SOAR for Children who have HIV/AIDS

# In 2015, youth aged 13 to 24 accounted for 22% of all new HIV diagnoses in the United States. Most of those new diagnoses among youth (81%) occurred among gay and bisexual males ([www.cdc.gov](http://www.cdc.gov) ). The CDC also informs, “youth with HIV are the least likely out of any age group to be linked to care and have a suppressed viral load (that is, having a very low level of the virus in the body, which helps the person stay healthy and greatly reduces the risk of transmitting HIV to others)” ([www.cdc.gov](http://www.cdc.gov)). Decreased access to retroviral therapy among this population can result in elevated viral loads, which may cause the child to be unable to work or perform functional activities at the same level as his or her peers. Children who have HIV/AIDS often have multiple disabling conditions, such as serious mental illnesses, cognitive disorders, and other chronic physical health conditions. SSA disability benefits provide income and health insurance, making it possible for many to gain access to housing, treatment and other supports.

# Disability Evaluation under Social Security (“The Listings”)

The following is a brief summary of the SSA listing for HIV infection in people up to age 18. This is only a sample from the listing and is not the complete listing. Please see the most recent and complete listing at Social Security’s website: <https://www.ssa.gov/disability/professionals/bluebook/114.00-Immune-Childhood.htm#114_11>

**114.11 Human immunodeficiency virus (HIV) infection**. With documentation as described in 114.00F1 and one of the following:

1. Multicentric (not localized or unicentric) Castleman disease
2. Primary central nervous system lymphoma
3. Primary effusion lymphoma
4. Progressive multifocal leukoencephalopathy
5. Pulmonary Kaposi sarcoma
6. Absolute CD4 count or CD4 percentage:
   1. For children from birth to attainment of age 1, absolute CD4 count of 500 cells/mm3 or less, or CD4 percentage of less than 15 percent
   2. For children from age 1 to attainment of age 5, absolute CD4 count of 200 cells/mm3 or less, or CD4 percentage of less than 15 percent
   3. For children from age 5 to attainment of age 18, absolute CD4 count of 50 cells/mm3 or less
7. Complication(s) of HIV infection requiring at least three hospitalizations within a 12-month period and at least 30 days apart
8. A neurological manifestation of HIV infection resulting in one of the following:
   1. Loss of previously acquired developmental milestones or intellectual ability
   2. Progressive motor dysfunction affecting gait and station or fine and gross motor skills
   3. Microcephaly with head circumference that is less than the third percentile for age
   4. Brain atrophy
9. Immune suppression and growth failure

# Additional SSA Form: SSA-4815-UF Medical Report on Child with Allegation of Human Immunodeficiency Virus (HIV) Infection

# The SSA-4815 is completed in addition to the SSA-3820 Disability Report- Child and SSA-827 Authorization to Disclose Information. This form aims at determining if the applicant meets the listing requirements set forth in the “Blue Book” of Child Listings. The SSA-4815 can be completed by a physician, nurse, or other member of a hospital or clinic staff who is able to confirm the diagnosis and severity of the HIV disease manifestations. For children and youth with HIV, SSA is looking for severe infections that typically accompany an HIV diagnosis, and causes marked and severe functional impairments (ssa.gov). SSA is also looking for information about the amount of infection in the child’s blood, relative to the child’s age, referred to as CD4 levels and recent hospitalizations. If the information provided in this form meets Listing 114.11, the applicant may receive a Presumptive Disability Decision for up to six months while additional medical records are reviewed. It’s important to remember that SSA’s definition of disability may be different from the clinical definition of HIV/AIDS or related opportunistic diseases. SSA focuses on diagnosis and functional impairment.

# Presumptive Disability

Presumptive disability (PD) payments are payments for disability or blindness that are available for up to six months while a person is awaiting a decision from the DDS. PD decisions for HIV impairment require some medical evidence before payments can begin. When an applicant meets the specific criteria contained in Section C, Opportunistic and Indicator Diseases of the SSA-4815, and has supportive medical documentation, the functional impairment information and the Medical Summary Report are not necessary. However, many applicants have diseases or other HIV-related health problems but do not meet the specific criteria contained in C. For these individuals, the functional impairment information and the rest of the information included in the Medical Summary Report are vital.

# Consideration of Side Effects

It is important to take note and document the side effects of medications, both acute and ongoing for applicants who may not meet the specific listing requirements. Indicate the frequency of doses of medications. Also document the accumulation of effects from various treatments, the duration of those treatments and the impact that it has on the applicant’s functioning.

# Resources

* Basic Statistics on HIV/AIDS for Children from the Centers for Disease Control and Prevention:

<https://www.cdc.gov/hiv/group/age/youth/index.html>

* SSA Guide for Providing Medical Evidence for Individuals with Human Immunodeficiency Virus (HIV) Infection: <https://www.ssa.gov/disability/professionals/documents/64-037.pdf>
* Social Security For People Living With HIV/AIDS: <https://www.ssa.gov/pubs/EN-05-10019.pdf>
* SSA Code of Federal Regulations on Presumptive Disability: <https://www.ssa.gov/OP_Home/cfr20/416/416-0933.htm>