Social Security Disability: Will Recommended Qualification Changes Help or Hinder Access to Services?

September 30, 2010 By Tim Horn

Not too long ago, HIV was considered to be a distressingly predictable disease. In almost all people infected with the virus, it was only a matter of time before the CD4 cell count dropped to a dangerously low level and opportunistic infections and cancers reared their life-threatening (and, indeed, life-ending) head. While the use of HIV drugs like Retrovir--best known as AZT in the late 1980s and early 1990s--could slow this process, rarely was primitive antiretroviral therapy able to restore health for any significant length of time.

Today's powerful antiretroviral (ARV) treatment regimens have virtually rewritten HIV's insidious script. No longer is the disease a one-way street. Even those who don't find out they're positive for the virus and enter care until their CD4 cells are in the double digits and/or hospitalized for an opportunistic infection (OI) can experience a return to immunologic and physical health. In turn, AIDS as we've long known it--defined since 1993 as a CD4 count of 200 below or the development of an OI--is no longer an inevitable and progressive stage of HIV disease, but a seemingly avoidable and reversible condition.

People living with HIV and their health care providers known this, but so do administrators who oversee public programs intended to provide safety nets to those who become disabled and can no longer fully support themselves due to disease. The Social Security Administration (SSA) has been providing disability benefits--Social Security Disability Income (SSDI) and Supplemental Security Income (SSI)--to people living with HIV for decades, using early-year knowledge of the disease to determine who qualifies for assistance and who doesn't. But as times and circumstances have changed, SSA is eager to overhaul its disability benefits criteria to reflect today's reality.

In 2009, SSA asked the National Academy of Science's Institute of Medicine (IOM) to establish the Committee on Social Security HIV Disability Criteria--made up of experts in the field of HIV care, including leading clinicians and community advocates--to recommend updates to the agency's disability benefits criteria for people living with HIV. IOM's report was released in draft form on September 13 and is on its way to SSA for review (see my initial AIDSmeds report here).

Not everyone who has seen the report is thrilled with its recommendations, however. Though it is now clear that the IOM recommendations are only intended for new SSA disability applicants--the agency made it clear to the IOM committee, when it commissioned the report, that it was not interested in revoking disability status of those living with HIV who currently receive SSDI or SSI; a move to the contrary could have potentially thrown the lives of thousands of people living with HIV into an economic tailspin--there are concerns about how these new criteria will affect new applicants who might come to depend on disability status, not only for income, but also health care and other supportive services.

Current Qualifications

SSA currently pays disability benefits through SSDI and SSI. Once disability benefits have been granted by SSA, other benefits are possible. For example, those who qualify for SSDI--individuals with a recent employment history and have paid into the Social Security income tax pool--are also deemed eligible for Medicare. An SSI determination, given to HIV-positive individuals with spotty recent employment histories and limited liquid assets, allows for Medicaid access. And both determinations can open the door to supportive care programs, such as housing assistance and food stamps.

To qualify, individuals must meet SSA's definition of disability, which differs for adults and children. For adults, disability is defined as "an inability to engage in any 'substantial gainful activity'"--a level of work activity and earnings, as determined by SSA--"by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months."

To save time and resources, and to both ease and streamline the administrative process of determining the functional capacity of each claimant, SSA adopted a list of serious medical conditions--the HIV infection listing of impairments (the Listing)--which are applied at the third step of a five-step review process conducted by the SSA in reviewing disability applications.

The Listing currently requires a diagnosis of an AIDS-related opportunistic infection or cancer. The list of allowable medical conditions for HIV-positive adults is, indeed, long and includes a variety of once-common bacterial, fungal, protozoan or helminthic, and viral infections; sepsis; meningitis; pneumonia; septic arthritis; endocarditis; and sinusitis.

A frequent misperception is that a CD4 cell count below 200--a defining characteristic of AIDS--automatically qualifies individuals for SSDI or SSI. While this may have been true in earlier years, it is no longer the case. According to SSA, [A] CD4 count below 200 [offers] supportive evidence when there are clinical findings, but not a definitive diagnosis of an opportunistic infection(s). However, a reduced CD4 count *alone* does not document the severity or functional consequences of HIV infection."

Of course, it's much more complicated than this. For example, some common manifestations among people living with HIV--such as neuropathy, neurocognitive problems and depression--aren't including in the Listing, they are included in other disability-qualifying listings maintained by SSA.

What's more, SSDI and SSI determinations are a matter of administrative law--and legal interpretation of the law--as much as they are about medical opinion. While a health care provider's written testimony in support of an SSDI/SSI claimant's application may fall short of proving that a specific diagnosis clearly *meets* an SSA listing, it tends to be legal representatives and administrative law judges (ALJs) who ultimately determine whether or not characteristics of the applicant's health *equals* an SSA listing. Even if an impairment doesn't clearly meet or equal an established SSA disability criterion, ALJs and an applicant's legal representative may still come to agree that it restricts employment and, thus, is an SSA-covered disability. A complex process, to be sure.

Still, things have changed considerably since the Listing was put into place in 1993. According to the IOM report:

New drugs and the concept of drug combinations evolved dramatically after 1996. HIV infection is now considered a chronic condition which, in optimal settings, allows high levels of functioning and prolonged

survival. Combinations of antiretroviral drugs suppress HIV replication, enabling a recovery of immune function as reflected in circulating CD4+ [cells] normal or near-normal levels in most persons. Success in treatment, however, is far from universal. Many HIV-infected persons harbor virus already resistant to one or more antiretroviral drugs, limiting CD4 recovery. Others are diagnosed at very advanced disease stages or at an older age, both predictors of poor response to treatment. Many others find the lifelong requirement for consistently excellent medication adherence to be impossible or are suffering from the side effects of current or previous antiretroviral therapy. Today, although many of the opportunistic diseases once common are now uncommon, they are still seen. Many patients respond well to treatment, but others, even in the era of potent HIV medications, fail to achieve control of HIV replication or are diagnosed in extremely late disease stages and have rapid progression or disabling complications. For all these reasons, the HIV Infection Listings are in urgent need of reconsideration and

revision.

In turn, the SSA commissioned IOM to examine the current listings for HIV infection and to suggest how they might be updated, considering the substantial changes in the disease since the introduction of potent combinations of antiretroviral drugs beginning in 1996. It is important to note, however, that SSA has updated its Listings on a few occasions since 1993 to reflect improvements in HIV care, albeit in collaboration with SSDI/SSI experts, not a committee of medical experts potentially view disability differently than legal experts.

What's Proposed

IOM's recommendations involve doing away with the current HIV Listing and replacing it with our groupings of health complications associated with disability in people living with HIV. A diagnosis of one disabling condition in one group will be needed to qualify, according to the IOM committee report.

Low CD4 Count

Although disability allowances in the 1993 Listings were based primarily on a diagnosis of an AIDS-related opportunistic infection or malignancy, the IOM report brings a qualifying CD4 count into the picture. Based on data reviewed by the committee members, an important indicator of disability today is a low CD4 count, specifically at or below 50 cells. This, the committee members feel, is a direct marker of HIV disease stage and a predictor of short-term mortality risk as well as of attenuated antiretroviral therapy response.

Many of the most serious opportunistic diseases in the 1993 Listings occur in individuals with low CD4 cell counts and thus would be captured by the recommended Listing, the committee members contend. However, the report authors recommend that this allowance should be reviewed periodically--3 years would be most practical--to assess the magnitude and stability of the individual's response to antiretroviral treatment.

Imminently Fatal or Serious Conditions

By contrast, the IOM committee members ound several HIV-induced diseases that remain so serious that they warrant a permanent disability allowance. These diseases are severely disabling, have a high short-term mortality risk, and respond minimally to conventional treatment.

Diseases to be considered imminently fatal include:

- HIV-associated dementia
- Multicentric Castleman's disease
- Pulmonary Kaposi's sarcoma
- Primary central nervous system lymphomas
- Primary effusion lymphoma
- Progressive multifocal leukoencephalopathy (PML)

HIV-Associated Conditions Without Listings Elsewhere in Other Body Systems

Disability allowance is also recommended for another group of conditions associated with HIV infection or side effects of treatment To qualify, however, applicants will need to prove that these conditions limit their bility to function in the workplace.

Because recovery from these may be possible with antiretroviral therapy, the IOM report authors

recommend that disability should, as with low CD4 counts, be considered a disability for three years and be reviewed regularly.
This list would include, but would not be limited to:

- Diarrhea
- Distal sensory polyneuropathy
- HIV-associated neurocognitive disorders
- HIV-associated wasting syndrome;
- Kaposi's sarcoma
- Lipoatrophy or lipohypertrophy
- Osteoporosis

HIV-Associated Diseases With Existing Listings Elsewhere
Many people living with HIV experience a higher rate or earlier onset of diseases that are grounds for disability claims using various non-HIV SSA listings. In turn, the report authors stress the importance of cross-referencing with medical eligibility listings--and there are several--not specific to people living with HIV when reviewing applications for HIV-positive people seeking benefits.
A potentially confusing application process, yes, but the IOM report also suggests an internal review of SSA procedures to reduce the risk of HIV-positive people dealing with non-HIV-related health complications from falling through the cracks. Specifically, the IOM report recommends an ongoing review of the forms employed to best capture the information needed for allowance determination, and rewriting all introductory material for those most directly involved in the determination process.
Examples include:

- Cardiovascular disease
- Chronic kidney disease, including HIV-associated nephropathy
- Diabetes
- Hepatitis
- Malignancies, not otherwise specified in the report

Potential Problems
Because qualifying for SSDI or SSI is required for people living with HIV to access Medicare or Medicaid, respectively, some community advocates are concerned that a huge swath of future HIV-positive people will face tremendous hurdles getting the care they need, if SSA overhauls its HIV Infection Listing based on the IOM recommendations.
Presently, Medicaid covers approximately one-third of people living with HIV/AIDS, while Medicare covers another third of those infected with the virus.
For HIV-positive people who are uninsured and do not qualify for SSI or SSDI (or do qualify for SSDI but haven't fulfilled the two-year waiting period for Medicare to kick in), AIDS Drug Assistance Programs have helped fill the void. Yet many state ADAP programs have either reduced their level of support or have

implemented waiting lists. Thus, it's uncertain if ADAPs will be in a position to provide for those who are sick--someone who is diagnosed with HIV at the same time as an opportunistic infection, with a CD4 count above 50 cells, for example--if current economic conditions continue and SSA adopts the recommended changes.

The Patient Protection and Affordable Care Act, passed by Congress and signed into law by the President in March 2010, should, for all intents and purposes, create a much broader range of health care options for people living with HIV, regardless of disability status or income. Unfortunately, community critics contend, health care reform--which should go into full effect in 2014--is by no means a sure thing, with states and members of Congress fighting its implementation through lawsuits and threats of withholding funds.

It is unfortunate that the IOM authors consciously opted not to discuss how changes to the SSA Listings could potentially affect access to care, given the uncertainties currently facing people living with HIV.

"Although the issues of ... access to care [is] critical in the discussion of Social Security disability benefits," the IOM report states, "in-depth discussion of the means by which people receive treatment and medications was deemed outside the Committee's scope."

In effect, another shifting variable has been thrown into the mix of uncertainties involving the future of health care in the United States for people living with HIV--what we know about access to care through ADAP, health care reform legislation and SSA disability status is going to get very fuzzy.

Still, it makes little sense for SSA to hold on to a seriously outdated list of medical qualifications for disability benefits because our health care system continues to fail in so many other respects. The question is, what will be the net effect of these various changes in terms of access to services for people living with HIV? After all, with so much talk about maximizing HIV testing outreach and getting everyone found to be positive in to care as quickly as possible, there's no room for widening gaps in U.S. health care.

The SSA review process is just beginning and it is unlikely that the agency will take action until 2012. There will be a public comment period--AIDSmeds and POZ will alert readers when the time comes--and plenty of discussion between activists and agency officials in the meantime. The future story of SSDI and SSI for people living with HIV has yet to be written.

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