

January 20, 2011

BY FACSIMILE AND US MAIL

Michael J. Astrue  
Commissioner of Social Security  
Social Security Administration  
P.O. Box 17703  
Baltimore, Maryland 21235-7703

Re: Comments re Revising Medical Criteria for Evaluating HIV Infection: Response to the Institute of Medicine's *HIV and Disability: Updating the Social Security Listings*

Dear Commissioner Astrue:

We write to address *HIV and Disability: Updating the Social Security Listings*, the September 2010 report published by the Institute of Medicine (IOM) in response to a request from the Social Security Administration (SSA) for guidance on updating the listings covering HIV. Set forth below are our reactions to the IOM report and our suggestions for effectively implementing IOM's recommendations.

The undersigned organizations and individuals agree with IOM that the HIV listings must be changed to reflect important current medical knowledge surrounding HIV infection. Advances in the understanding and treatment of HIV have significantly altered how individuals may be evaluated and found disabled by SSA. We applaud IOM for addressing these changes and formulating many well-researched and thoughtful recommendations. We do, however, have some concerns with IOM's report, as well as the guidance SSA will provide to implement changes, and have outlined these issues below.

The organizations and individuals submitting these comments have extensive expertise in the area of HIV-related treatment and representation of HIV-positive claimants at every stage of SSA's disability determination process. Through our many years working in legal and multidisciplinary agencies specializing in the needs of people living with HIV, we have learned the difficulties commonly faced by HIV-positive claimants. In addition, many of us have become very familiar with advances in medical understanding of HIV infection.

Most of us have been involved since 2003 with SSA's efforts to revise the criteria it uses for evaluating disability claimants living with HIV infection. Joint comments related to the criteria for evaluating immune system disorders generally and HIV infection specifically were submitted on July 8, 2003 ([http://www.lambdalegal.org/in-court/legal-docs/ltr\\_ssa\\_20030708\\_proposed-rules-revising-medical-criteria-for-evaluating-immune-system-disorders.html](http://www.lambdalegal.org/in-court/legal-docs/ltr_ssa_20030708_proposed-rules-revising-medical-criteria-for-evaluating-immune-system-disorders.html)), October 3, 2006 ([http://www.lambdalegal.org/in-court/legal-docs/ltr\\_ssa\\_20061201\\_proposed-rules-revising-medical-criteria-for-evaluating-immune-system-disorders.html](http://www.lambdalegal.org/in-court/legal-docs/ltr_ssa_20061201_proposed-rules-revising-medical-criteria-for-evaluating-immune-system-disorders.html)), and on May 19, 2008

*([http://www.lambdalegal.org/in-court/legal-docs/ltr\\_ssa\\_20080519\\_comments-re-revisiting-medical-criteria-for-evaluating-hiv-infection.html](http://www.lambdalegal.org/in-court/legal-docs/ltr_ssa_20080519_comments-re-revisiting-medical-criteria-for-evaluating-hiv-infection.html)). Our ongoing involvement stems in large part from our concerns about the obstacles disabled people with HIV continue to encounter when seeking approval for Social Security disability benefits. This background informs the additional comments provided below, and we thank you for receiving them.*

**A. We support IOM's recommendation to completely restructure the HIV listing, but call for clear guidance to adjudicators not to rely solely on CD4 count or the list of fatal and/or severely disabling HIV-associated conditions.**

The IOM recommendations, if implemented, would fundamentally change the structure of the HIV infection listings. Essentially, a claimant would be able to qualify for disability under four main categories: (1) claimants with CD4 cell counts less than or equal to 50 cells/mm<sup>3</sup>; (2) claimants with one or more of several types of fatal and/or severely disabling conditions that occur in connection with HIV infection; (3) claimants with severe HIV-associated conditions that are not included elsewhere in the Listing of Impairments; and (4) claimants with severe HIV-associated conditions that are included elsewhere in the Listing of Impairments.

Medical advances have changed the methods of assessment and, indeed, the lives of many people with HIV, and IOM's recommendations would help create a system that more closely reflects the realities of this situation. We believe that these four categories fairly represent the multiple ways that a person with HIV infection can manifest a disability.

Granting benefits to claimants with CD4  $\leq$  50 would clearly streamline the approval process without being overbroad. At the same time, we urge that SSA disability examiners and adjudicators must not become overly reliant on CD4 counts. Clear instruction must be provided to explain that individuals with CD4 counts above 50 can and very frequently do suffer from debilitating HIV disease. CD4 numbers should only be used to expedite disabled individuals through the approval process and should never be used against individuals as a barrier or an obstacle to approval.

SSA must provide clear instruction to explain that the list of fatal and/or severely disabling conditions is not exhaustive. Our concern is based on the experience of encountering SSA disability examiners and adjudicators who are unwilling to look beyond a given list of conditions, even when the list is marked as non-exhaustive. If IOM's recommendations are implemented, SSA must direct adjudicators to consider all fatal and/or severely disabling conditions, not just the ones on the list.

**B. We agree with IOM's recommendation to preserve measures of functional capacity, but suggest expanding upon these measures, including a measure for multiple hospitalizations in one year.**

IOM recommends that "SSA should continue to include measures of functional capacity in the HIV Infection Listings and update these measures with research advances." The recommendation aims to preserve the three measures of functioning used in the current listings: (1) limitation of activities of daily living; (2) limitation in maintaining social functioning; and (3)

limitation in completing tasks in a timely manner due to deficiencies in concentration, persistence, or pace. These measures are used for determining disability of claimants who suffer from debilitating HIV-associated conditions without diagnoses or effects mentioned elsewhere in the Listing of Impairments.

We agree that it is extremely important to retain and reinforce the measures of functional capacity. Under IOM's recommended design, examiners and adjudicators may over-focus on CD4 counts and fatal conditions, thereby discounting claimants with severe HIV-associated conditions that are not imminently fatal and fall outside other listings.

As we expressed in our 2008 letter, we have always been concerned about the reliance of SSA disability examiners and adjudicators on objective evidence of manifestations of HIV infection, without sufficient recognition of impact. The Rule should state specifically that manifestations of HIV infection may be established in the absence of objective findings, based on the claimant's treating physician's assessment of the *impact* of impairments and manifestations of impairments of the claimant.

The listings should also offer stronger guidance on best practices for physicians to document manifestations of functional limitations, and how examiners and adjudicators should respond if a claimant's provider has not sufficiently documented these limitations. For example, we are concerned that claimants may have perceptible manifestations of HIV-associated neurocognitive disorders, but that their treating physicians may inadequately document their observations.

In addition to the listed examples of limited functioning (ability to perform activities of daily living; maintenance of social functioning; and completion of tasks in a timely manner due to deficiencies in concentration, persistence, or pace), SSA should add a provision specifying a range of "repeated hospitalizations" as an example of limited functionality.

**C. We believe that the HIV listings should not merely cross-reference HIV-associated conditions with listings elsewhere, as the IOM report suggests, but give specific guidance on specific coinfections.**

We commend IOM for recognizing and addressing that as individuals with HIV are living longer and undertaking newer treatments, comorbid conditions and coinfections are occurring with increased frequency. IOM recommends cross-referencing HIV-associated conditions that have listings elsewhere. Additionally, IOM recommends "if the literature is found to show that HIV coinfection causes changes to the disease not effectively captured in other disability listings, SSA *may want to consider* adding the disease to the HIV Infection Listings."<sup>1</sup>

We believe the directive must be strengthened. Merely cross-referencing HIV-associated conditions does not speak to the unique and compounded situation of being coinfecting with HIV and another disease. We strongly encourage SSA to create separate listings language explaining coinfections. The IOM report already includes important information regarding common comorbidities.<sup>2</sup> We believe it is essential for this information to be included, with specificity, in

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<sup>1</sup> IOM Report, page 6-6, emphasis added

<sup>2</sup> See IOM Report, Chapter 6.

the new HIV listings and guidance. Our concern is that by only cross-referencing comorbidities, examiners and adjudicators will overlook any information regarding the particular and additional implications of coinfection and focus on the stand-alone listing for the cross-referenced condition. For example, IOM provides a detailed explanation of the interaction between HIV infection, HIV treatments and Hepatitis infection.<sup>3</sup> IOM also suggests changes to be made to the Hepatitis listing. However, we believe that SSA must retain all of this information within the HIV listing itself, possibly in the guidance or the introduction.

If you have any questions or wish for clarification regarding any of the above comments, please contact Lambda Legal Deputy Legal Director Hayley Gorenberg (212-809-8585, [hgorenberg@lambdalegal.org](mailto:hgorenberg@lambdalegal.org)) on behalf of the undersigned. We look forward to a productive continuing discussion as the process moves forward.

Sincerely,

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<sup>3</sup> IOM Report, 6-4—6-5

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