Patients and their providers need to know how the Social Security Administration (SSA) determines disability and how to defend active claims

The Social Security Administration (SSA) has released new “listings” or medical guidelines for HIV-based disability claims for the first time since 1991. SSA has also announced it will now conduct continuing disability reviews on HIV claims, as it does for most disability claims. Individuals applying for disability or whose claims are reviewed should have a clear understanding of how they and their doctors should document disability in order to qualify for Social Security benefits.

Revised Listings

Under the old listings, patients qualified for Social Security disability if they had an AIDS defining condition (Pneumocystis pneumonia, various bacterial, viral, fungal infections, skin conditions, Kaposi Sarcoma, severe diarrhea and dehydration, etc.) or “repeated manifestations of HIV” resulting in functional limitations. As of January 1, 2017, the new listings move away from AIDS-defining conditions and allow an award of disability when there is either a serious HIV-related condition, a qualifying CD4 count, repeated hospitalizations, or, as before, repeated manifestations of HIV.

Under the new listings, the following could qualify as disabling conditions:

- Serious HIV-related conditions, such as Multicentric Castleman disease, primary central nervous system or primary effusion lymphoma, progressive multifocal leukoencephalopathy, or pulmonary Kaposi sarcoma
- A low CD4 count (50 or less)
- CD4 of 200 or less (or CD4 percentage of less than 14), plus a low BMI or hemoglobin count
- Complications of HIV requiring hospitalization 3 times in a 12-month period
- Repeated manifestations of HIV that result in functional limitations (your ability to sit, stand, walk or lift objects as you would in everyday life or at work)

SSA has also rescinded a policy requiring HIV claims to prove duration (that a condition will last 12 months or more or result in death) because HIV/AIDS will no longer be treated as a terminal illness. This change may impact the evidence applicants are required to provide. Individuals who do not qualify for HIV disability may still meet the requirements for another physical or mental condition.

Continuing Disability Reviews (CDRs)

Social Security (SSA) conducts CDRs to determine if a disabled person has medically improved and is now able to work. In the past, SSA generally did not review HIV disability claims. Effective March 1, 2017, SSA will review HIV claims just as they do most others. However, SSA says they have no intention of conducting wholesale reviews of existing claims. HIV claims will be subject to review unless the claim is
based on Multicentric Castleman disease, primary central nervous system lymphoma, primary effusion lymphoma, progressive multifocal leukoencephalopathy, or pulmonary Kaposi sarcoma.

CDRs are based on the applicant’s condition when SSA determined disability:

- If improvement is expected, reviews could be done 6-18 months after approval
- If improvement is possible but can’t be predicted, review is about every 3 years
- If improvement is not expected, SSA will review claims every 7 years

CDRs may lead to the termination of benefits if there is clear, documented improvement in the person’s health condition(s). People receiving SSA disability should remain in care, attend regular medical appointments and take medication as prescribed.

**Documenting Your Disability**

SSA looks at medical records to determine disability. They request files from any doctors applicants tell them they have seen for their health condition(s). Providers may include HIV specialists, primary care doctors, psychiatrists, therapists, ER physicians and other providers. Documentation is the key to qualifying for disability or appealing a denial. Applicants must make sure providers fill out SSA’s forms and include clearly written notes. Applicants should make lists of all symptoms, conditions, side effects, and functional difficulties, and instruct their doctors to enter those lists into their files.

Functional capacity is based on the ability to function in normal everyday activities. Social Security has forms providers can fill out to document both medical and mental health functioning. Applicants should answer questions about their ability to function as if their worst day is every day.

**Where to Get Help Filing or Defending a Disability Claim**

Find a benefits counselor through an AIDS service organization or clinic if you are filing a new claim. If your claim is under review or has been denied, ask your service provider to help you find an attorney. Online searches will produce many sites that offer assistance, information or referrals to legal help.

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<thead>
<tr>
<th>There is a lot of information online for people filing Social Security Claims</th>
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<tr>
<td><strong>Social Security’s website</strong></td>
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<td>Application forms, medical and mental health functional capacity forms, information for applicants and providers: <a href="https://www.ssa.gov/disabilityssi/">https://www.ssa.gov/disabilityssi/</a></td>
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<tr>
<td><strong>Duke University Law School Health Justice Clinic</strong></td>
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<tr>
<td>Summarizes recent changes and other HIV Social Security related issues: <a href="https://law.duke.edu/healthjustice/resources/">https://law.duke.edu/healthjustice/resources/</a></td>
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<tr>
<td><strong>California HIV service providers, clinics, etc.</strong></td>
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<tr>
<td>CA Office of AIDS: 800-367-2437 <a href="https://npin.cdc.gov/ca/">https://npin.cdc.gov/ca/</a></td>
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<td><strong>For benefits counseling in San Francisco and LA:</strong></td>
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| APLA Health: 213-201-1615 [www.aplahealth.org](www.aplahealth.org)  
San Francisco AIDS Foundation: 415-487-3000 [www.sfaf.org](www.sfaf.org)  
Positive Resource Center: 415-777-0333 [www.positiveresource.org](www.positiveresource.org) |
| **For legal assistance in Los Angeles, San Francisco and across the state:** |
AIDS Legal Referral Panel: 415-701-1100 [alrp.org](alrp.org)  
Law Help California: [LawHelpCA.org](LawHelpCA.org) |
| **For all SSA forms and other information:**                  |
| Social Security Disability Facts: [www.ssdfacts.com/](www.ssdfacts.com/)  
Disability Benefits 101: [https://ca.db101.org/](https://ca.db101.org/) |