HIV and Disability

Updating the Social Security Listings

By the end of 2010, the Social Security Administration (SSA) expects that more than 3.3 million individuals will have applied for disability benefits on the basis that they have a physical or mental impairment that prevents them from engaging in any substantial gainful activity. Given the complex issues involved and the importance of its decisions, SSA’s process for deciding whether applicants (claimants) qualify for disability benefits is both time and resource intensive. As one approach to streamlining the process, SSA uses a screening tool called the Listing of Impairments—known as the Listings—to identify claimants who are so severely impaired that they clearly cannot work at all and thus immediately qualify for benefits. For claimants who do not meet the Listings criteria, SSA requires additional, often extensive, information about vocational capacity and other factors, such as work history, education, and age, to decide on their claims. The Listings screen, therefore, provides many claimants with a rapid decision and saves SSA substantial administrative costs.

SSA currently organizes the Listings under 15 body systems, such as the neurological, musculoskeletal, and immune systems. Because of the key role the Listings play, it is important that they conform to advances in medical treatment and diagnostic methods and also to the changing nature of employment in the United States. Accordingly, SSA revises the Listings periodically. SSA asked the Institute of Medicine (IOM) to provide guidance on updating the Listing covering human immunodeficiency virus (HIV) infection, which can lead progressively to a number of serious medical conditions, including the advanced stage of infection termed acquired immunodeficiency syndrome (AIDS). SSA first began providing disability benefits for people with AIDS in...
ditions typically associated with aging. Taken together, the combination of having a complex disease that requires equally complex treatment can be disabling, potentially leaving individuals unable to function or conduct daily activities, including holding a job. Disability can result from the disease itself (for example, HIV-associated dementia) or from comorbid diseases such as cardiovascular disease or osteoporosis, as well as from the adverse effects of treating the disorders. The HIV Infection Listings need to be updated to take these new factors—promising in some ways, challenging in others—into account.

Revising the Listings

Among its specific recommendations, the report calls for revisions to the HIV Infection Listings to incorporate assessments of a claimant's work-related functional capacity. The committee determined that no single test is yet available to fully measure an individual's functional capacity, although there are many different tools that can measure individual components. In lieu of a single test of functioning, the committee looked for alternate medically or diagnostically based tactics for identifying claimants whose disabilities automatically qualify them for benefits. Based on the medical literature, the committee identified several categories under which claimants should be considered disabled:

- Claimants with CD4 cell count (a common laboratory marker of disease stage for HIV/AIDS patients) less than or equal to 50 cells/

### FIGURE 1: Recommended Adult and Child HIV Infection Listings

<table>
<thead>
<tr>
<th>Adult</th>
<th>Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>CD4 ≤ 50 cells/mm³</td>
<td>Age-appropriate CD4 count or percentage</td>
</tr>
<tr>
<td>Imminently fatal or severely disabling conditions</td>
<td>Imminently fatal or severely disabling conditions</td>
</tr>
<tr>
<td>HIV-associated conditions without listings elsewhere</td>
<td>HIV-associated conditions without listings elsewhere</td>
</tr>
<tr>
<td>HIV-associated conditions with listings elsewhere</td>
<td>HIV-associated conditions with listings elsewhere</td>
</tr>
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mm³. Because CD4 counts can change in response to antiretroviral therapy, claimants allowed disability in this way should be regularly reevaluated.

- Claimants with several types of severe or fatal conditions that occur in connection with HIV infection should be considered permanently disabled.
- Claimants with severe HIV-associated conditions that are not included elsewhere in the Listing of Impairments should be allowed disability if the condition is found to limit functioning. Claimants allowed in this way should be regularly reevaluated.
- Claimants with severe HIV-associated conditions that are included elsewhere in the Listing of Impairments should be allowed disability if their conditions qualify under the other listing. Claimants allowed in this way should be regularly reevaluated.

Improving Consistency Across Ages

When children receiving disability benefits turn 18 years of age, they need to reapply to sustain their benefits. The IOM report recommends that to allow for a smooth transition, the HIV Infection Listing used for children should follow as closely as possible to that for adults. However, conditions specific to children and not found in adults should be retained. Such child-specific conditions should include neurological manifestations of HIV infection and HIV-related growth disturbances, and age-appropriate CD4 cell counts should be used in determining disability.

Maximizing Utility

The IOM report identified a series of actions that SSA can take to maximize the utility of the HIV Infection Listings. For example, the introductory text that precedes the detailed listings helps guide interpretations of how the listings are implemented. However, this text is currently confusing, disjointed, and difficult to read. SSA should rewrite the introductory text with the aims of simplifying and reorganizing the text to address appropriate audiences.

Additionally, SSA collects data on each claim submitted, and evaluating these data can be important in identifying trends and patterns in the management and care of HIV infection. Such insight can help in detecting newly emerging clinical manifestations of HIV infection, assessing long-term adverse events of treatment, determining the consequences of nonadherence and resistance to HIV therapies, and informing future changes to the Listings. To aid in these efforts, SSA should revise its current policy of not making its data publicly available, as allowing wider access to outside groups and analysts could result in improving the timeliness and applicability of the HIV Infection Listings.
Conclusion

The SSA claims process for people infected with HIV once reflected an early belief that HIV infection would result very quickly in an opportunistic infection or malignancy and lead to death over a short period. Medical advances and constant scientific progress have rendered those ideas out of date, as people infected with the virus can live longer, and more medically complicated, lives. Today, disability in HIV-infected claimants can be more precisely identified by clinical markers and specific sets of medical conditions. By updating the HIV Infection Listings to better reflect current clinical practice, SSA will be able to more accurately identify those people in need of Social Security disability benefits. ☀️