Updated: Revise Social Security HIV Disability Requirements Says Institute of Medicine

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The following article, originally published September 21, has been revised to reflect clarifications from the lead author of the IOM report.

A new report issued by the Institute of Medicine (IOM) on September 13 says the criteria used by the U.S. Social Security Administration (SSA) to gauge HIV-related disability is outdated and should be overhauled to include new qualifications based on CD4 cell counts and specific sets of medical conditions. The IOM recommendations—requested by SSA—will only apply to new Social Security disability applicants once the existing criteria are amended; current disability claimants will not be effected by the proposed changes.

The IOM recommendations, which have yet to be officially reviewed by SSA, reflect the fact that modern-day antiretroviral (ARV) therapy can often improve the health of HIV-positive people with low CD4 counts or a history of AIDS-related opportunistic infections and, in turn, effectively reduce the need for disability benefits. The report also stresses the need for disability benefits for people living with HIV experiencing certain non-AIDS-related complications and ARV treatment-related side effects that can lead to disability.

The HIV Infection Listings, established in 1993, are the criteria currently used to determine whether people living with HIV are disabled by their infection and eligible for benefits. For example, a person living with HIV and a history of employment may be eligible for Social Security Disability Insurance (SSDI)—and, with it, access to Medicare—once a serious AIDS-defining illness has been diangosed, such as Mycobacterium avium complex or cytomegalovirus. Other benefits, including Social Security Income (SSI) and Medicaid for people living with HIV who have limited employment histories, are also dependent on disability status as determined by SSA.

Since the Listings were created, the IOM report argues, HIV care has advanced and the disease has dramatically changed from a uniformly fatal condition to a potentially chronic manageable infection, in which CD4 cell recovery and a return to physical health—and ability to work—is an expected positive consequence of contemporary ARV treatment. Conversely, a number of non-AIDS-related health complications are becoming increasingly prevalent among people living with HIV receiving ARV therapy—such as neurocognitive impairment, chronic kidney disease, osteoporosis and a number of treatment-associated side effects—many of which can cause

disability and were not included in the original 1993 HIV Infection Listings.

To account for the more recent reality that opportunistic infections can be cured or prevented by ARV treatment and prophylaxis, the potential health consequences of ARV therapy and the increasing prevalence of conditions that can occur jointly with HIV infection, IOM is now recommending to SSA that people living with HIV meet one of the following criteria to qualify for disability benefits:

- A CD4 cell count at or below 50 cells per cubic millimeter of blood serum, a laboratory benchmark that indicates an advanced stage of illness.
- One of a few rare but fatal or severely disabling HIV-associated conditions, such as pulmonary Kaposi's sarcoma, certain lymphomas, dementia or progressive multifocal leukoencephalopathy (PML).
- An HIV-associated condition that appears in another section of SSA's full Listing of Impairment, such as cardiovascular disease, chronic kidney disease and hepatitis.
- An HIV-associated condition that is not already included in any other section, such as neuropathy, neurocognitive disorders and wasting syndrome.

In short, the IOM committee recommends that SSA move away from a list of less common AIDS-defining opportunistic infections and focus on manifestations and disease states that are more likely to be associated with disability today.

In addition to IOM's disability-defining criteria recommendations, it also stresses the importance of mandated, regular reassessments of a person's disability status by the SSA. "Since antiretroviral treatment often allows clinical improvement over a period of one or two years," the IOM report suggests, "the committee believes claimants allowed under such a listing should be reevaluated periodically for disability status. The committee believes three years would allow for a sustained response and is the maximum practical period for Social Security Administration (SSA) reassessment."

For example, in a person living with HIV deemed disabled because of a CD4 count below 50 cells, "if the claimant's CD4 count exceeds the minimum threshold and the claimant is not disabled according to other sublistings [after three years], he should no longer receive disability benefits. However, in the event that the CD4 count drops below 50 cells, his disability benefits should be reinstated."

Only those diagnosed with fatal or severe HIV-associated conditions (see the second bullet point above) will be granted permanent, "compassionate" disability status and will not be required to undergo medical reassessments.

IOM notes that the proposed revisions to the Listings affect new HIV-positive SSDI and SSI

applicants only and are not to be applied retroactively. "The protection of those with existing disability is a solid part of SSA," says Paul Volberding, professor of medicine at the University of California, San Francisco, and a lead author of the IOM report. "SSA was clear that revisions are not allowed to withdraw existing benefits."

Aware that some community activists are concerned about the possiblity of medical reassessments for those currently receiving SSA benefits, along with the suggestion that revisions for new claimants will create a two-tier system for disability beneficiaries, Volberding urges participation in the SSA review, which will likely involving a public comment period. "Community advocates should be engaged in this process, as the IOM recommendations are only the start of a discussion, not the end by any means," he says.

Another concern among some community activists is that the the IOM report only addresses changes to SSDI and SSI qualification requirements—the committee sidesteps the important issue of access to care that, for thousands of people living with HIV, is tied to SSA disability status. At present, people living with HIV who are uninsured can access Medicare or Medicaid, once they have been deemed disabled by SSA. While the new recommendations may make it easier for some people living with HIV to qualify for these public health insurance programs, it is possible that the absence of list of serious opportunistic infections—some of which can occur at CD4 counts above 50—will hinder the ability of others to access health care when they need it.

"Although the issues of … access to care [is] critical in the discussion of Social Security disability benefits," the IOM report authors write, "in-depth discussion of the means by which people receive treatment and medications was deemed outside the Committee's scope." SSA, in turn, will be left to grapple with the issue of how to retain people in care and on ARV treatment if the criteria for disability benefits are changed, a task that will likely be made much more difficult in light of existing AIDS Drug Assistance Program (ADAP) waiting lists for uninsured or under-insured people living with HIV and other changes stemming from the recent passage of health care reform legislation.

"We completely appreciate the linkage of disability to care access," says Volberding. "Now, one has to get an OI for easy access. The revisions we suggest would allow the many who are diagnosed with advanced stage disease but without an OI to gain access. The suggested changes would allow compassionate disability for those with still terrible complications and would clarify the relationship between HIV Listings and the existing ones for problems now appreciated as HIV related like cardiovascular disease.

"The whole combination of disability benefits with Ryan White and ADAP is a completely appropriate area for a community dialog," he adds, "but trying to ignore the difference between AIDS in 1993 and the situation today seems hard to hold too seriously."

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