

HIV AS A CHRONIC DISEASE: Handling HIV Disability Cases In the Era of Treatment¹

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Take home points:

- **Numbers aren't everything:** CD4 and Viral Load don't predict functioning
- **Most HIV cases won't be listings (at least not HIV listings),** but 14.08K may be possible
- **Many HIV cases won't be HIV** – HIV may not contribute to disability at all
- **HIV is often accompanied by mental illness** – you may have to develop the record. Key mental issues: Depression, PTSD, Cognitive deficits
- **Understand the underlying psychosocial issues, especially stigma** and how they affect treatment adherence, course of the disease, and drug/alcohol issues
 - Poverty, lack of health insurance, stigma, trauma, depression, PTSD, substance abuse, housing/homelessness issues
- **Be prepared to develop the record,** as many of your HIV+ clients will have skimpy medical records
- **Find a helpful HIV provider** to provide a medical source statement. HIV doctors/nurses/PA's are a rare breed. They will be more helpful than most providers and can help support the claimant's report of subjective symptoms like fatigue, pain, etc.
- **Be prepared to do some medical research** to counter assumptions about favorable course of HIV with antiretroviral medications

I. HIV – From Death Sentence to Chronic Disease

The first US cases of HIV were reported in 1981. At that time, the average life expectancy of a person first presenting with HIV was 6 months. Now, with antiretroviral therapy, a person age 35 diagnosed with HIV can expect to live another 32 years, depending on the nadir CD4 count.² Since 1996 and the introduction of combination antiretroviral drug therapy, HIV has transformed from

¹ This manuscript was originally prepared for the Spring 2011 NOSSCR Conference, and was updated in October 2011.

² Hogg et al (2008), cited in Committee on Social Security HIV Disability Criteria; Board on the Health of Select Populations; Institute of Medicine of the National Academies, *HIV and Disability: Updating the Social Security Listings* 33 (2010), available at <http://www.nap.edu/catalog/12941.html>.

an almost certainly fatal disease to a manageable chronic condition. For people who can access and maintain appropriate drug therapy, the prognosis is excellent. Most HIV infected people who die nowadays, die from something other than HIV. In our experience at the Duke AIDS Legal Project, those who die of complications of HIV generally have come into care late or had difficulties accessing or adhering to medications.

Medically, things have been getting better and better since 1996. In the early days of combination drug therapy, the drugs were toxic and many had major side effects, including peripheral neuropathy, lipodistrophy/lipoatrophy, chronic diarrhea, liver and renal toxicity, to name a few. The drug combinations involved daunting, complicated regimens with large numbers of pills that had to be taken at different times of day, some requiring refrigeration, some requiring that they be taken with food, others on an empty stomach. Now, a common first line treatment for HIV, Atripla, is a one-pill regimen that combines three drugs, taken once a day. This and other newer drugs have fewer and less debilitating side effects and the regimens are less complicated. Treatment has come a long way in 15 years.

This dramatic shift in the prognosis for people with an HIV diagnosis is reflected in the numbers of people claiming disability based on HIV. In 1999, there were roughly 30,000 claims for benefits for HIV infection. Of those, 39% were allowed. In 2009, the number of claims was down to 25,000, and the allowance rate had declined to 30%.³ In that year, 7816 claims were allowed based on meeting or equaling the HIV listings. Overall, between 1999 and 2009, about 35 percent of adult HIV claims were approved. Of those, 29 percent either met or equaled the 14.08 listing, and 6 percent were approved at Step 5. Among the claims denied during this period, about 40 percent were at Step 5, and 28 percent were at Step 4⁴

Advocates don't need to look at SSA data to know that HIV cases have become more difficult to win over the past decade. In our practice, which is limited to people with HIV, fewer clients have reasonable prospects of prevailing on a listing argument. Instead, most are approved based on a combination of impairments at Step 5. For a growing number of HIV positive clients, the HIV is not a factor in the allowance at all. Instead, common HIV comorbidities such as depression, PTSD, hepatitis C, or cardiovascular disease, or other unrelated conditions such as a bad back form the primary basis for approval. For those that do have relevant HIV-related symptoms, the most common that we see in our practice are fatigue, peripheral neuropathy, diarrhea, and cognitive deficits that manifest in slowed processing ("brain fog") and difficulties with concentration, attention, and memory.

³ Institute of Medicine, *supra* at 24.

⁴ Institute of Medicine, *supra* at 26.

II. The Demographics of HIV Today

An estimated 1,106,4000 adults and adolescents are living with HIV in the United States. About 20% of those people are unaware of their infection. Each year, about 56,300 people in the US become infected with HIV. About 18,000 people with AIDS die each year.⁵ We think of large urban centers as the primary location of HIV cases. However, while there are still large populations in cities, the epicenter of the epidemic is the southeastern United States, especially rural areas.

In North Carolina, there are presently an estimated 35,000 people living with HIV/AIDS, including those unaware of their status.⁶ In 2009, 957 new AIDS cases were diagnosed and reported in North Carolina. According to the CDC, North Carolina ranked 10th among all states and the District of Columbia in the number of new AIDS cases diagnosed in 2008 and is ranked 11th in the nation for estimated number of persons living with an AIDS diagnosis. In that same year, 1,710 new individuals were diagnosed with HIV.⁷

Men who have sex with men (MSM) remain the most heavily affected by HIV, and they are the only risk group in which HIV infections continue to increase. MSM account for 53 percent of new HIV infections, as well as 48% of people living with HIV. Individuals infected through heterosexual contact comprise 31 percent of annual new HIV infections and 28 percent of people living with HIV. Injection drug users represent 12 percent of annual new HIV cases and 19 percent of those living with the disease.

African Americans are the racial group most burdened by HIV. Blacks make up about 12 percent of the US population, account for 46 percent of those living with HIV and 45% of new infections. African American women are particularly hard hit. Although they have only about half the infection rate of African American men, their infection rate is almost 15 times that of white women.⁸

Even older adults are not immune from HIV. The number of senior citizens with HIV is surprising, and often this population is inadequately screened for the disease. I have encountered several women diagnosed with HIV after age 55 whose doctors failed to recognize obvious indicators of the disease for months and years, because the patients did not fit the HIV profile.

⁵ Centers for Disease Control, *HIV and AIDS in America: A Snapshot* (October 2010), available at <http://www.cdc.gov/hiv/aaa/snapshot.htm>

⁶ *North Carolina Epidemiologic Profile for HIV/STD Prevention and Care Planning*, NC Department of Health and Human Services Communicable Disease Branch, December 2010.

⁷ *Id.* at iii

⁸ *Id.*

We all know that deaths from HIV/AIDS have declined since the introduction of effective treatments. In 2007, there were only 11,295 deaths from HIV⁹, as compared with 50,610 who died in 1995 before the advent of the new drugs.¹⁰ Why do people still die of HIV/AIDS? When this question was asked of clinicians in 2004, the top reasons were: 1) Liver complications, 2) Poor adherence, and 3) Failure to diagnose until the disease is advanced 4) Non-Hodgkin lymphoma, 5) Non-AIDS cancer.¹¹

These reasons still ring true today in 2011. In our practice with HIV positive clients (both in disability and other cases), the clients who die tend to be those who were diagnosed late, have trouble adhering to treatment or have liver disease. Even when these clients don't die, they are generally the sickest. In these groups, mental health, substance abuse, and other psychosocial factors contribute heavily.

III. Psychosocial Factors

Some of our HIV positive clients are middle class (at least they were before acquiring an expensive life-threatening disease), educated, and endowed with sufficient social capital to navigate their medical care, benefits, housing, and other challenges. They take their medicine faithfully and never miss a doctor's appointment. They are in the minority of our clients.

Although no income, social, or racial group is immune from HIV, there is no escaping the fact that HIV now has its highest impact in communities of color and poverty. People living with HIV have a high incidence of mental illness, substance abuse, and trauma history. Each of those comorbidities is a risk factor for HIV.

A. Stigma

Additionally, people living with HIV still face enormous stigma. This is especially true in southern and rural areas, but remains a challenge even in "enlightened" major cities. The stigma comes from several sources. First, there are still lingering irrational fears of transmission – people with HIV are still our time's lepers. In spite of decades of education, people still worry that they can get HIV from casual contact, mosquitoes, toilet seats, or food.¹² (Think fast – do you know if you could

⁹ National Vital Statistics Reports, Vol. 58, No. 19, (May 20, 2010)

¹⁰ CDC Division of HIV/AIDS Prevention. U.S. HIV and AIDS cases reported through June 2000. Midyear edition Vol. 12, No. 1. Table 27. *Estimated deaths of persons with AIDS, by race/ethnicity and year of death, 1993 through 1999, United States*, available at www.cdc.gov/hiv/stats/hasr1201/table26.htm#fig26

¹¹ Mark Mascolini, *Why People With HIV Still Die – And Why They Don't Have To*, (2004) From International Association of Physicians in AIDS Care, available at, <http://www.thebody.com/content/art12281.html#2>

¹² FYI – HIV cannot be transmitted by any of these means. For excellent information about HIV transmission, check out the CDC's website: <http://www.cdc.gov/hiv/resources/qa/transmission.htm>

get HIV by drinking out of the same cup as someone who is HIV positive?¹³) Beyond the stigma related to fear of infection, there is “stigma by association.” That is, HIV is associated with homosexuality, sexual risk taking, and drug abuse. People assume that someone with HIV got it by doing something bad. Whichever source of stigma predominates, the reality is that stigma is real and is a major barrier to adequate care and prevention. Stigma also contributes to social isolation, as many people with HIV are unwilling to let friends and family members know about their disease.

1. Sensitivity within the law office. It is essential that advocates taking on disability cases involving HIV make sure that they and their staff understand how HIV is transmitted (and not transmitted), as well as the importance of extreme sensitivity of the client’s diagnosis. Because many people with HIV do not share their diagnosis with many people, it is important not to assume that friends or family members are aware of the diagnosis, even when such a person has accompanied the client to your office. People with HIV often tell friends or family members that they have cancer or some other illness to avoid the potential consequences of disclosure, such as rejection or further disclosures.

2. Stigma and medical care: Clients in rural areas that have HIV clinics in the community may be unwilling to be seen going to that clinic. So either they don’t get regular medical care or they establish care in another county, often in one of the three major academic medical centers in North Carolina. But they often lack transportation or the organization to make it to their medical appointments which may require a whole day’s travel and waiting. Other clients may be afraid for roommates or family members to see their medicines. Here are some examples encountered in North Carolina.

- A homeless client hid his medicines in an abandoned building so no one at the homeless shelter would see them. After a few weeks, he returned to retrieve his pills, and they had been stolen.
- Another semi-homeless client stayed with various friends and relatives for as long as they would keep him. He, too, was unwilling to have his medications with him, so he missed doses frequently, leading to resistance. He died of liver disease the day before he was approved at reconsideration.
- Another client gets medical care in an academic medical center 30 minutes from his home so that he will not be seen going to the local HIV clinic. He even refuses to apply for Medicaid because someone he knew in high school works in the Medicaid office. He has told only one friend about his HIV, keeping his diagnosis from even his immediate family. He frequently misses medical appointments because he lacks transportation. He is unwilling to

¹³ *Id.*

get a ride from anyone other than the one friend to whom he has disclosed, because he doesn't want to risk exposure of his HIV status.

- Another client feels so worthless because of his HIV that he doesn't take his medications regularly and frequently misses medical appointments.

Indisputably, the stigma of HIV contributes to our clients' difficulty staying healthy.

B. Life Circumstances

In addition to stigma, other factors contribute to the difficulties faced by many people with HIV in managing their disease. Few have health insurance, and they cannot access Medicaid without establishing disability. Because of their poverty, they often have inadequate or unstable housing. Without stable housing, clients miss medical appointments and medications, and are often lost to follow-up.

C. Trauma

A history of trauma is a huge risk factor for HIV.¹⁴ Traumas include experiencing or witnessing violence, murder, sexual abuse (including rape), and physical abuse; death of a spouse; household dysfunction; being sent to prison or reform school; childhood emotion neglect and physical neglect

A childhood trauma history contributes to many of factors that create risk of HIV: alcohol and substance abuse; risky sexual behavior; higher prevalence of STDs; re-victimization; and mental illness (including depression and PTSD).¹⁵ Trauma is also strongly associated with lack of adherence with HIV treatment, whether directly, or mediated through mental illness. In a study in North Carolina, researchers looked at the association between the number of lifetime traumatic events and non-adherence. Not surprisingly, the rate of non-adherence increased as the number of traumatic events increased. For people with five or more lifetime traumatic events, the non-adherence rate was 34%, three times that of patients who had no trauma experience.¹⁶ So not only do people with a trauma history have a higher likelihood of contracting HIV, they are also more likely than others not to adhere to their treatment regimen. And as discussed above, those who do not adhere get sicker or die.

¹⁴ Kathryn Whetten-Goldstein (Author) and Trang Quyen Nguyen *"You're the First One I've Told": New Faces of HIV in the South* (2002).

¹⁵ Felitti. *Am J Prev Med* 1998;14(4):245-58; Holmes. *JAMA* 1998; 280:1855-62; Greenberg. *Int J STD & HIV* 2001;12:777-83; Dube. *Am J Prev Med* 2005;28:430-8

¹⁶ Mugavero M, Ostermann J, Whetten K, Leserman J, Swartz M, Stangl D, et al. *Barriers to antiretroviral adherence: the importance of depression, abuse, and other traumatic events*, *AIDS patient care and STDs*, 2006 Jun;20(6):418-28.

D. Mental Illness

Mental illness is extremely common in people with HIV. See extended discussion below in connection with HIV comorbidities.

E. Substance Abuse

Many people living with HIV are either active drug users or alcoholics, or have a history of substance abuse. Many suffer from both substance abuse and mental illness. These conditions can lead to poor adherence, disconnection from medical care, risky behavior that leads to development of other conditions, including other STDs, and increased mortality risk.

Many of our disability clients are struggling with substance abuse. In fact, it is difficult to find clients with HIV who do not have substance abuse in their history. In very few cases do we reject a case on this basis. Although a full analysis of issues surrounding Drug Abuse and Alcoholism are beyond the scope of this paper, I can offer a few suggestions that are particularly relevant to cases of substance abusing clients with HIV.

- Don't reject clients with substance abuse issues out of hand. We have only lost one case on this basis, and almost all of our clients have some drug use or history in their records.
- Use disability as a carrot to encourage your client to seek treatment or to stay in treatment. Substance abusers are motivated by reward, not punishment. Find ways to reward positive steps toward sobriety.
- Many HIV clinics offer substance abuse and mental health treatment because of its importance to medication adherence. Explore these options.
- When you talk to the HIV provider, discuss the substance abuse and seek an opinion that it does not materially contribute to the client's disability.

F. Hello, client: Challenges for Advocate

These, then, are your clients. Representing them effectively requires unpacking the psychosocial issues that are inextricably linked to their medical conditions and prospects for disability. Also, because of the often inconsistent engagement in medical and mental health care, the client's medical records may be spotty, lacking documentation of subjective symptoms such as fatigue, pain, and depression. Unless the patient is being seen at a major medical facility, the records are likely to be brief and focused exclusively on tracking CD4 and viral load numbers, which can paint a rosier picture of the client's health and functioning than is actually the case. If the "numbers" show that the client has good response to antiretroviral

therapy, there will no doubt be numerous statements in the record that the patient is “doing well.” The client may not see the same provider for any length of time, so it may be difficult to find a medical source who can provide a statement of the client’s functioning. Also, even if there is a consistent medical provider, it may well be a nurse practitioner or physician’s assistant rather than an MD.

This presents several challenges for advocates:

- Beefing up the medical record
- Finding a medical provider who can give an opinion about the client’s functioning and the significance (or lack thereof) of CD4 and viral load numbers
- Teasing out mental illness that may not be prominent in the record or for which the client may not be getting treatment
- Addressing issues of Drug and Alcohol Abuse
- Addressing issues of noncompliance with treatment

IV. HIV Medical Overview

I begin this medical overview with a disclaimer. I am not a doctor. In this section I attempt to provide an overview of HIV/AIDS as it relates to disability claims, as I understand it. This section emphasizes those conditions/symptoms that we have encountered most frequently in many years of working exclusively with people living with HIV/AIDS. It is not exhaustive.

HIV is the human immunodeficiency virus, which is the virus that can lead to Acquired Immune Deficiency Syndrome, or AIDS. HIV is transmitted through blood or semen, as well as from mother to fetus. On introduction into the blood stream, HIV virus attaches to a particular immune cell, the CD4 or “T cell.” It essentially takes over the cells and turns them into factories to produce more HIV virus. Initially, the body is able to mount an immune response to the virus, and levels of the virus can stay low for many years. Eventually, though, the virus gets the upper hand and the level of virus increases and the number of the key CD4 immune cells (also known as “T cells”) drops dramatically. A normal level of CD4 cells is in the range of 500-1000.

Standard therapy for HIV is a combination antiretroviral therapy¹⁷. The current recommendation for initiation of antiretroviral therapy in the United States is:

- CD4 count less than 350 cells/mm³ or history of an AIDS-defining illness
- CD4 count between 350 and 500 cells/mm³ ¹⁸

¹⁷ This is variously referred to as “ARV Therapy”(Antiretroviral Therapy), “CART” (Combination Antiretroviral Therapy), and “HAART” (Highly Active Antiretroviral Therapy).

Members of the panel generating these recommendations were evenly divided as to whether treatment should be recommended for people with CD4 counts above 500. All of these recommendations assume that treatment will be lifelong and patients should be informed of the risk/benefit of therapy and the importance of adherence.¹⁹

In these days of advanced treatments, the term “AIDS” is less meaningful than it once was. The CDC criteria for an AIDS diagnosis includes people whose CD4 count falls below 200. Additionally, an AIDS diagnosis is given when a person has one of a number of opportunistic infections that are considered “AIDS defining.” These days, people less often suffer the opportunistic infections that once defined AIDS. Even if they do experience one of those conditions, or if their CD4 count dips below 200, treatment can suppress their virus to undetectable levels, and their immune system can be repaired, as evidenced by a return to normal or near normal CD4 counts. No longer does the pathway go only downward. The continuing utility of the term “AIDS” is that it does identify people whose immune systems have suffered grave offense. Recent studies are showing that nadir (lowest) CD4 count is predictive of morbidity and mortality. So the “AIDS” designation does identify people who may have a poorer prognosis. In practice, doctors mostly continue to refer to a person as having “AIDS” after he or she has recovered and no longer meet the AIDS criteria, but the disease is mostly referred to as HIV.

A. AIDS

AIDS-defining conditions are rare disorders to which people with normal immune systems are not susceptible. These conditions are seen infrequently in the era of combination drug therapy. The AIDS-defining conditions include:

- Candidiasis of bronchi, trachea, or lungs
- Candidiasis, esophageal
- Cervical cancer, invasive
- Coccidioidomycosis, disseminated or extrapulmonary
- Cryptococcosis, extrapulmonary
- Cryptosporidiosis, chronic intestinal (greater than 1 month's duration)
- Cytomegalovirus disease (other than liver, spleen, or nodes)
- Cytomegalovirus retinitis (with loss of vision)
- Encephalopathy, HIV-related
- Herpes simplex: chronic ulcer(s) (greater than 1 month's duration); or bronchitis, pneumonitis, or esophagitis
- Histoplasmosis, disseminated or extrapulmonary
- Isosporiasis, chronic intestinal (greater than 1 month's duration)

¹⁸ Department of Health and Human Services, Centers for Disease Control and Prevention, *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents*, at 27 (January 10, 2011).

¹⁹ *Id.*

- Kaposi's sarcoma
- Lymphoma, Burkitt's (or equivalent term)
- Lymphoma, immunoblastic (or equivalent term)
- Lymphoma, primary, of brain
- Mycobacterium avium complex or M. kansasii, disseminated or extrapulmonary
- Mycobacterium tuberculosis, any site (pulmonary or extrapulmonary)
- Mycobacterium, other species or unidentified species, disseminated or extrapulmonary
- Pneumocystis carinii pneumonia
- Pneumonia, recurrent
- Progressive multifocal leukoencephalopathy
- Salmonella septicemia, recurrent
- Toxoplasmosis of brain
- Wasting syndrome due to HIV²⁰

Other conditions that are not AIDS defining, but that are identified by the CDC as being HIV-related include:

- Bacillary angiomatosis
- Candidiasis, oropharyngeal (thrush)
- Candidiasis, vulvovaginal; persistent, frequent, or poorly responsive to therapy
- Cervical dysplasia (moderate or severe)/cervical carcinoma in situ
- Constitutional symptoms, such as fever (38.5 C) or diarrhea lasting greater than 1 month
- Hairy leukoplakia, oral
- Herpes zoster (shingles), involving at least two distinct episodes or more than one dermatome
- Idiopathic thrombocytopenic purpura
- Listeriosis
- Pelvic inflammatory disease, particularly if complicated by tubo-ovarian abscess
- Peripheral neuropathy²¹

As with the opportunistic infections, most of these conditions are seen very infrequently. The most common HIV complaints in the modern era include:

²⁰ Department of Health and Human Services, Centers for Disease Control and Prevention, 1993 *Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults*, Morbidity and Mortality Weekly Report 41(RR-17) (December 18, 1992).

²¹ *Id.*

- Fatigue
- Cognitive deficits (including memory, difficulty concentrating executive function)
- Peripheral Neuropathy
- Diarrhea
- Muscle aches
- Depression
- Weakness
- Painful joints
- Night sweats
- Weight loss
- Shortness of breath with activity
- Abdominal pain
- Gas/bloating
- Weight gain in the stomach area²²

An excellent resource on medical issues in HIV/AIDS is the recent report of the Institute of Medicine of the National Academy of Sciences, "HIV and Disability: Updating the Social Security Listings," <http://www.nap.edu/catalog/1294.html>, which was released in late 2010. This publication includes a very current overview of HIV in the context of the disability. It contains a thorough discussion of the key medical concepts. It is available for free online. If you don't get any other resource on HIV, get this one.

B. Key HIV symptoms for disability advocates:

1. Fatigue

Fatigue is probably the most common symptom experienced by people with HIV, and is well studied by researchers. In one study 64% of participants had fatigue.²³ Another study describes fatigue as "the most frequent and debilitating complaint of HIV-infected people, with estimated prevalence rates ranging from 55 to 65%."²⁴

Notably, the research has shown that fatigue has no association with physiological markers, including CD4 count or Viral Load. This is true for both the incidence and severity of fatigue. So good viral suppression and increasing CD4 counts should not

²² In addition to my own observations from my practice, see Anandan, Navaraj; Braveman, Brent; Kielhofner, Gary; Forsyth, Kirsty, *Impairments and perceived competence in persons living with HIV/AIDS.. Work*, Vol. 27 Issue 3 255-266, (2006).

²³ Schifitto G, Deng L, Yeh TM, Evans SR, Ernst T, Zhong J, et al. Clinical, laboratory, and neuroimaging characteristics of fatigue in HIV-infected individuals. *Journal of Neurovirology*. 2011 Feb;17(1):17-25

²⁴ Barroso J, Hammill BG, Leserman J, Salahuddin N, Harmon JL, Pence BW. Physiological and Psychosocial Factors that Predict HIV-Related Fatigue. *AIDS and behavior*. 2010 Dec;14(6):1415-27.

undercut a claimant's subjective complaints of debilitating fatigue. Numerous studies have shown that there is no connection.²⁵ In fact, there has been little success in identifying physiological markers of HIV fatigue. One study states, "our findings suggest that monitoring lab values has little utility in identifying a cause for fatigue."²⁶ One study reviewed possible physiological associations with fatigue, including antiretroviral drugs, cytokine dysregulation, and basal ganglia dysregulation. It reached no definitive conclusion other than that CD4 and viral load were not predictive of fatigue.²⁷

There are some conditions experienced by people with HIV for which fatigue can be a symptom. These include anemia hormonal imbalances (especially low levels of the male hormone testosterone and adrenal hormones), depression and anxiety, poor, and sleep disturbances.²⁸

Research has shown that fatigue in people with HIV correlates to various psychosocial factors. These include depressive mood, younger age, more education,²⁹ being unemployed, not being on antiretroviral therapy, having fewer years since HIV diagnosis, more childhood trauma, more stressful life events, and more psychological distress (PTSD, anxiety, and depression).³⁰ It makes sense that depression might be associated with HIV fatigue, but fatigue is present in many patients even in the absence of depression.

The many studies on HIV fatigue compellingly describe the functional impacts of this complaint. Barroso et al state that "the consequences of fatigue include having to stop working, limiting one's involvement with family and friends, and needing an entire day to get through the simplest of household chores."³¹ These studies have other interesting findings. In one study, the longer a subject had been HIV-infected, the less fatigue they reported. It was speculated that "they have learned adaptive coping strategies that have helped them live with HIV as a chronic, manageable illness; it is also possible that they have modified their lives in incremental steps to accommodate fatigue."³²

Lessons from fatigue research

These studies provide direction for the advocate representing an HIV positive client in a disability case. First, don't be deterred by CD4 count and viral load. Second, always ask your client about fatigue. Probe beyond simple answers about fatigue to

²⁵ *Id.*

²⁶ Barroso, *supra*

²⁷ Schifitto, *supra*

²⁸ Liz Highleyman, *A Comprehensive Look at HIV-Related Fatigue*, San Francisco AIDS Foundation Spring 2001, available at <http://www.thebody.com/content/art2640.html>.

²⁹ Schifitto, *supra*

³⁰ Barroso, *supra*

³¹ *Id.*

³² *Id.*

determine the extent to which the client is limiting her activities because of fatigue. Clients may overstate their abilities. They may state that they can clean the house, but it may take all day. They may be able to spend a day going to medical appointments, but it may take a day or two of rest to recover from the energy outlay required. Clients may not volunteer this information; advocates need to probe. A fatigue questionnaire may come in handy. Various practice guides have such questionnaires.

Support from medical sources: Even though abundant research makes clear that CD4 and viral load are not associated with fatigue, you will need to do some work with the judge to overcome a tendency to place great weight on those labs. You may need to submit some of the many studies, or, perhaps even better, get your medical source to explain this medical knowledge. We frequently include a paragraph such as this one in the medical source statements we draft for supportive providers.

[responding to DDS comments about exaggerated fatigue]: Specifically troubling are findings in Mr. X' Social Security file that his fatigue could not be expected, given his condition, "to degree alleged." Though Mr. X has had a historically high CD4 count during the time I have treated him, rising as high as 1208, research and clinical practice show that CD4 count numbers provide no reliable correlation with symptoms, and hold no particular weight in terms of threshold for disability. I have cared for persons with low CD4 counts and high HIV viral loads who have no symptoms. In contrast, I have cared for others who have severe symptoms despite a normal CD4 count and a low viral load (such as Mr. X). Mr. X suffers from debilitating fatigue and diarrhea despite his CD4 count. Controlling Mr. X's HIV infection does not solve his complaint of fatigue.

This statement came from an infectious diseases specialist at an academic medical center. In this case, our client had a CD4 count over 1000, but well documented fatigue. We were able to get an OTR.

2. Chronic Diarrhea/GI issues

Diarrhea and other gastrointestinal complaints are still common in the era of antiretroviral medications. We see this symptom in probably a quarter of the HIV positive disability clients that we represent. Diarrhea can range from mild and intermittent to regular and unrelenting. Even with diarrhea that is intermittent, when it is active and requires repeated unscheduled bathroom breaks, it is impossible to accommodate in a job.

Diarrhea can be caused by HIV itself or as a side effect of the HIV or other medications. This is a symptom that can be embarrassing for a client to discuss, so

it can be necessary to probe. Needless to say, it is critical to find out how many days in a week the client has diarrhea, how many bowel movements, the degree of urgency, whether he or she has had accidents. Many clients with severe diarrhea carry an extra pair of clothing with them if they will be away from home for any length of time.

3. Peripheral Neuropathy

Many HIV positive clients experience symptoms of peripheral neuropathy such as pain, weakness, burning, or numbness. Studies indicate that more than one-third of HIV patients have symptomatic distal sensory polyneuropathy.³³ One study found 57.2 percent of HIV-infected patients with signs of peripheral neuropathy.³⁴ In that study, predictors of peripheral neuropathy included older age, lower CD4 nadir, current ARV use, and past exposure to certain ARV medications (the “d” drugs). Not all patients with HIV-associated distal sensory neuropathy experience pain, but in this study 38% of subjects had painful neuropathy. Pain was associated with higher CD4 nadir and major depressive disorder.

Peripheral neuropathy can strike feet, hands or both. It is often severely painful, requiring narcotic pain medications. Researchers have observed that this condition “has a serious effect on patient quality of life, including on sleep and diverse aspects of physical and emotional functioning. Spontaneous pain is common, and clinicians and patients report that pain often does not respond fully to the usual analgesic medications.”³⁵

These symptoms can affect basic daily activities such as personal care, walking, gripping, and fingering. Clients with neuropathy will often have difficulties buttoning their clothes, tying their shoes, opening jars, or even holding a pen. The numbness in their feet may affect balance and gait. The pain can interfere with concentration, memory, and attention.

Often these are relatively mild symptoms and have not been evaluated by the medical provider or even mentioned. If the client complains of these symptoms, we obviously urge her/him to report the symptoms to the medical provider. If the client has access to specialty medical care, they should be sent for a nerve conduction study which is diagnostic for neuropathy.

Peripheral neuropathy in HIV positive patients can stem from either the HIV itself, or from the toxic effects of antiretroviral drugs. It is generally not reversible and can

³³ Institute of Medicine, *supra* at 67, citing studies.

³⁴ Ellis RJ, Rosario D, Clifford DB, McArthur JC, Simpson D, Alexander T, et al. *Continued high prevalence and adverse clinical impact of human immunodeficiency virus-associated sensory neuropathy in the era of combination antiretroviral therapy: the CHARTER Study*. Archives of Neurology. 2010 May;67(5):552-8.

³⁵ *Id.* at 553

require intense pain management. Early in the HAART era, neuropathy was a very common side effect of certain antiretrovirals. Many people with HIV who have been on ARVs since the beginning have severe neuropathy. In cases of severe pain, the clients are placed on strong narcotics, including methadone. These clients have to contend not only with the unremitting pain, but with the sedation of their pain medicines.

4. Cognitive Impairment

Those of us old enough to remember the pre-antiretroviral days can recall the scourge of AIDS dementia, which took hold in advanced cases of AIDS. Prior to the introduction of combination therapy in the US, about 20-30% of people with advanced HIV infection had symptoms of HIV-associated dementia (“HAD”).³⁶ With the introduction of the powerful drugs, dementia has become a rare occurrence.³⁷

However, HIV still causes several neurological disorders, known as HIV-associated neurocognitive disorders (“HAND”). These vary from mild to moderate and include mild cognitive motor disorder and mild neurocognitive disorder.³⁸ As many as 40% of people with HIV have some form of HAND.³⁹ The rates are higher – about 50% - - in more advance stages of HIV. They also tend to be more severe in those with the most immune compromise, such as people with a current CD4 less than 50, a nadir CD4 less than 200, and high viral load.⁴⁰ Treatment with ARVs may lead to some improvement in HAND symptoms, but this has not been well tested or documented⁴¹ Even with treatment, “neurocognitive responses to CART have been varied across individuals, and studies of HAND in treated patients have documented high persisting rates of mild-to-moderate neurocognitive impairment.”⁴²

A variety of causes for the high rates of HAND in the HAART era include irreversible brain injury prior to beginning treatment; incomplete viral suppression in the central nervous system because of poor penetration of some of the common antiretroviral drugs; the possibility that even very low levels of viral replication in the central nervous system could cause neural injury due to prolonged exposure to

³⁶ Lindl KA, Marks DR, Kolson DL, Jordan-Sciutto KL. *HIV-Associated Neurocognitive Disorder: Pathogenesis and Therapeutic Opportunities*. Journal of neuroimmune pharmacology : the official journal of the Society on NeuroImmune Pharmacology. 2010 Sep;5(3):294-309.

³⁷ Institute of Medicine, *supra*

³⁸ *Id.*

³⁹ *Id.*

⁴⁰ Heaton RK, Clifford DB, Franklin DR, Woods SP, Ake C, Vaida F, et al. *HIV-associated neurocognitive disorders persist in the era of potent antiretroviral therapy: CHARTER Study*. Neurology. 2010 Dec;75(23):2087-96..

⁴¹ *Id.*

⁴² *Id.*

inflammatory responses and neurotoxic viral proteins; possible neurotoxicity of HIV drugs; and long-term exposure to increased rates of metabolic abnormalities or increased B-amyloid deposition in the brain.⁴³ Whatever the cause, it is clear that HAND persists in spite of advanced medications that can effectively suppress the virus.

Qualitatively, these disorders are often characterized as mild, but they can have a significant impact on disability. One study notes, “quality of life is greatly affected, with these individuals suffering from disruptions in ability to perform activities of daily living, perhaps most importantly, that of adherence to the HAART regimen.”⁴⁴ In the pre-HAART era, patients had more impairment in motor skills, cognitive speed, and verbal fluency. In the era of HAART, neurocognitive impairments have tended to involve “memory (learning) and executive function impairment.”⁴⁵

As with fatigue, viral suppression does not protect against HAND. What does predict HAND is the client’s nadir CD4 count. These disorders can be present in a client who is otherwise “asymptomatic” and whose CD4 count has rebounded. In fact, this is true at a higher rate in the era of ARVs than pre ARV.⁴⁶ The strong association of neurocognitive disorders with nadir CD4 count has been one of the factors that has driven recommendations for earlier initiation of ARV treatment.

Because low nadir CD4 predicts HAND, it is especially important for advocates to find out just how low their clients’ CD4 count has gone. Particularly with clients who have come into care with advanced disease and very low CD4 count, advocates should inquire carefully about any cognitive difficulties the client may be having. This should include problems with memory, attention, concentration, and processing speed. Many clients with HIV will describe symptoms of “brain fog.”

Documenting HAND: In many HIV cases I see, there is some degree of cognitive impairment, but it is rarely documented objectively. Unless the impairment is quite severe and immediately noticeable, neither the treating physician nor Social Security has obtained any psychological or neuropsychological testing. The effects of HAND can be significant, but subtle, and can easily be missed. This is where an advocate can build a record. Ideally, if a client has signs of neurocognitive impairment, neuropsychological testing should be obtained. However, a full battery of neuropsych testing is expensive and will not be ordered by SSA. If a client has insurance, it may be possible to persuade the medical provider to send the client for testing if there are appropriate clinical indicators. Even if the provider is willing to make a referral, though, this will be difficult for patients without insurance. Even when clients are seen at major academic medical centers that have the relevant

⁴³ *Id.*

⁴⁴ *Id.*, citing MacArthur 2004.

⁴⁵ Heaton et al, *supra*

⁴⁶ *Id.*

specialists on staff, a specialty consultation may be unattainable for a client without insurance. In such cases, it may be possible to at least obtain basic IQ and memory testing at a reasonable cost. While it may not be as good, subtest scores can document impaired functioning in many of the relevant domains.

In a recent study of HIV neurocognitive disorder, the areas of testing that were identified were:

- Speed of information processing (Digit Vigilance Time; WAIS-III Digit Symbol; WAIS-III Symbol Search; Trail Making Test, Part A)
- Learning and Memory (Story Memory Test; Figure Memory Test)
- Abstraction/Executive Functioning (Halstead Category Test, Wisconsin Card Sorting Test – 64 item, Trail Making Test, Part B)
- Verbal Fluency (Controlled Oral Word Association Test; Letters F-A-S/P-M-R for Spanish speaking Bilinguals); Category Fluency (Animals)
- Attention/Working Memory (WAIS-R Digit Span, WAIS-III Letter-Number Sequencing; PASAT (1st channel only)
- Motor (Grooved Pegboard Test – dominant and non-dominant hands)⁴⁷

5. General Constitutional Symptoms

Clients with HIV may also complain of a vague constellation of constitutional symptoms, including malaise, joint pain, sleep disturbance, night sweats, and fevers. As with fatigue, these symptoms are not always well documented in the client's medical record because visits are short and he or she may not feel that there is anything that can be done about them, or the provider is more focused on the extent to which the virus is suppressed than on the client's quality of life.

In the first full interview with the client, the advocate should identify any of these symptoms and encourage the client to report them to their provider. By the time a hearing comes around, there may be a better record.

6. Drug Side Effects

As stated elsewhere in this paper, the first antiretroviral drugs were highly toxic and produced many debilitating side effects. Many people could not tolerate the drugs. Of those who did, many experienced long term effects, including permanent peripheral neuropathy. Over the last 15 years, more and more HIV drugs have come on line. They are generally less toxic and more easily tolerated, but many people still experience side effects.

⁴⁷ Heaton et al, *supra*

There are numerous HIV-specific resources for researching side-effects of ARVs, including the Department of Health and Human Services Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents⁴⁸

C. Comorbidities:

In addition to HIV symptoms, HIV is also complicated by comorbidities such as **Hepatitis C (and B), cardiovascular disease, endocrine disease, especially diabetes and insulin resistance, renal dysfunction, tuberculosis, mental illness, osteoporosis, and non-HIV cancers.** These comorbidities complicate management of HIV and lead to drug interactions. It can make it much more challenging for the client to keep up with medical appointments and medications. Many of our clients, at a young age, are taking 10, 20, or more medications daily. For the advocate, it can be challenging teasing apart the symptoms of these many conditions, and often the help of the provider is needed.

Another concern for people with HIV is **premature aging.** As the HIV population ages, it has been observed that even people whose HIV is “controlled” with respect to the key lab values of CD4 and viral load seem to experience typical conditions of aging earlier than the general population. This is particularly true after age 50. Some of the diseases of aging that are striking earlier in people with HIV are cardiovascular disease, osteoporosis, cognitive deficits, depression, high blood pressure, kidney problems, arthritis, diabetes, Alzheimer’s disease, and various forms of cancer. For some of these conditions, the increased risk may come from some HIV medications. It is also theorized that HIV may advance the aging process.

1. Mental Illness

Psychiatric disorders are common with HIV, and mental illness is a risk factor for HIV. In many cases, mental illness will be the main event, with the HIV having little or no role in the disability claim. The most common mental disorders seen in people with HIV are major depression, delirium, and anxiety, which are reported in 25 to 50 percent of individuals with HIV.⁴⁹ Post Traumatic Stress Disorder is also common in HIV, seen in 13 to 30 percent of people with HIV.⁵⁰

In some cases, clients’ psychiatric symptoms stem directly from the HIV diagnosis, either from stigma and social isolation or the stress of living with a life-threatening, chronic illness. Medical or behavioral health records will sometimes report the client’s expressions of shame or distress in connection with the diagnosis, or will

⁴⁸ Department of Health and Human Services Panel on Antiretroviral Guidelines for Adults and Adolescents, *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents* (January 10, 2011) available at www.aidsinfo.nih.gov/contentfiles/adultandadolescentgl.pdf

⁴⁹ Institute of Medicine at 35, citing Pence 2006.

⁵⁰ *Id.*

provide examples of stigmatizing experiences or social isolation. In these instances we argue that the resulting depression or PTSD is a manifestation of the HIV infection under Listing 14.08. (See discussion below.) This is a helpful way to argue mental illness at Step 3 when this illness might not alone satisfy a mental impairment listing.

In other cases, the client has a long history of mental illness, often accompanied by substance abuse. The illness may or may not have been treated. Sometimes the only treatment has been a hospitalization or two in times of crisis. In any case where the client's mental illness is un- or undertreated, it will be important to try to get the client into care.

Many HIV clinics have recognized the need to connect their patients to mental health care in order to improve adherence to treatment as well as prevent secondary HIV infection. Mental illness is tied closely to non-adherence and poorer health outcomes. It is also connected to risky behaviors that lead to further spread of the disease and acquisition of additional STDs. In some major medical centers, the infectious diseases clinic has a dedicated psychiatrist, psychologist or other mental health professional. If you have a client with un or under treated mental illness, this may be a way to connect your client to care. In less resource rich medical clinic settings, getting your client into treatment may be a major challenge.

2. Hepatitis

Hepatitis is a common co-infection with HIV. In our practice, we see more cases of Hepatitis C (HCV) than B (HBV). Both can lead to liver fibrosis (cirrhosis), liver cancer, and death. The incidence of Hepatitis C in the HIV population is estimated at approximately 15-30%.⁵¹ HIV infection has been shown to speed progression of HCV to end-stage liver disease. Co-infected patients may not respond as well to hepatitis treatment.⁵² Studies have not shown that Hepatitis C causes more rapid progression of HIV. What is clear, though, is that a patient co-infected with HIV and HCV is much more difficult to manage, given the interactions of the diseases and the liver toxicities of many of the antiretroviral medications. One question is which disease to treat first. Most experts recommend starting ART and getting the HIV under control if the CD4 count is under 200.

Hepatitis C is a disease with a long course. It may take 20 years for the disease to become symptomatic. So for many co-infected clients, the Hepatitis C has little or no effect on the client's functioning. However, even when asymptomatic, fatigue is can be a problem. Skin abnormalities may also be present. As the disease advances, cognitive impairment may occur. Needless to say, many of these

⁵¹ New York State Department of Health AIDS Institute, HIV Guidelines, Hepatitis C, updated May 2010, available at <http://www.hivguidelines.org/clinical-guidelines/adults/hepatitis-c-virus/>

⁵² Institute of Medicine, *supra* at 81-82.

symptoms are also present in HIV infection and it can be difficult to tease them apart.

The psychosocial characteristics of many HIV positive patients may adversely affect HCV disease progression. The most obvious concern is the high rate of substance use among people with HIV. Many of our clients are actively drinking or drugging, which contributes to the progress of their disease. Others suffer from depression, which is a contraindication for hepatitis C treatment because a frequent side effect of the treatment is depression. It is common to see a client who is ready for Hepatitis C treatment but who is not placed on treatment because of depression or substance use.

3. Cardiovascular Disease

It is believed that people with HIV are at greater risk of cardiovascular disease than the general population.⁵³ It is not clear why this is so. One notion is that HIV and the drugs that treat it can lead to increased lipid levels.⁵⁴ Another idea is that HIV causes chronic inflammation, which is also a risk for cardiovascular disease.⁵⁵ Handling cases of HIV with cardiovascular disease involves no special considerations beyond the increased risk factor.

4. Diabetes

People with HIV have an increased incidence of diabetes. In a study of HIV-infected men, participants were more than four times likely to have diabetes than the general population. Diabetes was particularly associated with several classes of ARVs, the protease inhibitors and nucleoside reverse transcriptase inhibitors (NRTIs)⁵⁶. In another study, diabetes was associated with a nadir CD4 count of less than 300.⁵⁷

5. Chronic Kidney Disease

About 30 percent of people with HIV have some form of abnormal kidney function. Chronic kidney disease can put people at increased risk of progression to AIDS-defining illnesses and death.⁵⁸ It also complicates treatment of HIV because of the renal toxicity of some antiretroviral drugs.

⁵³ Institute of Medicine, *supra* at 78.

⁵⁴ *Id.*

⁵⁵ Satlin MJ, Hoover DR, Glesby MJ. *Glycemic Control in HIV-Infected Patients with Diabetes Mellitus and Rates of Meeting American Diabetes Association Management Guidelines*. AIDS patient care and STDs. 2011 Jan;25(1):5-12.

⁵⁶ *Id.*

⁵⁷ Institute of Medicine, *supra* at 81, citing (Winston et al., 2008).

⁵⁸ Institute of Medicine, *supra* 79, citing Szczech et al., 2004b)

HIV-associated nephropathy is notable for its quick progression to end-stage renal disease. The prevalence of this condition is uncertain. One study put it at 6.9%. However results of kidney biopsies from HIV infected people show HIV-associated nephropathy in 40 to 60 percent of specimens.⁵⁹

6. Osteoporosis

Osteoporosis has been found to be more prevalent in people with HIV than the general population, with studies suggesting rates ranging from 3 to 33 percent.⁶⁰ As with most HIV associated conditions, there is no clear causation, but possibilities include the virus or antiretroviral medications.⁶¹ Osteoporosis can lead to fractures and frailty.

7. Cancers

Since the introduction of HAART, AIDS-defining cancers have dramatically decreased. The cancers include Kaposi's sarcoma, invasive cervical cancer, and non-Hodgkins lymphoma. While these conditions are less common, they still do occur and generally are aggressive. These cases are likely to be approved at the state agency level.

In the era of HAART, there has been a rise in the rates of non-AIDS- defining cancers. The rate of these cancers is thought to be about twice that of the general population.⁶² The most common of these cancers are cancers of the anus, liver, lung, oropharynx, and Hodgkin's lymphoma.⁶³ Other than Hodgkin's lymphoma, these cancers are not any more severe than in the general population, and do not pose any special challenges for treatment. Hodgkin's lymphoma, however, may be more aggressive in people with HIV.⁶⁴

D. Medication Adherence

In order for antiretroviral drugs to effectively control HIV, it is essential that patients take their medications daily, as prescribed, for the rest of their lives. Adherence to medical regimens is a challenge for all conditions – from hypertension, to lipidemia, to diabetes. Unfortunately, the consequences of non-adherence or inadequate adherence to HIV therapy is more significant than for many other conditions. With poor adherence to HIV medications, the virus can mutate and develop resistance. This can require a change of regimen, which is something providers like to avoid.

⁵⁹ Institute of Medicine, *supra* 80, citing Shahinian et al, 2000, and Szczech et al, 2004a.

⁶⁰ Institute of Medicine, *supra* 71

⁶¹ *Id.* at 73

⁶² *Id.* at 83

⁶³ *Id.* citing (Nguyen et al, 2010.)

⁶⁴ *Id.*, citing (Powles et al., 2009.)

While the universe of available drugs and combinations has grown in the years since combination drug therapy was first introduced, there are still limits to what is available. Not all drugs can be tolerated by all people, so doctors emphasize the importance of strict adherence so that the arsenal of HIV medications will not be limited.

Because lack of adherence is strongly associated with increased morbidity and mortality, and has serious public health implications⁶⁵ there has been a great deal of research on adherence. Some of the predictors of poor adherence include the psychosocial factors discussed above, including mental illness (especially depression, anxiety, PTSD, bipolar disorder) trauma history, poverty, drug abuse, stigma, low education, lack of trust in the health care system, conspiracy theories, complexity of the regimen, memory problems, lack of insurance, and homelessness. Additionally, these are very strong, toxic drugs. Although the newer drugs are generally well tolerated, many do have side effects that are especially problematic in the first weeks or months. Many clients feel better without the medicine that with it.

In addition to medication non-adherence, it is often difficult to maintain clients in HIV care, and missed appointments are common. These kinds of problems can be related to the same factors as listed above, as well as lack of transportation.

It is important to be aware of the factors that contribute to poor adherence so that you can be prepared to address this issue. We have never lost a claim noncompliance (yet), but are always vigilant for references to non-adherence in the medical records so that we can address the issue pre-emptively.

V. The HIV Listings

The HIV listings were initially introduced in 1993, in response to the growing AIDS epidemic. The listings are at **14.08** of the Adult Disability Listings. They are primarily organized around the CDC's AIDS defining conditions. The 14.08 listing also includes several cross-references to other listings for HIV /AIDS related conditions that are described elsewhere in the listings (e.g. hepatitis, peripheral neuropathy, cardiovascular conditions, skin conditions).

In addition to the AIDS-defining conditions, there is a "catch-all" to cover people who have "repeated manifestations of HIV" but no single condition that is AIDS defining. The "repeated manifestations" listing (originally "N", and now "K") includes functional criteria nearly identical to those used for mental impairments.

⁶⁵ People with HIV are more infectious when their virus is not suppressed, so they are more likely to transmit HIV. And the virus they transmit will be drug-resistant, which means the person they might infect may come into care already resistant to some drug regimens.

The listings were updated in 2008 when the entire immune system listing was revised, but the HIV section maintained the same basic structure of AIDS defining conditions, plus the catch-all. The 2008 changes were mainly organizational, though they also included expansion of the introduction to the listings to include a more detailed discussion of medication adherence and side effects. As discussed below, the SSA is in the process of revising the HIV listings, though this process has been underway so long it is unknown when any changes will actually be put forward.

A. 14.08 A-J

The 14.08 A-J listings cover conditions that are AIDS defining. These days, we see few cases that meet these listings. The ones that do meet the A-J listings tend to arise in two circumstances: 1) a client who is failing treatment, frequently due to nonadherence or inability to tolerate the regimen; and 2) a client who is newly diagnosed and presents with advanced disease. (It is not uncommon for clients to come into care with a CD4 count of 0.)

These latter day AIDS cases may present with an opportunistic infection that is fatal, such as PML (Progressive multifocal leukoencephalopathy). Cases of this nature will be approved at the state agency level. However, many claimants present with an AIDS-defining condition that is treatable, with either antiretroviral or other medications. So they may suffer from a condition in the A-J list, but recover from it and return to work or other regular activities. This is one way in which the pre-HAART model of the listings simply doesn't fit with the modern course of HIV.

In cases where claimants recover from the A-J listed condition, state agencies can go either way. If the condition occurred prior to the alleged onset date, the A-J condition will likely not "count." If the condition occurred after the alleged onset date, but was cured, the state agency will often turn down a listing claim. We see this regularly in several situations. One is HIV wasting, where the client had a dramatic weight loss that would have satisfied 14.08H, but with treatment returned to baseline weight. This is common in situations where a client presented with advanced disease and then had a miraculous recovery once placed on ARVs. It is unlikely that the weight loss will win the day, either at the state agency or in front of an ALJ.

Pneumonia: Another commonly seen A-J issue involves pneumonia. In the pre-HAART era, patients frequently presented with a rare pneumonia that affects only immune compromised people, pneumocystis pneumonia, known as "PCP."⁶⁶ This pneumonia is listed at 14.08B7. In the HAART era, people with HIV are still

⁶⁶ This condition was previously known as *pneumocystis carinii pneumonia*, hence "PCP." More recently, it was determined that a different agent was responsible for the condition, and it has been re-identified as *pneumocystis jiroveci*. The "PCP" label endures.

vulnerable to PCP, and patients with a CD4 under 200 are treated prophylactically for this condition. Additionally, when HIV-infected patients present with pneumonia, they are generally treated presumptively for PCP because of the grave danger the condition presents. As a result, many people with HIV will have medical records with a diagnosis of “presumed PCP pneumonia,” or even “PCP pneumonia.” In most of these cases however, the patient was never tested for PCP, which requires a sputum sample for definitive diagnosis. So if your client or the medical records report PCP pneumonia, don’t open the champagne yet. Unless you can find lab results showing PCP, the state agency will not accept a listing. It is also possible that a cured case of PCP might not be sufficient to get a favorable decision. However, our experience with PCP in the North Carolina DDS has generally been that if it can be documented, even a cured case of PCP will support a 14.08B7 listing. We just rarely find documented PCP any more.

Infections: Many people with HIV still experience frequent infections, including community acquired pneumonia, staph infections, thrush, and herpes simplex or zoster. It is rare to see these at the level required in the 14.08 A-J listings, but they can nonetheless have a major impact on the client’s ability to function.

B. The “Repeated Manifestations” Listing: 14.08K

Fortunately, all the conditions that don’t quite meet the 14.08 A-J listings can still be stitched together to meet a listing: 14.08K:

K. Repeated (as defined in 14.00I3) manifestations of HIV infection, including those listed in 14.08A-J, but without the requisite findings for those listings (for example, carcinoma of the cervix not meeting the criteria in 14.08E, diarrhea not meeting the criteria in 14.08I), or other manifestations (for example, oral hairy leukoplakia, myositis, pancreatitis, hepatitis, peripheral neuropathy, glucose intolerance, muscle weakness, cognitive or other mental limitation) resulting in significant, documented symptoms or signs (for example, severe fatigue, fever, malaise, involuntary weight loss, pain, night sweats, nausea, vomiting, headaches, or insomnia) and one of the following at the marked level:

1. Limitation of activities of daily living.
2. Limitation in maintaining social functioning.
3. Limitation in completing tasks in a timely manner due to deficiencies in concentration, persistence, or pace.

The 14.08 listing is the one we most frequently consider in our HIV cases. It fits fairly well with the HAART-era experience of HIV. There is often no one condition

or symptoms that is disabling, but the combination of all of the conditions severely impacts functioning.

1. Manifestations

Our approach to 14.08K is to start by identifying all possible HIV manifestations, as well as any side effects of HIV drugs, which can be counted as a “manifestation.” Manifestations include conditions that are caused by or exacerbated by HIV. This will include conditions that are identified in A-J, but which lack the requisite severity or findings. Examples of A-J items that we often see include diarrhea, weight loss, infections, peripheral neuropathy, and hepatitis. In addition to the A-J items, we include here fatigue, cognitive impairment, sleep disturbances, avascular necrosis, renal insufficiency, diabetes exacerbation, candidiasis (thrush), muscle weakness, pain, night sweats, and any mental distress or impairment that arguably stems from or is exacerbated by the HIV.

Once we identify the possible HIV manifestations, we generally speak with the treating HIV provider and get her/his opinion on which of our proposed manifestations list they can endorse. Sometimes the provider will suggest additional other conditions or symptoms that they believe are related to the HIV. We try to get the provider to give us an opinion that includes an RFC and as much of the following as possible:

- An overview of the medical history and course of treatment.
- A prognosis.
- An explanation of the medical issues in the case, including how various conditions may be related.
- A list of manifestations of HIV (including conditions caused by or exacerbated by HIV)
- Observations of the client during visits, including mood, appearance, reports of subjective complaints, and difficulties functioning.
- An opinion that the client’s statements of functional limitations (e.g. need for naps, difficulties with daily activities, limits on walking, standing, etc.) are credible and consistent with the objective medical evidence.
- If the client has a history of substance abuse, an opinion that the substance abuse does not materially contribute to the finding of a disability.

- If the client has a history of non-compliance with medication, an explanation of the reasons for the non-compliance (e.g. medication side effects, difficulties accessing medications, cognitive difficulties, etc.) and/or a statement that compliance would not restore the client's ability to work.
- A brief statement of some medical or scientific point that might be important. For example, if the client has a high CD4 count and/or undetectable viral load, a statement that those lab values do not correlate to fatigue, cognitive impairment or other condition.

We find that HIV providers are more open to helping us with medical source statements than providers in other specialties. I think this is because it is not glamorous or lucrative to work with HIV-infected patients. Most of the providers working in this area are doing it because they are dedicated and care about their clients. This level of care will often extend to helping with disability claims. We try to make it easy for them by drafting statements for them based on our telephone conversation.

2. Functional component of the 14.08K listing

In addition to identifying the manifestations, an advocate must also present the claimant's functional limitations that stem from the HIV manifestations. The three categories of functional impairment are identical to those listed in the mental impairments. It should be noted that for 14.08K, it is only necessary to establish one of the categories of functional limitation, although it is rare that only one will apply.

- **Activities of Daily Living:** As discussed above in connection with fatigue and cognitive impairment, many people with HIV have adjusted their daily routines so as to cope with their limitations, so they may not perceive themselves to be as limited as they are. It is important to ask how long it takes to do tasks, whether they have to "recover" from undertaking activities such as going to appointments, cleaning, etc., and what kind of help they get from others, including their children.
- **Social Functioning:** As discussed earlier, **stigma**, both external and internal, is very common with HIV. Be sure to ask your client who knows about their HIV. They may have contributed to social isolation by keeping their diagnosis secret. They may have withdrawn from activities such as church, or stopped going out with friends. Some clients with visible impairments, such as skin disorders or lypodystrophy (fat accumulation) may avoid social contact for fear that people will figure out they have HIV.

- ***Difficulties with task completion due to deficiencies in concentration, persistence, or pace.*** Many people living with HIV are able to manage their daily activities, but at a slower pace. Common HIV manifestations such as fatigue, depression, cognitive disorder, weakness, pain, etc., will affect the domains of concentration, persistence or pace. Note that this is an “OR.” We often send providers an RFC questionnaire that asks about the percentage of time the client would be off task or unable to keep up the pace. This is useful not only in developing and RFC, but also in establishing this part of the HIV listing.

There is nothing particularly unique to building the functional portion of an HIV case – this is garden variety disability work. Anyone who has developed evidence and testimony concerning fatigue, pain, cognitive impairment or other subjective symptoms knows where to go with this. As in any case, it is important to talk to the client’s family, friends, and others who may be aware of their functioning. For people with HIV, that may include infectious disease clinic social workers and HIV or mental health case managers. Most case managers know their clients well and are willing to help. If something helpful can be said, they will say it. Rather than bringing them to the hearing as a witness, we prefer to get written statements. If necessary, though, a case manager can be a helpful witness and a strong ally. Judges generally consider them to be more impartial than family members (though, in fact, they are usually biased in the client’s favor). The main concern with case managers/social workers is keeping them from overstating the client’s case and giving opinions that are reserved to experts.

C. Continuing Disability Reviews

As people with HIV continue to do better and better on treatment, some may find themselves subject to a continuing disability review (“CDR”). SSA performs two types of CDRs: Medical and work-triggered. A work-triggered CDR may be initiated if a client returns to work and completes a trial work period, if substantial earnings are posted to the recipient’s wage record, or if the recipient informs SSA that he or she has recovered or returned to work. But work activity alone will not result in a CDR if the person had been receiving benefits for at least 24 months. Such cases will only be subject to a medical CDR as discussed below. Further protection against a CDR is afforded to SSDI recipients using a “ticket to work” or SSI recipients working under a “PASS” (“Plan for Achieving Self Support”).

Medical CDRs are scheduled based on the extent to which medical improvement is expected. The time frames are as follows:⁶⁷

- Medical Improvement Not Expected (MINE): once every 5-7 years.

⁶⁷ 20 CFR § 404.1590(d), § 416.990(d).

- Medical Improvement Possible (MIP): once every 3 years.
- Medical Improvement Expected (MIE): 6-18 months following finding of disability.

There is a special provision for people with HIV. If disability was approved based on meeting an HIV listing (14.08) prior to 1991, Social Security does not initiate a CDR.⁶⁸ However, an HIV positive person will be subject to a medical CDR if disability was approved based on some other condition.

In medical CDR's, the same considerations discussed above, such as fatigue, diarrhea, cognitive decline, and inability to sustain work on a regular and continuing basis, will be relevant.

D. SSA's Current Work to Revise the HIV Listings

IOM Study & Recommendations

In 2009, the Social Security Administration commissioned the Institute of Medicine of the National Academy Sciences to study and report on HIV and Disability listings. It formed the Committee on Social Security HIV Disability Criteria to recommend improvements to the HIV listings. This commission was yet another phase in the process that began in 2003 to re-assess the HIV listings. The basic question addressed by the IOM was how to bring HIV disability criteria in line with advances in science and medical treatment of HIV disease. Further, the stated objective was to streamline the adjudication process by identifying cases that could be approved quickly, as well as provide guidance to adjudicators on cases requiring more subtlety.

The committee sought to find "current equivalents" to the CDC AIDS definitions that provided the structure for the original listings. The IOM issued its report in late 2010.⁶⁹ In its recommendations, the committee abandoned the current listing structure and substituted four new criteria:

1. **CD4 count** at or below 50 cells/mm³, reviewed after 3 years to assess the claimant's response to treatment. (Instead of listings for opportunistic infections.)
2. **Imminently Fatal Conditions** – conditions with a high short-term mortality risk and minimal response to treatments.
3. **HIV-Associated Conditions Without Listings Elsewhere in Other Body Systems.** These conditions or treatment side effects would have to be

⁶⁸ POMS 28003.005(C).

⁶⁹ Institute of Medicine, *supra*.

accompanied by functional limitations, and would be subject to review after 3 years.

4. **HIV-Associated Diseases With Listings Elsewhere.** These would be “cross-reference” listings that occur at a higher rate or with earlier onset in the HIV populations, such as cardiovascular disease and chronic kidney disease.

In addition to the recommendations about disability criteria, the committee made recommendations with respect to the disability process, including an ongoing review of forms used in the disability process, rewriting all introductory material for adjudicators. Importantly, the committee recommended expanding the universe of health care professionals who can provide input in the determination process.

A group of HIV advocates has been monitoring SSA’s efforts to revise the listings since the process began in 2003. Their letter to the Commissioner commenting on the IOM recommendations is included with these materials.

VI. Conclusion:

Clients with HIV/AIDS are diverse, inspiring, sobering, frustrating, funny, and full of rewards. We hope these materials will help you provide them with the high quality representation they need and deserve