE CONTROL AND PREVENTION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, QUESTIONS AND ANSWERS: HIV PREVALENCE ESTIMATES—UNITED STATES, 2006, http://www.cdc.gov/hiv/topics/surveillance/resources/qa/prevalence.htm. For example, the CDC reports that black men have an HIV prevalence rate of 2,388 per 100,000 people, which is six times as high as the rate for white men (395 per 100,000) and black women have an HIV prevalence rate of 1,122 per 100,000 people, which is 18 times as high as the rate for white women (63 per 100,000).

^{40.} CENTER FOR DISEASE CONTROL AND PREVENTION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, QUESTIONS AND ANSWERS: HIV PREVALENCE ESTIMATES—UNITED STATES, 2006, http://www.cdc.gov/hiv/topics/surveillance/resources/qa/prevalence.htm.

^{41.} CENTER FOR DISEASE CONTROL AND PREVENTION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, HIV/AIDS STATISTICS AND SURVEILLANCE, http://cdc.gov/hiv/topics/surveillance/index.htm (last visited Sept. 23, 2009).

as diabetes, neuropathy, chronic hepatitis C, subtle cognitive impairment, and depression.⁴²

The discovery and development of new therapeutic strategies against HIV infection is a high priority for the NIAID. Research supported by NIAID has already greatly advanced understanding of HIV and how it causes disease. This knowledge provides the foundation for NIAID's HIV/AIDS research effort and continues to support studies designed to further extend and improve the quality of life of those infected with HIV.⁴³

The Food and Drug Administration has approved thirty antiretroviral drugs to treat people with HIV. These drugs fall into four major classes: Reverse transcriptase (RT) inhibitors, protease inhibitors, entry and fusion inhibitors, and integrase inhibitors. RT inhibitors interfere with the critical step during the HIV life cycle known as reverse transcription. During this step, RT, an HIV enzyme, converts HIV RNA to HIV DNA to block HIV from replicating in a cell. Protease inhibitors interfere with the protease enzyme that HIV uses to produce infectious viral particles. Entry and fusion inhibitors interfere with the virus' ability to fuse with the cellular membrane, thereby blocking entry into the host cell. Integrase inhibitors block integrase, the enzyme HIV uses to integrate genetic material of the virus into its target host cell. There are also multidrug combinations that incorporate drugs from more than one class into a single product. The drugs do not cure HIV infection or AIDS but can suppress the virus. Thus, individuals with HIV must continuously take antiretroviral drugs.⁴⁴

Doctors recommend that people infected with HIV take a combination of antiretroviral drugs known as highly active

^{42.} A recent study notes that as an individual's CD4 cells reproduce over many years, they become less functional, and suggests that the premature aging of CD4 cells is linked to faster disease progression in HIV-positive individuals. Weiwei Cao et al., *Premature Aging of T cells Is Associated With Faster HIV-1 Disease Progression*, 50 J. Acquired Immune Deficiency Syndrome, Feb. 2009, at 137-47.

^{43.} NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES, DEPARTMENT OF HEALTH AND HUMAN SERVICES, TREATMENT OF HIV INFECTION, (2007), http://www.niaid.nih.gov/factsheets/treat-hiv.htm.

^{44.} Id.

antiretroviral therapy, or HAART.⁴⁵ This is because, as HIV reproduces itself, variants of the virus emerge, including some that are resistant to antiretroviral drugs. Combining drugs from at least two different classes of antiretroviral drugs can effectively suppress the virus when used properly. This can reduce an individual's viral load (the measure of the quantity of HIV virus in the blood) to very low levels and can delay the progression of HIV for prolonged periods. Developed by NIAID-supported researchers, HAART has revolutionized how people infected with HIV are treated. HAART works by suppressing the virus and decreasing the rate of opportunistic infections. While people infected with HIV have impaired immune systems that are susceptible to opportunistic infections, therapies such as HAART often allow the immune system to recover and protect an individual from other infections. Thus, antiretroviral drugs provide a way for the immune system to remain effective, thereby improving the quality and length of life for people with HIV.46

Judith A. Aberg, M.D., Directory of Virology, Bellevue Hospital Center, and Associate Professor of Medicine, New York University School of Medicine, spoke at the conference on HIV sponsored by the SSA on September 10, 2008. Dr. Aberg confirmed that while there have been remarkable advances in HIV treatment, only fifty to sixty percent of people respond to antiretroviral therapy, many people remain undiagnosed until late in the disease process, and nearly fifty percent of people with HIV/AIDS in need of antiretroviral treatment are not receiving therapy.

Clearly, late diagnosis and treatment makes a difference. Data indicates that individuals diagnosed with AIDS at the time of initial presentation were fifty-five percent more likely to die of an HIV-related cause, and that more than fifty percent of deaths occurred

^{45.} NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES, DEPARTMENT OF HEALTH AND HUMAN SERVICES, GUIDELINES FOR THE USE OF ANTIRETROVIRAL AGENTS IN HIV-1-INFECTED ADULTS AND ADOLESCENTS (2008), available at http://aidsinfo.nih.gov/contentfiles/AdultandAdolescentGL.pdf.

^{46.} NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES, DEPARTMENT OF HEALTH AND HUMAN SERVICES, TREATMENT OF HIV INFECTION (2007), available at http://www.niaid.nih.gov/factsheets/treat-hiv.htm.

within four months of a diagnosis.⁴⁷ Dr. Aberg confirmed that people diagnosed late are more difficult to treat, and are less likely to fully benefit from antiretroviral treatment.

Effective suppression of HIV requires strict adherence to potent medications with serious side effects. While rates of adverse drug effects that limit treatment have been declining with the introduction of newer antiretroviral regimens, adverse affects from antiretroviral drugs are common, and may be a reason for switching or discontinuing therapy. Many individuals are resistant to at least one drug. Also, a pathogen-specific inflammatory response that may be triggered by initiation, re-initiation, or a change to a more active antiretroviral therapy, called Immune Reconstitution Inflammatory Syndrome (IRIS), may severely complicate treatment.⁴⁸

Medical advances have substantially improved the prognosis of many, but not all, opportunistic infections. Opportunistic infections may still result in persistent illness or death unless there is significant immune improvement, such as is often seen in HIV with HAART (although this is not necessarily a rapid improvement). Further, other complications to treatment abound. Studies suggest drug resistance of six to eighteen percent in people who are new to antiretroviral treatment. Further, incomplete adherence can result from complex regimens. Substance abuse, drug side effects, interactions between psychotropic and antiretroviral agents, toxicity, co-infection with other conditions, and affective disorders may further adversely affect compliance. Access to adequate treatment and education may also affect treatment response.⁴⁹

Cases in which individuals have HIV infection present SSA adjudicators with special challenges. Records for such cases may

^{47.} Judith E. Sackoff et al., Causes of Death among Persons with AIDS in the Era of Highly Active Antiretroviral Therapy: New York City, 145 ANNALS OF INT'L MED., September 2006, at 397-406.

^{48.} NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES, DEPARTMENT OF HEALTH AND HUMAN SERVICES, GUIDELINES FOR THE USE OF ANTIRETROVIRAL AGENTS IN HIV-1-INFECTED ADULTS AND ADOLESCENTS 95 (2008), available at http://aidsinfo.nih.gov/contentfiles/AdultandAdolescentGL.pdf.

^{49.} Id.; Marshall Forstein et al., American Psychiatric Association, Guideline Watch: Practice Guidelines for the Treatment of Patients with HIV/AIDS, at 3 http://www.psychiatryonline.com/content.aspx?aID=44070 (last visited Oct. 5, 2009).

contain a complex combination of constantly-evolving drug treatment modalities that have diverse effects on different individuals. The records evidence a range of responses to treatment based on compliance with treatment, socioeconomic factors, and mental health issues. The condition is not regularly considered by ODAR adjudicators. Implementing methods to improve the way that adjudicators handle cases where HIV is a severe impairment would improve the processing of those cases at the hearing level, and allow adjudicators to more accurately determine whether an individual with HIV meets the requirements of a listing under the sequential evaluation process. Such methods, in turn, might be used and have positive implications for other cases that contain special conditions.

VI. SOCIAL SECURITY ADMINISTRATION REGULATION OF HIV INFECTION

Under the five-step Social Security disability evaluation process, if an individual is not working and has a severe impairment, a SSA adjudicator then considers whether the medical severity of the individual's impairment or impairments meets or equals one of the listing of impairments.⁵⁰ The listing of impairments that adjudicators use to define adult disability in the sequential evaluation process includes, in listing 14.00, immune system disorders that cover a wide variety of conditions, including systemic lupus erythematosus, systemic vasculitis, systemic sclerosis and scleroderma, polymyositis or dermatomyositis, undifferentiated connective tissue disorder, immunoglobulin deficiency syndromes, inflammatory arthritis, and HIV infection.⁵¹ Listing 14.08 deals specifically with HIV infection.

HIV infection was not included in the recent initial list of Compassionate Allowances. However this author suggests that HIV

^{50. 20} C.F.R. § 404.1509, § 404.1520(a)(4)(ii)-(iii); 20 C.F.R. § 416.909, § 416.920(a)(4)(ii)-(iii); 20 C.F.R. § 404, Subpart A, Appendix 1. In the case of documented HIV infection, as described in 14.00E of the preface to the Immune System listings, when an individual meets listing-level requirements for HIV under 14.08, a separate finding on the duration of the impairment is not required. Policy Interpretation Ruling Titles II and XVI: Evaluation of Human Immunodeficiency Virus Infection, Social Security Ruling 93-2p, available at http://www.ssa.gov/OP_Home/rulings/di/01/SSR93-02-di-01.html.

^{51. 20} C.F.R. § 404, Subpart A, Appendix 1.

is a special condition and that individuals with HIV infection present adjudicators with a wide array of challenges. Thus, listing 14.08 is a good starting point for studying ways that the SSA may consider additional methods to improve the process by which adjudicators consider cases with special conditions that they may not handle on a regular basis.

The SSA recently updated how it handles listing-level immune system disorders. On March 18, 2008, the SSA published Final Rules regarding revised medical criteria for evaluating immune system disorders.⁵² These changes became effective on June 16, 2008. The Social Security Administration specifically noted, in March of 2008, that after considering the advances in treatment and resulting increases in longevity, the agency did not initially "believe that there had been sufficient progress in the treatment and control of HIV infection to warrant any change" to listing 14.08 for HIV. As a result of public comments, however, the SSA determined that changes might be appropriate, and invited further comments and suggestions on how to update and revise the listings for HIV through an Advance Notice of Proposed Rulemaking.⁵³

Currently, an individual with HIV infection may be found disabled under listing 14.08. Documentation of HIV infection must be provided, and must include "laboratory evidence" or "other generally acceptable methods consistent with the prevailing state of medical knowledge and clinical practice." Laboratory tests used to satisfy the listing standard of documentation include HIV antibody tests, positive "viral load" tests, HIV DNA detection by polymerase chain reaction, a specimen that contains HIV antigen, a positive viral culture for HIV from peripheral blood mononuclear cells, and other tests "that are highly specific for detection of HIV and that are consistent with the prevailing state of medical knowledge." Other acceptable documentation of HIV provided without the definitive laboratory evidence must also be consistent with the prevailing state of medical knowledge and clinical practice, and must be consistent

^{52.} Revised Medical Criteria for Evaluating Immune System Disorders, Final Rules, 73 Fed. Reg. 14,409 (March 18, 2008).

^{53. 73} Fed. Reg. 14,583.

^{54. 20} C.F.R. § 404, Subpart A, Appendix 1, 14.00F(1)(a)-(b).

^{55.} Id. at 14.00F(1)(a)(i)-(vi).

with other evidence in the case record.⁵⁶ To meet listing-level requirements for HIV, the medical evidence must also include documentation of the manifestations of HIV.⁵⁷

Listing 14.08 for HIV infections requires documentation of the condition and one of the following: bacterial infections; fungal infections; protozoan or helminthic infections; viral infections; malignant neoplasms; conditions of the skin or mucous membranes; HIV encephalopathy; HIV wasting syndrome; diarrhea; other infections that are either resistant to treatment or that require hospitalization or intravenous treatment three or more times in a twelve-month period; or "repeated" manifestations of HIV infections that result in significant, documented symptoms or signs (for example, severe fatigue, fever, malaise, involuntary weight loss, pain, night sweats, nausea, vomiting, headaches, or insomnia) and one of the following at the "marked" level: limitation of activities of daily living, limitation in maintaining social functioning, or limitation in completing tasks in a timely manner due to deficiencies in concentration, persistence, or pace.⁵⁸

The terms "repeated" and "marked" are defined in the regulations. The term "marked" means "more than moderate but less than extreme" and may arise if "several activities of function are impaired, or even when only one is impaired, as long as the degree of limitation is such as to interfere seriously with your ability to function independently, appropriately, effectively, and on a sustained basis." The term "repeated" means that the manifestations occur on an average of three times a year, or once every 4 months, each lasting 2 weeks or more; or the manifestations do not last for 2 weeks but occur substantially more frequently than three times in a year or once every 4 months; or they occur less frequently than an average of three times a year or once every 4 months but last substantially longer than

^{56.} Id. at 14.00F(1)(b). The documentation requirement for HIV confirms that a decreased CD4 count increases the susceptibility to opportunistic infection but that such a reduced CD4 count, while useful as supportive evidence along with clinical findings where there is not a definitive diagnosis of an opportunistic infection, does not alone establish a definitive diagnosis of HIV or document the severity of functional limitations of HIV. Id. at 14.00F(2).

^{57.} Id. at 14.00F(3)-(5).

^{58. 20} C.F.R. § 404, Appendix 1 to Subpart P, 14.08 A-K.

^{59. 20} C.F.R. § 404, Appendix 1 to Subpart P, 12.00.

2 weeks. Your impairment will satisfy this criterion regardless of whether you have the same kind of manifestation repeatedly, all different manifestations, or any other combination of manifestations; for example, two of the same kind of manifestation and a different one. You must have the required number of manifestations with the frequency and duration required in this section. Also, the manifestations must occur within the period covered by your claim.⁶⁰

As a result of comments and suggestions received in response to the Advance Notice of Proposed Rulemaking, the SSA hosted, on September 10, 2008, a one-day conference, titled "HIV Infection in the Disability Programs," to receive expert opinions regarding evaluation of HIV by the SSA and how the overall process can be improved.

The conference included presentations by physicians, hospital directors, and legal aid and education groups. Conference presenters spoke about the history of HIV infection, listing-level requirements for HIV infection, ideas for the improvement of regulations related to HIV disability, the relation of HIV infection and mental health, and HIV infection in children and adolescents. Conference participants confirmed how the impact of HIV on functioning is unique to each patient, and remarked on how the conference was a positive step toward improving the disability process for individuals with HIV.

VII. PROCESS IMPROVEMENT FOR SPECIAL CONDITIONS

The SSA's disability determination process is logical for many frequently handled, well-known, and well-understood conditions. However, there are a significant number of cases that consider special or other conditions that are not as well-known or regularly considered by SSA ODAR adjudicators. For example, in a statement at a compassionate allowance outreach hearing on rare diseases in December of 2007, Stephen Groft, Pharm. D., Director of the National Institute of Heath Office of Rare Disease, confirmed that with approximately 7000 inherited or acquired rare diseases affecting between 25 to 30 million people in the United States, there is no one predictable pattern of progression of the disorders that may

^{60. 20} C.F.R. § 404, Appendix 1 to Subpart P, 14.00(I)(3).

eventually result in mental or physical disability.⁶¹ As a result, individuals with such special conditions who are seeking disability may experience delay and unwarranted denials.

Further challenges include instances where not all of the conditions that an individual is experiencing are identified at the onset of the application process; the lack of a standard form relating to a specific special condition to carefully document symptoms, related conditions, and limitations; physicians who are not specialists with specific knowledge of a special condition; lack of treatment due to socioeconomic and other factors; and doctors and other care providers who might not understand the SSA disability standard and who do not know what information to submit for the adequate analysis of a special condition.

In this section, the author recommends changes that the SSA could implement for people with special conditions, which would result in SSA ODAR adjudicators giving more focused attention to claims from individuals who are unresponsive to treatment, suffer from the combined impact of several conditions, or have special conditions that are not commonly handled on a regular basis by SSA adjudicators. There are several alternatives that SSA adjudicators could use to increase the efficiency with which such cases are They include using electronic tools to sort cases by diagnosis code or other relevant factors such as age; using specialized medical source statements in combination with SSA forms for special conditions to improve the probability of accurately assessing individuals with special conditions; allowing a cadre of attorneys or judges with special training to screen cases with special conditions; and continually considering ongoing advances in technology and treatment as they relate to special conditions to ensure the ongoing accurate screening and review of these cases.

^{61.} Compassionate Allowance Outreach Hearing on Rare Diseases: Hearing Before the Social Security Administration, 110th Cong. (2007) (statement of Stephen Groft, Pharm.D., Director, NIH Office of Rare Diseases), available at http://www.socialsecurity.gov/compassionateallowances/agenda1204.htm.

A. Sorting by Diagnosis Code: Chicago Adjudication Screening Tool Pilot Program

SSA adjudicators could dramatically improve workload management through the use of sophisticated electronic screening tools. While the SSA is in the early stages of analyzing the characteristics of individuals who request hearings before ODAR adjudicators, the use of such technology during the prehearing review process could significantly improve case management at the hearing level. Use of such technology could streamline the prehearing review process, ensure accountability by requiring a record of the review, and simplify the hearing process when the record contains a prehearing review report with a summary of the record and reasons why the case was not decided prior to a hearing.

Regular processing of cases at the ODAR hearing level includes hearings. Due to the increase in requests for hearings, the high number of pending cases at the hearing level, and the projected increase in requests for hearings, in 2007, the SSA modified prehearing proceeding procedures. In undertaking this change, the SSA hoped to address the increased workload at the hearing level by deciding cases in a more efficient manner and processing cases without infringing on the right of an individual to a hearing. To do this, the agency published a rule that allows attorney advisors to conduct prehearing proceedings if "new and material evidence is submitted, there is an indication that additional evidence is available, there is a change in the law or regulations, or there is an error in the file or some other indication that a wholly favorable decision could be issued."

The SSA intended the amendment to the attorney advisor program to significantly reduce the high number of cases pending at the hearing level.⁶³ In September of 2008, Judge Ron Bernoski,

^{62.} Amendment to the Attorney Advisor Program, 72 Fed. Reg. 44,763 (Aug. 9, 2007) (interim final rule with request for comments). Senior attorney advisors, hearing office directors, supervisory attorney advisors, and attorneys in the regional offices at the GS-13 level and above were authorized to issue fully favorable decisions under the interim final rule.

^{63.} From November 1, 2007, through June 27, 2008, attorney adjudicators issued 17,254 decisions. Initiatives to Eliminate the Social Security Administration Hearing Backlog Status as of June 27, 2008, available at

President of the Association of Administrative Law Judges, noted support for this measure, noting specifically that such prehearing review by an attorney may narrow the issues of a case, lead to a settlement prior to hearing, or result in the resolution of the case prior to the case going to an administrative law judge, thus positively impacting the judge's docket and the disability case backlog.⁶⁴ As part of the SSA's ongoing effort to reduce the number of claims pending at the hearing level and issue timely, legally sufficient decisions, on July 13, 2009, the SSA extended, for two years, the rule authorizing attorney advisors to conduct certain prehearing procedures and issue fully favorable decisions.⁶⁵

To determine if fully favorable decisions can be rendered, adjudicators, including some attorney advisors, can screen cases that are referred to them from representatives, claimants, or staff as potentially fully favorable decisions. Adjudicators also receive cases to screen after case intake into a hearing office. The cases are chosen for screening based on specified profiles that may include the age, education, vocational history, and condition of the individual filing a request for hearing. Where enough evidence exists to support a finding of disability, an adjudicator issues a favorable decision without waiting for a hearing, thus saving the individual, as well as the SSA, the time and money required to complete a hearing process.

To further improve the speed and quality of the ODAR disability hearing process, under the leadership of Regional Chief Administrative Law Judge, Paul C. Lillios, the Chicago Adjudication Screening Tool (CAST) was developed to efficiently identify cases for potential adjudication at the earliest opportunity. Data available through CAST included commonly implemented adjudicator screening criteria, and allowed for adjudicators to run searches based on an individual's age, initial determination date, and many other

http://www.ssa.gov/legislation/BacklogStatus071808.pdf. In February of 2009, the Office of the Chief Administrative Law Judge issued a new attorney adjudicator worksheet for attorney adjudicators to complete when unable to issue fully favorable decisions, in order to reduce subsequent time screening cases.

^{64.} Testimony Before the Subcomm. on Social Security of the H. Comm. on Ways and Means, 110th Cong., (2008) (statement of J. Ron Bernoski, President, Association of Administrative Law Judges),, available at http://waysandmeans.house.gov/hearings.asp?formmode=view&id=7390.

^{65.} Attorney Advisor Sunset Date Extension, 74 Fed. Reg. 33,3327 (July 13, 2009).

factors that can be tailored to workload needs. The tool also was designed to allow adjudicators to screen cases based on diagnosis code. Diagnosis codes identify and classify diseases and conditions numerically.

CAST was designed to provide the most comprehensive information available about cases in the SSA today. The tool allowed ODAR adjudicators to access critical information, regardless of their proficiency with spreadsheet use, to easily find relevant, upto-date, and accurate information. The data was in an easily understandable format that was simple to tailor to specific needs. This tool enhanced the ability of adjudicators, through a standardized practice, to determine prior to a hearing if a favorable disability determination could be rendered based on specific profiles and screening criteria.

In a study in the Detroit ODAR in December of 2008, CAST data revealed nineteen cases where HIV infection was the primary diagnosis code. Of those cases, four, or twenty-one percent, were found eligible for payment. Two individuals were found to meet listing 14.08 and two individuals were found disabled at step five of the sequential evaluation process after being found unable to do other work.

The CAST study in the Detroit ODAR was brief but indicates that future use of such an electronic screening tool could benefit individuals with special conditions who have filed for disability by allowing for screening for possible fully favorable decisions by diagnosis code. In the two cases in which individuals were found disabled at step five of the evaluation process as unable to do other work, one individual was an older individual who had lost about twenty-five percent of his body mass and another had complications related to HIV infection and postpolio sequelae. In the two cases in which individuals were found to meet the listing requirements, both individuals met the requirements of listing 14.08 due to marked limitation in activities of daily living or the ability to maintain concentration, persistence, or pace due to symptoms including fatigue, diarrhea, and gastrointestinal problems. The allegations of the individuals in these cases were supported by treatment notes from treating sources and were further supported, in one case, by accompanying family member confirmation of ongoing problems.

The results of the study of case screening by diagnosis code using CAST are consistent with results of the SSA Chicago Office of

Quality Performance (OQP) screening unit. Since March 31, 2008, that office has been screening ODAR cases in order to identify possible fully favorable decisions that do not require hearings. As of mid-September 2008, the screening unit had reviewed over 880 cases. Of those cases, 198, or 22.5%, resulted in fully favorable decisions.⁶⁶

As a result of its success on a regional level, CAST was recently approved for use as a national disability adjudication reporting tool. These tools, maintained by the SSA's Division of Information Technology and Integration, contain data extracted daily from hearings and appeals data and case processing management system data. Adjudicators at the hearing level can now use the Division of Information Technology and Integration's screening tool to screen for cases in a specific hearing office based on hearing request date, age of claimant, diagnosis code, education, alleged onset date of disability, and other factors. The Detroit CAST study confirms that it is effective to search by diagnosis code for individuals with special conditions in order to prevent individuals with these chronic conditions from waiting unnecessarily for a hearing.

B. Using Specialized Medical Source Statements for Prehearing Review of Special Conditions

Adjudicators may consider medical opinions when making disability determinations.⁶⁷ Medical source statements may contain medical opinions submitted by acceptable medical sources.⁶⁸ These statements, based on a source's treatment records and examinations of an individual, are opinions about an individual's physical and/or mental abilities to perform work-related activities on a sustained basis. A medical source statement of the ability of an individual to do physical work-related activities requests an opinion regarding an individual's ability to lift/carry, sit/stand/walk, use the hands and feet, climb, balance, stoop, kneel, crouch, crawl, hear, see, and work

^{66.} State of the Region-Chicago Fiscal Year 2008, Social Security Administration, Office of Disability Adjudication and Review, Nov. 2008, p. 4.

^{67. 20} C.F.R. § 404.1527(a)(2); 20 C.F.R. § 416.927(a)(2).

^{68.} Acceptable medical sources are licensed physicians, licensed or certified psychologists, licensed optometrists, licensed podiatrists, and qualified speech-language pathologists. 20 C.F.R. § 404.1513(a); 20 C.F.R. § 416.913(a).

around certain environmental conditions.⁶⁹ Administrative findings regarding whether an individual is disabled or unable to work are reserved to the Commissioner. However, adjudicators must evaluate all the evidence in the case record, including statements by the individual and others about the impairment and how it affects the individual's functioning, and must weigh medical source statements to determine the extent to which the opinion is supported by the record.⁷⁰

Generally, opinions from treating sources receive more weight due to the ability of such a source to provide a longitudinal record and comprehensive perspective on an individual's medical condition. Further, treating source opinions may be given controlling weight if the opinion is well supported and not inconsistent with other evidence in the record.⁷¹ Thus a medical statement from such a source can be quite helpful to an adjudicator, especially in the case of an individual with a special condition.

In the current disability process, SSA adjudicators also consider SSA disability reports and function reports when making disability determinations. These agency forms are used to request information from an individual about his or her illnesses, injuries, and conditions and how they affect the individual; work history; medical records; medications; tests; education; proficiency with the English language; and daily activities.⁷² Adjudicators might also be asked to consider

^{69.} An example of a medical source statement of an individual's ability to do physical work-related activities can be found in Social Security Administration Form HA-1151-BK, available at http://www.dshs.wa.gov/pdf/ccs/RFQ0735-256K.pdf.

^{70. 20} C.F.R. § 404.1512 and 1527(a), (b), (d); 20 C.F.R. § 416.912 and 927(a), (b), (d); Policy Interpretation Ruling Titles II and XVI: Medical Source Opinions on Issues Reserved to the Commissioner Social Security Ruling 96-5p (1996), http://www.ssa.gov/OP_Home/rulings/di/01/SSR96-05-di-01.html; 20 C.F.R. § 404.1527(d)(2); 20 C.F.R. § 416.927(d)(2).

^{71. 20} C.F.R. § 1527(d)(2); 20 C.F.R. § 416.927(d)(2).

^{72.} See Disability Report – Adult, Form SSA-3368-BK, available at http://www.ssa.gov/online/ssa-3368.pdf; Function Report – Adult, Form SSA-3373-BK, available at http://www.disabilitydoc.com/storage/ssa3373-Function%20Report-Adult.pdf. The SSA-3373-BK asks questions about where an individual lives; and whether the individual cares for others, cares for pets, requires assistance for caring for others, has personal care problems, needs special reminders, can prepare meals and do house and yard work, drives, uses public

special forms when they consider a case where an individual is experiencing conditions such as asthma or epilepsy. These forms request specific, detailed information from an individual about his or her condition, treatment, and medications to help adjudicators determine the severity and limiting effects of the condition. The current medical report form used by the SSA for individuals with allegations of HIV infection requests information on how the HIV infection was diagnosed, opportunistic and indicator diseases, and other manifestations of HIV infection.⁷³

The generalized medical source statement, disability report, and function report forms used by the SSA today may miss some problems and symptoms related to HIV infection, or other special conditions. Specialized medical source statements that improve the probability of accurately assessing individuals with special conditions, used alone or in combination with the SSA's medical report on HIV, will improve the prehearing review process for cases in which HIV infection is a condition. The wider dissemination and use of a specialized medical source statement and the SSA's medical report on HIV will further improve this process.

The SSA may consider the use of a specialized medical source statement that is based on more detailed criteria for measuring quality of life and functional abilities to further improve its adjudicatory Such criteria have proved useful in oncology, where performance status measures help to quantify a cancer patient's general well being. These measures are scales of objective criteria for measuring quality of life in individuals with incapacitating disease. Quality of life is the degree to which a person is able to function at a usual level of activity without or with minimal compromise of routine activities. With cancer patients the measurement helps to determine whether a person can receive chemotherapy, if the adjustment of doses of medication is necessary, and to improve quality of life. The most generally-used scoring systems are the Karnofsky score and the Zubrod score. The Zubrod score is used in World Health Organization (WHO) publications.

transportation, shops, handles money, has hobbies and interests, and participates in social activities.

^{73.} Medical Report of Adult with Allegation of Human Immunodeficiency Virus (HIV) Infection, Form SSA-4814-F5, available at http://www.legisit.com/forms/SSA-4815-F5.pdf.

The Karnofsky score runs from 100 to 0. In this system, 100 is "perfect" health and 0 is death. It is named after Dr. David A. Karnofsky, who described the scale with Dr. Joseph H. Burchenal in 1949:⁷⁴

- 100 Normal, no complaints, no signs of disease.
- 90 Capable of normal activity, minor signs or symptoms of disease.
- 80 Normal activity with effort; some signs or symptoms of disease.
- 70 Cares for self; unable to carry on normal activity or to do active work.
- 60 Requires occasional assistance but is able to care for most needs.
- 50 Requires considerable assistance and frequent medical care.
- 40 Disabled; requires special care and assistance.
- 30 Severely disabled; hospitalization is indicated but death not imminent.
- 20 Very sick; hospitalization necessary; active supportive treatment necessary.
- 10 Moribund; fatal processes progressing rapidly.
- 0 Dead.

At 100, a person is able to carry out normal activity and can work, and needs no special care. At 70, a person is unable to work, but is able to live at home, care for most personal needs, and requires a varying degree of assistance. At 40, a person is unable to care for himself, and requires the equivalent of institutional or hospital care.

The Zubrod score, named after C. Gordon Zubrod, and also called the WHO or Eastern Cooperative Oncology Group (ECOG) score, runs from 0 to 5, with 0 denoting perfect health and 5 death:⁷⁵

• 0 - Asymptomatic (fully active, able to carry on all predisease activities without restriction).

^{74.} D.A. Karnofsky & J.H. Burchenal, The Clinical Evaluation of Chemotherapeutic Agents in Cancer in EVALUATION OF CHEMOTHERAPEUTIC AGENTS, 196 (C.M. MacLeod ed.) (1949), available at http://www.acsu.buffalo.edu/~drstall/karnofskyoriginal.html.

^{75.} M.M. Oken et al., Toxicity and response criteria of the Eastern Cooperative Oncology Group, 5 Am. J. CLIN. ONCOL. 6, 649-55 (1982).

- 1 Symptomatic but completely ambulatory (restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature. For example, light housework, office work).
- 2 Symptomatic, <50% in bed during the day (ambulatory and capable of all self care but unable to carry out any work activities. Up and about more than 50% of waking hours).
- 3 Symptomatic, >50% in bed, but not bedbound (capable of only limited self-care, confined to bed or chair 50% or more of waking hours).
- 4 Bedbound (completely disabled; cannot carry on any self-care; totally confined to bed or chair).
- 5 Death.

A comparison between the Zubrod and Karnofsky scales has been validated in a large sample of patients:⁷⁶

- Zubrod 0 equals Karnofsky 100; 90-100
- Zubrod 1 equals Karnofsky 80-90; 70-80
- Zubrod 2 equals Karnofsky 60-70; 50-60
- Zubrod 3 equals Karnofsky 40-50; 30-40
- Zubrod 4 equals Karnofsky 20-30;10-20

The WHO has also developed a staging system for HIV disease based on clinical symptoms, which may be used to guide medical decision making. This system is effective in resource-poor communities, where medical facilities are sometimes poorly equipped, and it is not possible to use CD4 and viral load test results to determine the right time to begin antiretroviral treatment:⁷⁷

- Clinical stage I is asymptomatic HIV with noted persistent generalized lymphadenopathy.
- Clinical stage II includes moderate unexplained weight loss (under 10% of presumed or measured body weight), recurrent respiratory tract infections (sinusitis, tonsillitis,

^{76.} G. Buccheri et al., Karnofsky and ECOG performance status scoring in lung cancer: a prospective, longitudinal study of 536 patients from a single institution, 32A EUR, J. CANCER 7, 1135-41 (1996).

^{77.} World Health Organization, Interim WHO Clinical Staging of HIV/AIDS And HIV/AIDS Case Definitions for Surveillance (2005) http://www.who.int/hiv/pub/guidelines/clinicalstaging.pdf; AVERTing HIV and Aids, *The Different Stages of HIV Infection*, http://www.avert.org/stages-hivaids.htm (last visited Oct. 11, 2009).

- otitis media, pharyngitis), herpes zoster, angular cheilitis, recurrent oral ulceration, papular pruritic eruptions, seborrhoeic dermatitis, and fungal nail infections.
- Clinical stage III includes unexplained severe weight loss (over 10% of presumed or measured body weight); unexplained chronic diarrhea for longer than one month; unexplained persistent fever (intermittent or constant for longer than one month); persistent oral candidiasis; oral hairy leukoplakia; pulmonary tuberculosis; severe bacterial infections (e.g. pneumonia, emphysema, pyomyositis, bone or joint infection, meningitis, bacteraemia); acute necrotizing ulcerative stomatitis, gingivitis or periodontitis; and unexplained anemia (below 8 g/dl), neutropenia (below 0.5 billion/l) and/or chronic thrombocytopenia (below 50 billion/l).
- Clinical stage IV includes HIV wasting syndrome. pneumocystis pneumonia, recurrent severe bacterial pneumonia, chronic herpes simplex infection (orolabial, genital or anorectal of more than one month's duration or visceral at any site), oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs), extrapulmonary tuberculosis, Kaposi's sarcoma, cytomegalovirus infection (retinitis or infection of other organs), central nervous HIV toxoplasmosis. encephalopathy, extrapulmonary cryptococcosis including meningitis, disseminated nontuberculous mycobacteria infection, progressive multifocal leukoencephalopathy, chronic cryptosporidiosis, chronic isosporiasis. disseminated mycosis (extrapulmonary histoplasmosis, coccidiomycosis), recurrent septicaemia (including non-typhoidal Salmonella), lymphoma (cerebral or B cell non-Hodgkin), invasive cervical carcinoma, atypical disseminated leishmaniasis, and symptomatic HIVassociated nephropathy or HIV-associated cardiomyopathy.

A specialized medical source statement relating to the specific symptoms of a special condition could improve the probability of accurately assessing the condition of an individual with such a condition. Such a form should allow an individual who has filed for disability, or a medical source that is treating the individual, to specifically note medical conditions that allow an adjudicator to more easily assess functional abilities and general well being. Using HIV

infection as an example, for ease of completion and consideration, a form should contain a checklist of various conditions associated with HIV infection that are relevant to a disability determination the listing step of the sequential evaluation process. The conditions listed in the WHO HIV guidelines and the Social Security Administration's current medical report form for HIV infection would be helpful in this regard.

An acceptable medical source can also offer an opinion regarding an individual's physical capacity for work. A section of a specialized medical source form could ask the source to give an opinion regarding the ability of the individual to perform sustained work. This is defined as work on a regular and continuous basis, i.e., eight hours per day, five days per week, or an equivalent work schedule. The source could check whether an individual can perform very heavy, heavy, medium, light, sedentary, less than sedentary work; and note if the individual is unable to perform even sedentary work. The source should note the basis for the conclusion, i.e., observations of the individual, a review of the medical history, or consultation with other health care providers; and should note the length of time the individual has been at the listed level of functioning and the period of treatment.

If the records do not sufficiently clarify the question of whether the individual is disabled under the Act, an acceptable medical source can be asked to give an opinion regarding an individual's remaining work-related capabilities. An acceptable medical source can give an opinion regarding an individual's judgment, ability to concentrate and follow instructions, stamina, endurance, mobility inside and outside the home, emotional volatility, and cognitive difficulties; and can note whether an individual has trouble with restricted functioning and needs help with activities of daily living. An acceptable medical source can also be asked to give an opinion regarding an individual's symptoms and problems, commenting specifically about the severity and duration of the symptoms, and whether the severity and duration of reported symptoms are proportionate to the expected severity and duration of the medically determinable impairment. The opinion can report whether the condition of the individual would cause the individual to miss two or more work days of work per month because of the individual's conditions; would limit the individual's ability to reliably adhere to a work schedule; would limit the individual's ability to perform full time work; or would require the individual to seek assistance for personal care, shopping, meal preparation, or household help.

A specialized medical source statement should include queries regarding the changes the individual has experienced in the way his or her body is working, pain, body appearance, the ability to perform self care, appetite, work-like activities, and changes made to compensate for health changes. The statement should also identify potential barriers to adherence such as substance abuse, low literacy, mental health considerations, and lack of prescription drug coverage; and include a checklist for adverse effects from medications. An example of such a specialized medical sources statement, relating specifically to HIV, is available in Appendix A. The form is based on the Social Security Administration Form SSA-4814-F5, Medical Report on Adult With Allegation of Human Immunodeficiency Virus (HIV) Infection, and allows an acceptable medical source to report an opinion regarding the capacity of an individual to perform sustained work and the general well being of an individual based on WHO standards; identify signs, symptoms, and opportunistic infections; and confirm the severity of symptoms and the length of treatment.

Specialized medical sources statements from acceptable medical source may be particularly helpful when adjudicators consider cases relating to special conditions, especially if the statement is from a treating source who has treated an individual for a sufficient length of time, and often enough, to be aware of an individual's longitudinal history and of the overall medical record.⁷⁸ Having such a statement in the record when considering a case where an individual has a special condition would allow an adjudicator, at a glance, to take into

^{78. 20} C.F.R. § 404.1502, § 404.1513; Titles II and XVI: Considering Opinions and Other Evidence from Sources Who Are Not "Acceptable Medical Sources" in Disability Claims; Considering Decisions on Disability by Other Governmental and Nongovernmental Agencies, Social Security Ruling 06-03p, available at http://www.socialsecurity.gov/OP_Home/rulings/di/01/SSR2006-03-di-01.html. An acceptable medical source may provide medical treatment and evaluation in an ongoing relationship with an individual involving treatment and evaluation of a type and frequency that is typical for the condition of the individual. Under SSA regulations, if the opinion of a treating source on the issues of the nature and severity of the individual's impairments is well supported by medically acceptable clinical and laboratory diagnostic techniques, and not inconsistent with the other substantial evidence in the record, then it will be given controlling weight. 20 C.F.R. § 404.1527(d)(2).

account an individual's underlying conditions, concomitant medications, and history of drug intolerance and other issues. Such a statement would also help an adjudicator consider, in a case where an individual has HIV infection, whether that individual faces ongoing limitations despite the selection of a medication regimen that seeks to maintain viral suppression, improved immune function, and general well being.

In an Adult Function Report Form (SSA-3373-BK) in a case in the CAST study, one individual reported no problems with personal care, no need for special reminders to take medication, no problems with meal preparation, that he went outside as often as possible, and no problems with shopping or money. The form contained many "I don't know" answers. In contrast, a review of the individual's treating source opinion form, which was specifically crafted by a representative to focus on HIV, revealed significant issues related to poor judgment, stamina, endurance, cognitive difficulties, restricted social functioning, and restricted ability to maintain activities of daily living. The treating source, in fact, recommended that the individual needs a home chore provider to assist with cooking, cleaning, laundry, shopping, and household chores.

Specialized medical source statements used in conjunction with SSA forms that clarify the limitations and needs of individuals with special conditions will enhance the ability of ODAR adjudicators to assess these difficult cases. Creating and updating forms sent to acceptable medical sources that treat individuals with special conditions can emphasize to medical sources the need for clarification to ensure information is not misconstrued and will ensure that decisions are not made based on apparent inconsistencies. Given the technological advances now available, the SSA could offer such a form electronically to make the form more accessible and easier to complete. This would allow for the improved assessment of cases of individuals with special conditions.

C. Training, and the Review of Special Conditions Regionally or Nationally

Transferring cases with special conditions may allow the SSA to focus resources to enhance the assessment of these cases. The SSA recently began to transfer cases between offices to redistribute the workloads and more efficiently process cases. For example, in

February of 2008, the Office of the Chief Administrative Law Judge (OCALJ) announced the Service Area Realignment and permanent case transfers plan. Under this plan, offices with large backlogs transfer new hearing requests and unscheduled pending cases to hearing offices that are more quickly able to process the cases. This plan helps the most heavily impacted hearing offices to more efficiently processing their workloads.⁷⁹ The SSA plans to continue this transfer activity in fiscal year 2009 and may expand the program in the future to assist other hearing offices.

The SSA is also addressing the backlog in hearing offices throughout the nation with National Hearing Centers. During fiscal vear 2008, the National Hearing Center in Falls Church, Virginia, assisted the Chicago Region by holding hearings on Detroit and Cleveland cases. The strategy behind National Hearing Centers is to address the hearings backlog and reduce case processing time by increasing adjudicatory capacity. In fiscal year 2009, the Falls Church National Hearing Center will assist the Flint and Indianapolis hearing offices. In a statement to the United States House of Representative Committee on Ways and Means on September 16. 2008, Frank Cristaudo, Chief Administrative Law Judge of the SSA. confirmed the positive feedback from individuals using that National Hearing Center. 80 To further address the hearing backlog, the SSA is building additional national hearing centers throughout the country, including one that opened recently in Albuquerque, New Mexico. 81

Similarly, the SSA could increase the effective consideration of cases involving special conditions by focusing the consideration of

^{79.} For example, prior to the implementation of this plan, the number of cases pending in the Chicago Region exceeded 1,000 cases per ALJ. In contrast, cases pending in the Boston Region were less than 300 per ALJ. Transferring the cases allowed the Chicago Region to transfer out over 25,000 cases, lowering the pending case number to fewer than 800 per ALJ in the Chicago Region for fiscal year 2008.

^{80.} Testimony Before the Subcomm. on Social Security of the H. Comm. on Ways and Means, 110th Cong., (2008) (statement of Frank A. Cristaudo, C.A.L.J., Office of Disability Adjudication and Review, Social Security Administration), available

http://waysandmeans.house.gov/hearings.asp?formmode=printfriendly&id=7384 81. Press Release, Commissioner Astrue & Senator Bingaman, Social

Security Administration, Tour New National Hearing Center in Albuquerque (April 15, 2009) http://www.socialsecurity.gov/pressoffice/pr/albuquerqueNHC-pr.htm.

these cases to a limited number of hearing offices throughout a region or the nation. Currently, each hearing office receives cases based on geographical region and the physical address of the individual seeking benefits. Adjudicators consider a wide variety of conditions, and very often without the benefit of the medical expertise of a physician during the hearing process. Adjudicators may complete determinations on certain conditions on a regular basis—disorders of the back, affective disorders, diabetes, and asthma come to mind—but may consider other conditions only a few times throughout the course of a fiscal year. There are a large number of medical conditions, both physical and mental; voluminous medical records accumulated by the time a case reaches the hearing level; and a push each year for adjudicators and other SSA employees to increase their productivity.

Allowing the review of such cases regionally or nationally would allow a limited number of adjudicators with expertise on certain conditions to process those cases more effectively than could be done with less expertise in a general hearing office. HIV infection is an example of a special condition that is complex: it affects individuals differently, and has a wide and evolving array of treatment modalities. Thus, appropriate training and experience, as well as continuing medical education, are important components in adequately considering cases where individuals have a special condition such as HIV infection.⁸²

^{82.} A specialty office or offices considering special conditions would benefit from specialized training and guidance on the conditions under consideration as well as, at the outset, a review of the rules regarding the weight given to treating physician opinions, the role of non-physician evidence, the evaluation of mental impairments, pain, and other subjective symptoms as they relate to HIV. A review could include information on relevant Social Security Rulings such as 85-15 (nonexertional impairments/capability to work), 99-2 (chronic fatigue), 02-2 (interstitial cystitis), 03-2 (reflex sympathetic dystrophy), 06-3 (evidence that must be used to establish medically determinable impairments and evidence to be considered to evaluate the nature and severity of the impairment). Training could also include guidance related to HIV psychiatry. Clinical experience and research provide substantial evidence that HIV directly infects the brain. The involvement of psychiatrists in the diagnosis and treatment of individuals with HIV/AIDS is important because of the prevalence of HIV-related neuropsychiatric complications and psychiatric comorbidity for individuals with HIV. American Psychiatric Psychiatry: APA HIV Program http://www.psych.org/Resources/OfficeofHIVPsychiatry.aspx. Helpful training for

ODAR adjudicators with specialized knowledge can more easily understand a complicated disorder where diagnoses may be based more on symptom-based, clinical observation than test results. Just as primary care providers without HIV experience, such as those in rural areas, should identify experts in the region who will provide consultation when needed, SSA adjudicators considering these special cases should be able to seek consultation when needed. HIV is a lifelong infection that can require treatment through several stages of growth and development. Thus, cases in which HIV infection is a condition require flexibility to appropriately consider individuals who—while they share the same condition—may have fundamental differences with unique biomedical and psychosocial considerations.

With its new electronic system, the SSA can automatically and precisely organize cases for faster processing. Functioning in the electronic environment allows the SSA to store data in a centralized and secure repository, reduce the time it takes to send and receive information, minimize manual actions, eliminate the need to handle and store voluminous paper files, automatically create exhibit lists, provide online access to hearing notices, reduce the possibility of processing and closing a case without resolving outstanding issues, automate the mailing of decisions, and facilitate review of the evidence. The system would easily accommodate the consideration of cases with special conditions on a regional or national basis, which could result in a more efficient and effective process for handling these cases.

The SSA recently reinstituted an attorney adjudicator program, which allows the SSA's most experienced ODAR attorneys to spend a portion of their time making disability decisions in cases where enough evidence exists to issue a favorable decision without waiting for a hearing. Allowing qualified ODAR attorneys to assist with the processing of cases with special conditions on a regional or national basis would help to concentrate the knowledge for the special cases with certain capable individuals. It would also allow the ODAR Administrative Law Judges to focus on their regular docket of pending cases.

specific conditions is already available to ODAR adjudicators at http://training.ba.ssa.gov/ot/.

An example of how such a process might be effective is the Chicago Region's Office of Quality Performance (OQP) screening unit. The unit began screening ODAR cases in March of 2008, focusing on cases with characteristics such as an individual's age, basis for denial at the initial determination level, and condition. The goal of screening is to identify possible on-the-record decisions. The unit, trained by the Chicago ODAR Regional Office, is staffed with ten employees and reviews cases from backlogged Michigan offices. An ODAR Senior Attorney sits with case examiners and serves as a resource person and issues decisions. The Chicago ODAR Regional Office also provides ongoing mentoring for the examiners, as well as consultation on individual cases. Between March and mid-September of 2008, the screening unit reviewed over 880 cases, issuing fully favorable decisions in 198, or 22.5%, of the cases. Other OOP screening units have since been established throughout the country.

Modifications to the case processing system to allow for the review of special conditions regionally or nationally could allow for the effective, efficient processing of cases with special conditions. Allowing adjudicators with specific knowledge of special conditions could further enhance the decision making process. Such modifications could prevent resistance to or delayed favorable disability decisions resulting from knowledge deficits, stigma, or differences in evaluation styles, which would benefit individuals with special conditions who are seeking disability.

D. Consider Ongoing Advances in Technology and Treatment

While highly active antiretroviral therapy (HAART) can reduce an individual's viral load and may delay the progression of HIV, HIV persists even in individuals who are receiving aggressive antiretroviral therapy and have no readily detectable HIV in their blood. Factors such as age, genetic differences among individuals, the level of virulence on an individual strain of virus, and coinfection with other microbes may all affect the rate and severity of disease progression. However clearly drugs that fight infections

associated with HIV infection have improved and prolonged the lives of individuals infected with HIV.⁸³

Current treatment regimens involve taking several antiretroviral drugs each day from at least two different classes, some of which result in unpleasant side effects such as nausea, diarrhea, and vomiting. Complicated drug regimens, combined with significant side effects, may results in low adherence to the regimen. Also, antiretroviral drugs may cause more serious medical problems including metabolic changes such as abnormal fat distribution, abnormal lipid and glucose metabolism, and bone loss. Thus ongoing studies seek simpler, less toxic, and more effective drug regimens. New drugs in development to treat HIV infection include new protease inhibitors and more potent, less toxic RT inhibitors. Other drugs are in development and are being designed to interfere with entirely different steps in the virus' lifecycle. These new categories of drugs include:

- Entry inhibitors that interfere with HIV's ability to enter cells.
- Integrase inhibitors that interfere with HIV's ability to insert its genes into a cell's normal DNA.
- Assembly and budding inhibitors that interfere with the final stage of the HIV life cycle, when new virus particles are released into the bloodstream.
- Cellular metabolism modulators that interfere with the cellular processes needed for HIV replication.
- Gene therapy that uses modified genes inserted directly into cells to suppress HIV replication. These cells are designed to produce T cells that are genetically resistant to HIV infection.

In addition, scientists are exploring whether immune modulators help boost the immune response to the virus and whether they may

^{83.} NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES, DEPARTMENT OF HEALTH AND HUMAN SERVICES, HOW HIV CAUSES AIDS, at 5-6 (2004), available at http://www3.niaid.nih.gov/topics/HIVAIDS/Understanding/How+HIV+Causes+AIDS/.

^{84.} NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES, DEPARTMENT OF HEALTH AND HUMAN SERVICES, TREATMENT OF HIV INFECTION (2007), http://www.niaid.nih.gov/factsheets/treat-hiv.htm.

make existing anti-HIV drugs more effective. Therapeutic vaccines also are being evaluated for this purpose and could help reduce the number of anti-HIV drugs needed or the duration of treatment.⁸⁵

Antiretroviral therapy for treatment of HIV has improved steadily since the introduction of combination therapy. New drugs offer new mechanisms of action; improvements in potency; activity against multi-drug resistance viruses; and better dosing, convenience, and tolerability. Adherence to antiretroviral therapy strongly correlates with HIV viral suppression, reduced rates of resistance, and increase in survival, and an improved quality of life. As treatment for HIV infection evolves, the availability of new treatment agents and new clinical data may change therapeutic options and preferences for people with HIV infection. Guidelines thus should be updated frequently, and adjudicators must exercise good judgment in making decisions tailored to unique individual circumstances and in the ongoing review of cases to measure the success of any treatment received after a favorable disability decision.

VIII. CONCLUSION

In the 2008 fiscal year, requests for ODAR hearings increased and the agency lost experienced administrative law judges through attrition. During that same year, the SSA processed 575 thousand hearings and more than 2.6 million initial disability claims.⁸⁸ Despite ongoing challenges, the SSA made significant progress in implementing its initiatives to eliminate the hearing backlog and prevent its recurrence. By mid-year in fiscal year 2008, ODAR reported accomplishments that include a reduced number of aged cases, opening the National Hearing Center, hiring additional

^{85.} Id.

^{86.} NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES, DEPARTMENT OF HEALTH AND HUMAN SERVICES, GUIDELINES FOR THE USE OF ANTIRETROVIRAL AGENTS IN HIV-1-INFECTED ADULTS AND ADOLESCENTS 1 (2008), available at

http://aidsinfo.nih.gov/contentfiles/AdultandAdolescentGL.pdf.

^{87.} Id. at 92.

^{88.} SSA's Performance and Accountability Report for (FY) Fiscal Year 2008: Management's Discussion and Analysis, Social Security Administration 12, available at http://www.ssa.gov/finance/.

administrative law judges, transitioning seventy-five percent of the pending workload to electronic folders, and implementing a service area realignment plan. Regarding the Compassionate Allowances initiative, the Office of Retirement and Disability Policy developed and expanded the use of automated screening tools and continued to update agency rules and regulations to reflect advances in medical science.⁸⁹

In 2009, the SSA has continued to make significant progress in reducing its backlog of cases at the ODAR hearing level. The SSA has continued to appeal to medical professionals and organizations for ways to improve its criteria for evaluating diseases and conditions so that the criteria reflect the real difficulties faced by people living with these diseases and conditions. On August 7, 2009, Deputy Commissioner David V. Foster confirmed in an agency broadcast that the SSA expects increased initial disability claims in 2010, and that ODAR is expected to expand its capacity to handle the additional projected receipts due to the recession. Mr. Foster noted further, however, that the disability backlog has decreased over 19,000 cases from the start of the year.

The SSA has made recent progress to improve the disability process for individuals with special conditions. Given the various strategies and potential future improvements available, the challenge for the SSA is to select the best options for ODAR hearing adjudicators, to best serve individuals who have filed for disability. The complexity of the conditions and the importance of new technology as it relates to treatment as well as the handling of cases at the ODAR hearing level require the SSA to seek novel ways to improve the process. Modifications will improve the process by which individuals are served at the hearing level. Ongoing energy directed in this way will further the mission of providing timely and

^{89.} OFFICE OF DISABILITY ADJUDICATION AND REVIEW, SOCIAL SECURITY ADMINISTRATION, PLAN TO ELIMINATE THE HEARING BACKLOG AND PREVENT ITS RECURRENCE, SEMIANNUAL REPORT 2 (Fiscal Year 2008), available at http://www.ssa.gov/disability/Semiannual_Report_FY08.pdf.

^{90.} For detailed information on a state-by-state basis on the progress that the SSA has made toward the reduction in cases at the ODAR hearing level, see Hearings Backlog Reduction Update Booklets, Fiscal Year 2009, Second Quarter, available at http://www.socialsecurity.gov/appeals/congressional-booklets.html.

legally sufficient hearings and decisions to individuals, and greatly and positively affect the individuals involved in these cases.

IX. APPENDIX A: SAMPLE FORM FOR HEALTH CARE PROVIDER - HIV INFECTION

Date: Claimant's Name: Claimants's Address:						· · · · · · · · · · · · · · · · · · ·	
		Provid				(please	
Health	Care	Provider	Addı	ress	and	Phone	Number

You are asked to give an opinion and information to assist the Social Security Administration in making a disability determination. In evaluating your patient's claim for disability benefits, we review the medical record for evidence of the presence and severity of the patient's medically determinable impairments. Where the medical record is not sufficiently clear, additional statements from treating health care providers such as you are especially relevant evidence upon which we can rely in determining eligibility for disability benefits. Your opinions and statements are important for our review, and we are grateful for your thoughtful and thorough consideration of these questions. Please be aware that your statements are only one part of the evidence that we consider in evaluating your patient's claim, and will be evaluated along with other evidence to assess your patient's medical condition and functional abilities. Your statements alone are not sufficient to cause us to either grant or deny benefits. But without your statements, we are unable to fully evaluate your patient's application. Thank you for your assistance.

You are asked to give an opinion regarding your patient's ability to performed sustained work. Sustained work is defined as work a regular and continuous basis, i.e., eight hours per day, five days per week, or an equivalent work schedule:

__Very Heavy Work. Frequent lifting and carrying of objects weighing 50 pounds or more. Requires standing or walking up to six hours of an eight-hour workday. Physical demands are in excess of those in Heavy Work category.

__Heavy Work. Frequent lifting or carrying of objects up to 50 pounds. Requires standing or walking up to six hours of an eight-hour workday. Physical demand requirements are in excess of those for Medium Work category.

__Medium Work. Frequent lifting or carrying of objects up to 25 pounds. Requires standing or walking up to six hours of an eight-hour workday. Physical demand requirements are in excess of those for Light Work category.

__Light Work. Frequent lifting or carrying of objects up to 10 pounds. Even though weight lifted may be very little, light work requires a good deal of walking or standing, off and on, for a total of approximately six hours in an eight-hour workday. To be considered capable of performing a full or wide range of light work, you must have the ability to do substantially all of these activities. If someone can do light work, that person could also do sedentary work, unless there are additional limiting factors such as loss of fine dexterity or inability to sit for long periods of time.

__Sedentary Work. Lifting objects up to 10 pounds at a time and occasionally lifting or carrying articles such as docket files, ledgers, and small tools, Being on one's feet is required occasionally. Although a sedentary job is defined as one that involves sitting, a certain amount of standing and walking is often necessary in carrying out job duties. Jobs are sedentary if walking and standing are required occasionally, but no more than two hours per eight-hour workday.

__Unable to perform even sedentary work on a regular and continuous basis, i.e., eight hours per day, five days per week, or an equivalent work schedule.

How long have you treated the patient?

How long has your patient's condition resulted in this level of functioning?

The Social Security Administration understands that HIV infection may result in opportunistic infection, as well as signs and symptoms that are related to or traceable to the disease or its treatment, but that are not accurately considered to be opportunistic

infection. Some of those signs and symptoms include severe fatigue, fever, malaise, weight loss, pain, night sweats, nausea, vomiting, headaches, insomnia, or diarrhea. Further, the Social Security Administration recognizes that HIV impacts the mental, emotional and cognitive health of those who are infected, and that individuals with HIV infection may suffer mental and emotional limitations in addition to physical limitations. Please identify signs or symptoms of HIV infection or its treatment that your patient exhibits or has been affected by, the estimated frequency of occurrence in the same 1-year period, and the approximate date of each episode. In forming your answer to this question, please consider your patient's condition from [date] to the present.

Please note further if your patient has the following:
Marked Limitation of Activities of Daily Living
Marked Limitation in Maintaining Social Functioning
Marked Limitation in Completing Tasks in a Timely Manne
due to Deficiencies in Concentration, Persistence, or Pace
Regarding his or her mental condition, please note specifically i
your patient has trouble with:
Responding appropriately to a task or problem
Racing thoughts
Understanding instructions
Poor focus
Processing instructions and performing accordingly
Sleep disturbance
Following appropriate steps to complete a task
Memory problems
Concentrating on a task until it is completed
Stamina/endurance
Completing tasks in a reasonable amount of time
Affective disorders
Poor judgment
Emotional volatility
Social isolation/restricted social functioning
Vision problems
Being easily overwhelmed
Irritability
Cognitive difficulties or loss of cognitive abilities

Dementia
Restricted daily activities/mobility/balance
Panic attacks/anxiety
_
Has your patient had any of these medical problems? Please note
treatment dates.
BACTERIAL INFECTIONS (14.08A)
1 MYCOBACTERIAL INFECTION, (e.g., caused by <i>M. avium-intracellulare</i> , <i>M. kansasii</i> , or <i>M. tuberculosis</i>), at a site other than the lungs, skin, or cervical or hilar lymph nodes, or pulmonary tuberculosis resistant to treatment; or 2 NOCARDOSIS; or
3 SALMONELLA BACTERIMIA, recurrent non-typhoid;
or
 MULTIPLE OR RECURRENT BACTERIAL INFECTION(S), including pelvic inflammatory disease, requiring hospitalization or intravenous antibiotic treatment 3 or more times in a 1-year period. FUNGAL INFECTIONS (14.08B)
1 ASPERGILLOSIS; or
2 CANDIDIASIS involving the esophagus, trachea, bronchi, or lungs, or at a site other than the skin, urinary tract, intestinal tract, or oral or vulvovaginal mucous membranes; or
3 COCCIDIOIDOMYCOSIS, at a site other than the lungs or
lymph nodes; or
4 CRYPTOCOCCOSIS, at a site other than the lungs (e.g., cryptococcal meningitis); or
5 HISTOPLASMOSIS, at a site other than the lungs or lymph
nodes
6 MUCORMYCOSIS; or
7. PNEUMOCYSTIS PNEUMONIA or extrapulmonary
Pneumocystis infection.
Protozoan or Helminthic Infections (14.08C)
1 CRYPTOSPORIDIOSIS, ISOSPORIASIS, OR
MICROSPORIDIOSIS, with diarrhea lasting for 1 month or
longer; or
2STRONGYLOIDIASIS, extra-intestinal; or
3 TOXOPLASMOSIS of an organ other than the liver, spleen,
or lymph nodes.

__ VIRAL INFECTIONS (14.08D)

- 1. __ CYTOMEGALOVIRUS DISEASE, at a site other than the liver, spleen, or lymph nodes; or
- 2. __ HERPES SIMPLEX VIRUS causing mucocutaneous infection (e.g., oral, genital, perianal) lasting for 1 month or longer; or infection at a site other than the skin or mucous membranes (e.g., bronchitis, pneumonitis, esophagitis, or encephalitis); or disseminated infection; or
- 3. __ HERPES ZOSTER, disseminated or with multideratomal eruptions that are resistant to treatment; or
- 4. _ PROGRESSIVE MUTIFOCAL LEUKOENCEPHALOPATHY.

__ MALIGNANT NEOPLASMS (14.08E)

- 1. __ CARCINOMA OF THE CERVIX, invasive, FIGO stage II and beyond; or
- 2. __ KAPOSI'S SARCOMA with extensive oral lesions; or involvement of the gastrointestinal tract, lungs, or other visceral organs; or
- 3. __ LYMPHOMA (e.g., primary lymphoma of the brain, Burkitt's lymphoma, immunoblastic sarcoma, other non-Hodgkin's lymphoma, Hodgkin's disease); or
- 4. __ SQUAMOUS CELL CARCINOMA OF ANAL CANAL OR ANAL MERGIN.

__ Skin or Mucous Membranes (14.08F)

CONDITIONS OF THE SKIN OR MUCOUS MEMBRANES, with extensive fungating or ulcerating lesions not responding to treatment (e.g., dermatological conditions such as eczema or psoriais, vulvovaginal or other mucosal *Candida*, condyloma caused by human *Papillomavirus*, genital ulcerative disease).

__ HIV ENCEPHALOPATHY (14.08G)

HIV ENCEPHALOPATHY, characterized by cognitive or motor dysfunction that limits function and progresses.

__ HIV WASTING SYNDROME (14.08H)

HIV WASTING SYNDROME, characterized by involuntary weight loss of 10 percent or more of baseline (computed based on pounds, kilograms, or body mass index (BMI)) or other significant involuntary weight loss; with either chronic diarrhea with 2 or more loose stools per day lasting for 1 month or longer; or chronic weakness and

documented fever greater than 38°C (100.4°F) for the majority of 1 month or longer.

__ DIARRHEA (14.08I)

DIARRHEA, lasting for 1 month or longer, resistant to treatment, and requiring intravenous hydration, intravenous alimentation, or tube feeding.

- __ INFECTIONS RESISTANT TO TREATMENT OR REQUIRING HOSPITALIZATION OR INTRAVENOUS TREATMENT 3 OR MORE TIMES IN A 12-MONTH PERIOD (14.08J)
 - 1. __ SEPSIS; or
 - 2. __ MENINGITIS; or
 - 3. __ PNEUMONIA; or
 - 4. SEPTIC ARTHRITIS; or
 - 5. __ ENDOCARDITIS; or
 - 6. __ SINUSITIS, documented by appropriate medically acceptable imaging.

Are the patients' complaints attributable to one or more medically determinable impairments? YES / NO

Is the severity and duration of the symptoms proportionate to the expected severity and duration of the medically determinable impairments? YES / NO

Is the severity of the symptoms and the effects on function consistent with the total medical and nonmedical evidence, including statements by the patient and others, your observations of the patient, and the patient's alteration of behavior or habits? YES / NO

Does the patient need a home care provider for help with personal hygiene or activities of daily living? YES / NO

You are asked to give an opinion regarding your patient's performance status measures help to quantify his or her general well being. At 100, a person is able to carry out normal activity and can work, and needs no special care. At 70, a person is unable to work, but is able to live at home, care for most personal needs, and requires a varying degree of assistance. At 40, a person is unable to care for himself, and requires the equivalent of institutional or hospital care.

100 - normal, no complaints, no signs of disease							
90 - capable of normal activity, minor signs or symptoms							
of disease80 - normal activity with effort; some signs or symptoms							
of disease							
70 - cares for self; unable to carry on normal activity or							
to do active work							
60 - requires occasional assistance but is able to care for							
most needs 50 - requires considerable assistance and frequent							
medical care							
40 - disabled; requires special care and assistance							
30 - severely disabled; hospitalization is indicated							
although death not imminent 20 - very sick; hospitalization necessary; active							
supportive treatment necessary							
10 - moribund; fatal processes progressing rapidly							
0 - dead							
Sources that form the basis of your conclusion:							
My observations of the patient							
My review of the patient's medical history							
Consultation with other treating health care providers							
Statements and complaints of the patient, whom I believe to be credible							
Other (please describe)							
Comments:							
SIGNATURE:							
PRACTICE AREA:							
PRINTED NAME:							
DATE:							