
PUBLIC BENEFITS

Table of Contents

I.	INTRODUCTION	2
II.	Disability Income Programs	3
A.	California State Disability Insurance (SDI)	3
1.	Eligibility requirements	3
2.	Determining Benefit Amounts	5
3.	Claims processing	6
4.	Appeals	6
5.	Duration and amount of benefits	6
6.	Interaction with unemployment benefits	7
B.	Social Security-sponsored programs	8
1.	Social Security Disability Insurance (SSDI)	9
2.	Supplemental Security Income (SSI) – Title XVI	12
3.	Claims processing and disability determination	14
C.	Veterans Administration disability benefits	26
1.	Service connected compensation	26
2.	Nonservice-connected pension	26
3.	Special monthly pension	27
4.	Special issue of HIV and “willful misconduct”	27
5.	Relationship of VA income to SSDI/SSI	28
6.	Claim processing	28
III.	Health Care Programs	29
A.	Medi-Cal	29
1.	Eligibility	29
2.	Coverage and scope of services	33
3.	Medi-Cal processing	34
4.	Penalties for transfers of assets	35
5.	Special programs	36
6.	Serostim	37
7.	ADAP	38
B.	Medicare	39
C.	Veterans Administration Health Care	40
1.	Hospital care	40
2.	Outpatient care	40
D.	California HIV-specific programs	41
1.	AIDS Drug Assistance Program (ADAP)	41
2.	CARE/HIPP	42
IV.	Special Needs Trusts	44
APPENDICES		
	Appendix A: Additional Resources	56

Appendix B: List of Social Security Forms	58
Appendix C: Social Security Form 4815-F5	59
Appendix D: Form 4814-F5, Question 42a. Supplemental Information	68

PUBLIC BENEFITS¹

I. INTRODUCTION

There is a myth out there that public entitlement programs are designed to be navigated by the public. Anyone who has ever tried to walk into a Social Security office to get a question answered knows how untrue that myth is. Dealing with a government bureaucracy is frustrating at the best of times, but doing so while facing a life-threatening illness — in order to access disability and health benefits — is a tremendous burden. Yet, because of its tremendous drains on health and income, almost all people with AIDS need some form of public assistance. Therefore, no matter what type of legal matter you are helping an ALRP client with, be aware that this struggle to maintain income and health coverage is always a piece of the backdrop.

This chapter is intended to give you a basic understanding of the government entitlement programs your ALRP client will most likely be applying for or receiving. It will help you be a better advocate, either in helping your client access the disability benefits and health care services she needs, or in helping her to preserve her entitlements if other life circumstances change. If you are planning to directly represent your client in Social Security appeals, we advise you to contact the AIDS Legal Referral Panel in order to acquire a copy of *Social Security Appeals for HIV Disability: An Advocate's Manual* (AIDS Legal Referral Panel, 1995).

In this chapter we will survey the most important public entitlement programs for people with HIV. First, we will look at disability programs that provide monthly income when one becomes too disabled to work. These include State Disability Insurance, Social Security, SSI, and veterans' benefits. Second, we will look at the health care programs that many people with HIV rely on to be able to handle the sky-high costs of HIV treatment. These include Medi-Cal, Medicare, veterans' health care, and some drug and insurance reimbursement programs specially designed for people with HIV. The ways in which all of these programs interact with private insurance benefits is discussed in greater detail in the Insurance chapter.

In all of the public benefits programs discussed in this chapter, HIV presents unique issues: What AIDS drugs and innovative treatments will public healthcare programs cover? What constitutes disability based on HIV? If you read nothing else in this chapter, I suggest you look at the section on the Social Security "Listings" for HIV. These are the regulations that set out what a person with HIV must demonstrate medically in order to prove she is disabled. Proving this is a prerequisite for accessing Social Security benefits, Medi-Cal, Medicare, and extended COBRA coverage. Taking a look at the hoops she must jump through to achieve this may be eye-opening.

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II. Disability Income Programs

A. California State Disability Insurance (SDI)

SDI is a state-sponsored short-term partial wage-replacement insurance plan for individuals who cannot work or need to reduce their work hours due to a medical condition. This program is administered by the Employment Development Department (EDD), the same agency that administers unemployment insurance benefits.

SDI is perhaps the most trouble-free of any of the entitlement programs, largely because it uses a rather lenient standard of disability. For SDI disability is defined as “any mental or physical illness or injury which prevents an individual from performing her regular or customary work.”² Therefore it is fairly rare to see an individual denied SDI based on a disability determination.

1. Eligibility Requirements

- She is unable to do her regular or customary work for at least eight consecutive days.
- She is employed or actively looking for work at the time she becomes disabled.
- During the previous period, (see below) she must have earned at least \$300 from which SDI deductions were withheld³.
- She is under the care and treatment of a licensed doctor or accredited religious practitioner during the first eight days of her disability. She must remain under care and treatment to continue receiving benefits.
- She must complete and mail a claim form within 49 days of the date she became disabled or she may lose benefits.

Her doctor must complete the medical certification of her disability.

Ineligibility:

A client is not eligible for SDI benefits if she...

- Is claiming or receiving Unemployment Insurance.
- Became disabled while committing a crime resulting in a felony conviction.
- Is receiving workers' compensation benefits at a weekly rate equal to or greater than the SDI rate.

² California Unemployment Insurance Code, Section 2626

³ In order to have paid in sufficiently, the individual's employer must have been deducting contributions from her payroll check or, if self-employed, she must have voluntarily paid in. Private employers are not required to participate in SDI if they have an equivalent short-term disability insurance program. Also, government employers often work exclusively under other retirement systems that supplant SDI for their employees (such as State Teachers' Retirement System, Public Employees' Retirement System, etc.).

- Is in jail, prison, or recovery home because she was convicted of a crime.
- Fails to have an independent medical examination when requested to do so.

2. Determining Benefit Amounts

EDD calculates an individual's weekly benefit amount using a 12-month base period. The base period is determined by the onset of disability. The amount of earnings within the base period determines the benefit level during disability.

For a disability claim to be valid, an individual must have at least \$300 in wages in the base period. If there are no earnings reported within the base period, the individual will be ineligible for monthly SDI benefits.

This base period covers 12 months and is divided into four consecutive quarters. The quarter of an individual's base period in which she was paid the highest wages determines her weekly benefit amount. Refer to the Disability Insurance Weekly Benefit Chart for further information. <http://www.edd.ca.gov/direp/dicfp-wba.pdf>. Using the following, you may determine your client's base period for her claim.

For claims beginning prior to January 1, 2003:

<i>For Disabilities Beginning in...</i>	<i>The Base Period is...</i>
November, December, January	Preceding July 1 - June 30
February, March, April	Preceding October 1 - September 30
May, June, July	Preceding January 1 - December 31
August, September, October	Preceding April 1 - March 31

An example: A claim beginning June 20, 2002, uses a base period of January 1, 2001, through December 31, 2001.

For claims beginning on or after January 1, 2003: *Note that the base period calculation stays the same, but the year is divided into quarters differently.

<i>For Disabilities Beginning in...</i>	<i>The Base Period is...</i>
January, February or March	Preceding October 1 - September 30
April, May or June	Preceding January 1-December 31
July, August, September	Preceding April 1 - March 31
August, September, October	Preceding July 1 - June 30

An example: A claim beginning February 14, 2003, uses a base period of October 1, 2001, through September 30, 2002.

3. Claims processing

SDI benefits are not payable until the eighth day of disability, unless an individual is hospitalized on the disability date. Claims for SDI benefits must be made within the 41 days following the first compensable day of disability. In other words, individuals must file their claims within 49 days of the onset of disability, or within 42 days if they were hospitalized when the disability began. If this deadline is missed, it will be extended upon a showing of good cause.

4. Appeals

If an individual needs to appeal any adverse action under the SDI program, there is a 20-day deadline for filing the appeal. This is significantly shorter than the deadlines of the other programs discussed in this chapter. To submit an appeal to EDD, complete the Disability Insurance Appeal Form, DE 1000A, that is mailed with disqualification notices or you may also send SDI a detailed letter. Be sure to include your client's social security number, their printed name and their signature. Be sure to provide additional information documenting your client's disability and additional information showing that your client had SDI taxes withheld from her check during her base period.

If SDI continues to deny benefits, your client will have an opportunity to have a hearing before an Administrative Law Judge. Information on requesting a hearing will be sent to your client along with her second disqualification letter. You may also contact the local California Unemployment Insurance Office of Appeals.

5. Duration and amount of benefits

SDI benefits are paid every two weeks, lasting for one year. The benefit level depends on the amount paid in during the base period. Weekly benefit amounts are usually approximately 55-60 percent of the earnings shown in the highest quarter of an individual's base period. The maximum benefit is \$602.00 per week. Individuals can receive SDI even if they are being paid a reduced amount by their employer (sick pay, etc.), as long as the weekly wage loss is equal to or higher than the weekly SDI benefit. In this way, SDI can work to supplement and extend the duration of sick pay that is already accrued on the job. (However, your client should report any sick leave pay, wages, workers' compensation benefits or other income to SDI to avoid being accessed an overpayment, penalty, or being disqualified from the program.) SDI benefits are not taxable, unless the individual was already receiving unemployment benefits at the time the SDI claim was filed.

6. Interaction with unemployment benefits

SDI and unemployment benefits may not be received concurrently. Because SDI requires the recipient to be unable to work, while unemployment benefits requires the individual to be both able to work and actively seeking work. This can become a

Notes:

Chapter 7: Public Benefits

B. Social Security-sponsored programs

The Social Security Administration (SSA) administers two types of entitlement programs for disabled individuals: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). A disabled person may be eligible for either one or both of these programs.

How Social Security defines disability...

Disability under Social Security is based on an inability to work. A client must be **"unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to last for a continuous period of not less than 12 months or result in death."**

To understand the meaning of this definition, it is necessary to examine each part separately.

An individual will be considered disabled if:

- 1) She cannot perform the work she did before becoming disabled, AND
- 2) SSA decides that she cannot adjust to other work because of her medical condition(s), AND
- 3) Her disability also must last or be expected to last for at least a year or is to result in death.

How This Definition of Disability Applies To People With HIV Infection

Generally speaking, people with HIV infection fall into two broad categories:

1. People with symptomatic HIV infection, including AIDS; and
2. People with HIV infection but no symptoms.

In order for your client to receive any Social Security benefit, she must demonstrate that her condition severely limits her ability to work. A person with symptomatic HIV infection (category # 1) who is severely limited in her ability to work will be able to receive Social Security benefits based on her HIV-positive status. On the other hand, some people with HIV infection are not impaired by that particular condition but may have another condition, such as mental illness or Hepatitis-C, that does severely limit her ability to work, and you should pursue coverage on that basis.

1. Social Security Disability Insurance (SSDI)

SSDI (also referred to as SSA, Title II, or simply “Social Security”) is an insurance-type program triggered by total disability. It pays a monthly benefit to disabled individuals who have paid sufficient “premiums” in the form of Social Security contributions (FICA payroll deductions or self-employment taxes). Once an individual’s benefits begin, SSDI payments continue until death or until the individual is no longer disabled.

(a) Non-Medical Eligibility Requirements

In order to be eligible, your client must:

- Be disabled under Social Security’s standards,
- Have a lawful immigration status, and
- Have sufficient work history (“fully insured”)*.

*Most people qualify for Social Security disability through their own work history; however, some individuals may be eligible for disability benefits based on the work history of another:

- Disabled widows and widowers age 50 or older could be eligible for a disability benefit on the Social Security record of a deceased spouse.
- Disabled children age 18 or older could be eligible for dependent's benefits on the Social Security record of a parent who is getting retirement or disability benefits or on the record of a parent who has died. (The disability must have started before age 22.)
- Children under the age of 18 qualify for dependents benefits on the record of a parent who is getting retirement or disability benefits or on the record of a parent who has died, merely because they are under age 18.

Limited income and resources are NOT a requirement for SSDI. Since SSDI is not a means-tested benefit, other income has no effect on one’s eligibility to receive SSDI. The exception to this rule is that if a beneficiary is receiving Workers Compensation payments or State Disability Insurance (SDI), SSA may reduce her SSDI so that the combined benefits total no more than 80% of her base salary.⁴ However, SSDI payments can be suspended or ended by work activity, even if the client's disability has not improved⁵.

It is possible for a person to be eligible for both SSI and SSDI benefits. If your client meets the work requirements of the SSDI program and the requirements of the SSI program, she may be eligible for an SSI check if her SSDI benefit is less than the maximum SSI benefit. In such instances, the SSI payment will be reduced dollar for dollar by the amount of the SSDI payment, except for \$20 which is disregarded as income exclusion.

⁴ 20 C.F.R. § 404.408.

⁵ Full benefits continue during a trial work period (TWP), regardless of the amount earned. If work continues after the TWP and is found to be substantial gainful activity, benefits are suspended, but can resume if earnings drop below the substantial gainful activity level during the Extended Period of Eligibility (and there has been no demonstrated medical improvement). Work deductions are imposed for earnings (above the exempt amount) of an auxiliary (spouse or child) who is receiving benefits on the disabled worker's account. See SSA Publication No. 05-10095, March 2003 at <http://www.ssa.gov/pubs/10095.html>

Determining whether your client has a sufficient work history

Sufficient work history means having paid Social Security taxes in enough quarters, either through the FICA payroll deduction or through self-employment tax.

Individuals can earn up to a maximum of four work credits per year. * Please note that the amount of earnings required for a credit increases each year as general wage levels rise. Work history requirements are updated on the web at www.ssa.gov.

The number of work credits an individual needs for disability benefits depends on their age when they became disabled. Generally your client will need 20 credits earned in the last 10 years ending with the year she became disabled. However, younger workers may qualify with fewer credits. As of November 2003, the work history rules are as follows:

- **Before age 24**—Your client may qualify if she has six credits earned in the three-year period ending when her disability starts.
- **Age 24 to 31**—Your client may qualify if she has credit for having worked half the time between age 21 and the time she become disabled.
(Example: if your client became disabled at age 27, she would need credit for three years of work (12 credits) out of the past six years—between age 21 and age 27).
- **Age 31 or older**—In general, your client will need to have the number of work credits shown in the chart shown below. Unless she is blind, at least 20 of the credits must have been earned in the 10 years immediately before she became disabled.

Born After 1929, Become Disabled At Age	Credits Needed
31 through 42	20
44	22
46	24
48	26
50	28
52	30
54	32
56	34
58	36
60	38
62 or older	40

(b) Benefits

Although an individual's right to receive SSDI accrues on the date she becomes permanently disabled, benefits do not become payable until the sixth month after the onset of disability. There is no outside deadline for filing SSDI claims. However, SSA will not pay more than one year's worth of retroactive benefits.⁶

The monthly benefit level is based on your client's lifetime average earnings covered by Social Security.⁷ An individual's monthly SSDI benefit can range from a couple of hundred dollars to well over \$1000, depending on her work history. In addition, a monthly benefit is available for a dependent spouse or the dependent children of an SSDI recipient beneficiary.

(c) Health Care

- **Public Health Insurance**
 - Medicare: After a disabled individual has received SSDI for 24 months, she is automatically entitled to Medicare coverage. Since there is a five-month waiting period for SSDI benefits to begin, Medicare entitlement will begin 29 months after the onset of disability.
 - Medi-Cal: Depending on her financial status, a client may also be eligible for Medi-Cal as a "medically needy" individual.
- **Private Health Insurance**
 - If an individual leaves work due to disability (as opposed to becoming disabled sometime after leaving work), she may be entitled to 29 months of COBRA coverage, instead of the usual 18. The purpose of this extension is to bridge the gap from private coverage to Medicare entitlement. It is important to keep in mind that she can only get this extension if she receives a disability determination from SSA and provides it to her former employer within 60 days of receiving it, and under no circumstances after the initial 18 months have elapsed. Remember, the disability determination must reflect a disability onset date that matches or precedes termination of employment⁸.

2. Supplemental Security Income (SSI) – Title XVI

Many clients may be applying for a combination of both SSI and SSDI.

SSI is a need-based program administered by the Social Security Administration to provide benefits to low income individuals who are disabled, blind, or over 65 years old.

⁶ 20 C.F.R. § 404.621.

⁷ To receive an estimate of what one's benefits would be, send a completed Form SSA-7004 (Request for Earnings and Benefit Estimate Statement) to a regional processing office or go to <http://www.ssa.gov/mystatement/>.

⁸ 29 U.S.C. §1162(2)(A). Note that if an individual is not eligible for SSDI or SSI, the Social Security Administration, under an agreement with the Department of Labor, will make a disability determination for the sole purpose of the COBRA extension. COBRA disability determinations are made at the federal DDS in Baltimore, and not regionally and must be made by the 18th month of COBRA coverage.

A base SSI benefit amount is set by the Social Security Administration. State governments have the option to increase that amount through the State Supplemental Payment (SSP). Total SSI benefit levels therefore vary from state to state.

(a) Eligibility

To qualify for SSI, an individual must:

- 1) be 65 years of age or older, blind, or disabled;
- 2) be financially needy;
- 3) reside in the US; and
- 4) have the requisite US citizenship or legal immigration status.

SSI differs from SSDI in that it is based on a claimant's financial need rather than on employment history. Disability is determined exactly as it is in the case of SSDI (see above). Financial need is based on the following tests of income and resources.

Income

For an individual to be eligible for SSI, she must have monthly “countable income” below the SSI benefit level. As of October 2003, an unmarried Californian’s monthly “countable income” must be under \$757. A married couple in California must have monthly “countable income” below \$1344. (Because these benefit levels change frequently, check www.socialsecurity.gov to confirm these amounts.) Countable income over the monthly benefit level will result in ineligibility for SSI during the month in which the income was received⁹.

Income, for SSI purposes, may be earned income, unearned income or in-kind gifts and services, such as food, clothing or shelter. Not all income is “countable.” All but \$20 of unearned income (e.g., other disability benefits) is countable for SSI purposes. Less than half of the wages one earns despite one’s disability are countable, due to the “earned income exclusion.”¹⁰

Resources

A single individual may not have available resources exceeding \$2000. A married couple may not have available resources exceeding \$3000. Some property is not considered an available resource, for instance the house one lives in, and a car under \$4500 in value or one that is used for medical purposes, regardless of its value¹¹.

(b) Benefits

⁹ Due to SSA’s method of “retroactive monthly accounting,” the amount will not be adjusted for two months.

¹⁰ These rules are relevant to ongoing SSI eligibility. At the application stage, however, monthly wages for non-blind individuals wages over \$810 will be deemed “substantial gainful activity” in 2004, and will trigger a finding that the individual is not disabled. Income issues are discussed generally in 20 C.F.R. §416.1100 *et seq.* Check www.socialsecurity.gov for the current “SGA” amount.

¹¹ 20 C.F.R. § 416.1201 *et seq.* Because of these limitations, a client’s benefit is jeopardized by the sudden receipt of any lump sum disbursements, such as settlements, inheritances or court judgments, which are considered income in the month they are received and resources in every subsequent month in which they are aren’t spent. Before your client receives any large sums, it is important to consider ways of shielding the award, such as through a special needs trust. Although there are no SSI penalties for giving away money after it is received in order to attain or maintain SSI eligibility, there can be consequences with respect to Medi-Cal entitlement.

One's entitlement to SSI accrues as of the application date¹² or the onset of the disability, whichever is later. There is no waiting period, so payments will begin at the start of the month following the accrual date.

As of January 2003, the monthly maximum SSI benefit for California residents who are not blind is \$757 for an adult individual, \$1344 for a married couple, and \$650 for a disabled child. This is the amount received if she has no other income, is "independent living" and has kitchen facilities. This benefit amount may change based on her living arrangements¹³. If she does have other unearned income, such as an SSDI benefit, SSA will ignore \$20 of it (this is the "set aside") and will pay the difference between that amount and the SSI benefit amount. If she is earning income, SSA will ignore more than half of it, using a special "earned income exclusion." For current benefit levels in other states, contact a local SSA office, or call 1-800-772-1213.

The benefit level is also affected by one's living arrangements. A disabled individual who lives in someone else's home and does not pay a fair share of the rent will receive SSI at a lower level. A homeless person, or someone who does not have access to a working kitchen, will receive a supplement known as a "restaurant meal allowance."

(c) Presumptive SSI

Some disabilities are so severe and obvious that Social Security acknowledges there is a high probability the claim will be approved. In these cases, SSA will issue benefits to the claimant for up to six months while the claim is being processed¹⁴. If the claim is subsequently denied, the claimant is under no obligation to pay the money back.

In the case of HIV infection, a completed Medical Report (Form 4814-F5) in which the claimant's physician indicates that the disability criteria are met, will qualify the claimant for presumptive SSI payments. The claimant still must submit evidence supporting the disability claim in the application process so that SSA's evaluators can make a final determination.

(d) Relevance for health care

SSI recipients are categorically eligible for Medi-Cal. When SSI is awarded, notice is automatically sent to Medi-Cal, which issues a Medi-Cal Beneficiary Identification Card (BIC), entitling the individual to use Medi-Cal.

If an individual whose Medi-Cal is categorically linked to SSI entitlement begins to earn income at a level that would disqualify her for SSI, Social Security will continue to

¹² If a claimant makes first contact with SSA by calling 1-800-772-1213, the date of that call will be considered the "protective filing date" and benefits will accrue as of then, instead of the date on which the written application is formally submitted.

¹³ To confirm the current Maximum Monthly Payment Amounts check SSA Publication No. 05-11125 at <http://www.ssa.gov/pubs/11125.html#max>.

¹⁴ 20 C.F.R. § 416.931 *et seq.*

authorize categorical Medi-Cal coverage in order to enable her to continue to work and be self-sufficient¹⁵.

If an individual receives both Medi-Cal and Medicare, Medicare will be the primary health insurance, and Medi-Cal will pay deductibles, co-payments, the Medicare Part B premium, and most expenses excluded by Medicare, such as outpatient drugs.

Finally, an SSI award is sufficient to extend COBRA benefits to 29 months (see above). If an SSI recipient has private health insurance (for instance through COBRA), Medi-Cal may pay the private health insurance premiums through a program known as “HIPP” (Health Insurance Premium Payment).

3. Claims processing and disability determination

(a) Claims processing

SSA district office

SSI and SSDI claimants file their claims at a Social Security district office. If they are unable to get to an office they may apply by phone by calling 1-800-772-1213. The district office will complete the application file. This includes collecting forms from the claimant, eliciting information about the claimant’s condition, medical records, activities, education and past work and job duties, as well as obtaining a release form to permit SSA to access the claimant’s medical records. A worker in the district office will then interview the claimant regarding her financial, citizenship and residential eligibility.

If an SSI claimant submits a completed HIV medical report (Form 4814-F5), at this time representing the physician’s belief that the disability criteria are met, the district office can order payment of presumptive SSI benefits. In all HIV cases, the district office should mark the file TERI (terminal illness) in order to expedite the processing.

The claimant should also directly submit medical records, as well as other evidence, including third party statements by friends, relatives, roommates, or social workers who are aware of the disabling effects of the claimant’s condition.

The state agency

The district office then forwards the claimant’s file to the California Department of Social Services Disability Evaluation Division whose function is to make disability determinations for SSA. This agency is referred to as the DED, or simply “the state agency.”

At the state agency, the file will be assigned to a disability analyst. The analyst manages the file until a decision is made by one of the state agency’s medical consultants. The disability analyst will request medical records from all sources mentioned in the Initial Application. The analyst also has the authority to order presumptive SSI payments, if the district office failed to do so. If the analyst determines that the information from the

¹⁵ This is known as “1619b Extended Medicaid.” 20 C.F.R. § 416.265 - § 416.269; *see also* POMS, SI A02302.030 *et seq.*

claimant's physician is inadequate to make a determination of disability, the analyst may order the claimant to be undergo a consultative examination by an agency physician or psychiatrist¹⁶.

If the disability analyst feels there is not sufficient information in the file relating to the claimant's ability to function, she may request additional information from the claimant by means of a "Daily Activities Questionnaire" (Form DEP 2059). The Daily Activities Questionnaire allows the claimant to describe in detail how her HIV condition (including the treatment for the condition) adversely affects her ability to engage in daily tasks, to function socially, and to concentrate.

The analysts and the medical consultants will use Social Security's five-step sequential evaluation to determine if the individual is disabled. The analysts are usually willing to speak with the claimant's advocate, and use them to help obtain additional information.

Appeals

If the claim is denied, the claimant has 60 days from the receipt of the denial to request a reconsideration. Receipt of the denial is presumed to be five days after it is sent, so the claimant generally has 65 days from the date of the notice. The request for reconsideration is filed at the district office which, again, forwards the materials to the state agency. The file will go to a different analyst. The same procedures are used in making a determination at the reconsideration level as were used at the initial application level.

If the claim is denied again at reconsideration, the claimant has 60 days from receipt of the denial to request a hearing before an Administrative Law Judge (ALJ). The request should again be filed at the district office, which will forward the file to the Office of Hearings and Appeals (OHA). Once the file is at the OHA, all correspondence should be sent directly to the OHA. At the OHA, the claim will be assigned to an ALJ and scheduled for a hearing.

If the denial at the reconsideration stage was not on the merits, but rather based on regulations that may be unconstitutional, the ALJ hearing may be bypassed so that the federal district court can hear the constitutional question¹⁷.

At the time of filing a request for an ALJ hearing, the claimant may request a decision on the record. If there is not sufficient evidence in the file for the ALJ to make a favorable decision, the claim will not be denied. Instead, the claimant will be scheduled for a hearing as if the paper review never happened¹⁸. This paper review is especially important since many OHA's are backlogged, and it can take months to get a hearing date.

If the claim is denied at the hearing level, the claimant may request review by the Appeals Council in Baltimore. The Appeals Council does not hold a new hearing,

¹⁶ 42 C.F.R. § 404.1517.

¹⁷ See Expedited Appeals, 20 C.F.R. § 404.923, § 416.1423.

¹⁸ 20 C.F.R. § 404.948, § 416.1448.

although it may grant oral argument on request. The Appeals Council review is generally limited to errors of law or abuse of discretion by the ALJ, although new medical evidence will also be considered. The Council may uphold the ALJ's decision, reverse the decision, or remand to the ALJ for another hearing. A denial at the Appeals Council level may be appealed to the federal district court.

(b) Sequential evaluation of disability claims

All evaluators of disability claims use a five-step sequential evaluation process to determine disability.¹⁹ The evaluation is based on the Social Security Act's definition of disability as "the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which has lasted or can be expected to last for a continuous period of not less than 12 months [or result in death²⁰]." In performing the evaluation, the following five questions are asked in turn. (*See Figure 1.*)

Step 1: Substantial gainful activity (SGA)

The threshold question of the evaluation is whether the claimant is currently engaging in "substantial gainful activity," or work. Substantial gainful activity involves performing significant physical or mental duties, or both, that are productive in nature. The work does not have to be full-time to be substantial; part-time can be enough. Gainful activity means work typically performed for pay or profit, whether it is actually profitable or not²¹.

Monthly earnings of \$810 or more are presumed to constitute substantial gainful activity. If an employer keeps an HIV-positive employee on the payroll despite the fact that she is no longer productive, SSA will only consider evidence that the wages paid are more a subsidy than work-related earnings.

If the claimant is found to be engaging in substantial gainful activity, she will be considered "not disabled" and the evaluation will end here. Otherwise, the evaluator moves on to Step 2 of the analysis.

Step 2: Severe impairment

The second question in the evaluation is whether the claimant suffers from a severe impairment that is expected to last at least 12 months or result in death. This is a preliminary question simply to determine if there is enough of an impairment present to continue on with the analysis. In order to show severe impairment, the claimant must show: impairment, severity, and duration.

Under the regulations, an "impairment" must "result from anatomical, physiological, or psychological abnormalities which can be shown by medically acceptable clinical and laboratory diagnostic techniques." Case law indicates that an impairment is "severe" if it has more than "a minimal effect" on an individual's ability to work. All HIV-related

¹⁹ 20 C.F.R. § 416.920.

²⁰ 42 U.S.C. § 423(d)(1), § 1382c(a)(3)(A) (1988). See also 20 C.F.R. § 404.1505.

²¹ See 20 C.F.R. § 404.1572 *et seq.*; § 416.971 *et seq.*

impairments that meet a Listing (see next section) are considered to have met the duration requirement.

If the claimant cannot show the existence of a severe impairment, the evaluation stops here and the claimant is found to be “not disabled.” Otherwise, the evaluator moves on to Step 3 of the sequence.

Step 3: Meeting or equaling the Listings

This is a crucial part of the evaluation, since the claimant has the potential to win her claim at this point. Here the claimant attempts to prove she suffers from a condition that has already been included in a list of impairments that Social Security has deemed to be disabling. These conditions are set forth in the regulations known as “Listings.”²² If the claimant has one of those impairments, she will be found disabled without further analysis.

If a claimant’s condition is not actually included in the Listings, but is of similar severity and duration as a listed condition, a claimant may be considered to have “equaled” the Listings, and will be found disabled without further analysis²³.

There are specific Listings setting out what factors constitute HIV disability. Additionally, some claimants with HIV may also meet Listings based on non-HIV factors. For instance, there are Listings for psychological disorders and substance addiction as well.

If the claimant’s medical condition is found to meet or equal a Listing, the claimant will be found disabled, the evaluation will end here, and benefits will begin. Otherwise, the evaluator moves on to Step 4 of the sequence.

Step 4: Past relevant work

In this step the claimant must prove she cannot perform any “past relevant work.” Generally, past relevant work is defined as any work the claimant has done in the last 15 years. SSA will evaluate the claimant’s ability to perform past relevant work by considering the functional limitations she experiences in performing work activities, and comparing those to the job responsibilities of her past work. To assess her limitations, the evaluator reviews the medical evidence and determines her “residual functional capacity.” The assessment must also take into consideration “non-exertional” impairments such as mental difficulties, pain unrelated to physical exertion, balance, sensitivity to environmental conditions, etc. After the residual functional capacity is assessed, it is compared to requirements of the claimant’s former jobs. If the claimant is found to be capable of performing past relevant work, she will be found to be not disabled. Otherwise, the evaluator moves on to the final step of the sequential evaluation.

²² 20 C.F.R., Pt. 404, Subpt. P, App. 1.

²³ Medical “equivalence” is discussed in 20 C.F.R. § 404.1526.

Step 5: Ability to perform other work

Once the claimant's evidence has demonstrated she cannot perform any past relevant work, the burden shifts to SSA to prove the claimant is nonetheless capable of adjusting to other work that exists in the national economy. At this stage, vocational factors such as age, education and work experience are considered. In determining if an individual can perform other work, the evaluator uses guidelines known as the "Grid."²⁴ The Grid is designed to assess vocational potential based on physical factors alone. Therefore, if a claimant has been determined to have "non-exertional" impairments, the Grid alone cannot be used to deny the claim. Instead, SSA will be forced to rely on testimony of a vocational expert. This is especially important for young claimants since, under the Grid, young people are usually found to be suitable for some type of work in the national economy.

If SSA proves that the claimant is able to do "other work," the claim will be denied. Otherwise, there will be a finding of disability. (This five-step process is represented in the chart below.)

²⁴ 20 C.F.R. Pt. 404, Subpt. P, Appendix 2.

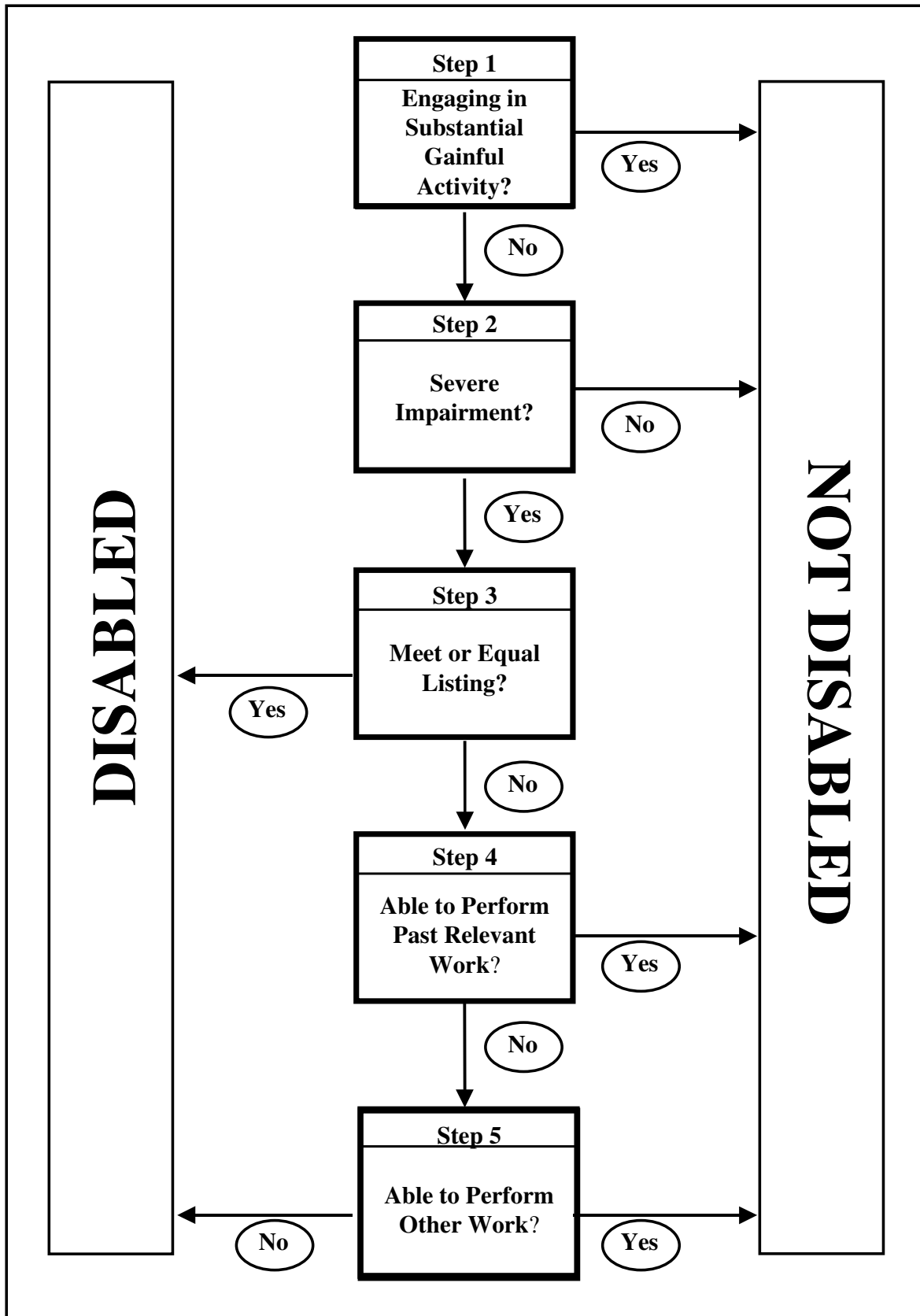


Figure 1: The Five-Step Sequential Evaluation of Disability

(c) HIV-Specific Listings and Their Troubled History

In July of 1993, the Social Security Administration issued – for the first time since the beginning of the AIDS epidemic – final regulations describing what an individual with HIV must prove in order to meet a disability Listing. Before these regulations were issued, many people living with HIV experienced inordinate delays in the processing and approval of their disability claims. In many instances, these delays resulted in the death of the claimant before a penny of disability money was paid.

In the early days of the AIDS epidemic, SSA relied simply on the surveillance definition of AIDS promulgated by the Centers for Disease Control (CDC)²⁵. Individuals with an AIDS diagnosis were considered to have met the Listings; people without that diagnosis did not. The lack of fit between an AIDS diagnosis and actual disability is obvious. Many individuals had an AIDS-defining illness but were quite functional. Others had a variety of opportunistic infections which were not AIDS-defining, but which were quite disabling. This result is not surprising, since the CDC issued its definition of AIDS for epidemiological purposes, and not for the purpose of determining functionality of particular individuals.

Moreover, since the CDC developed its AIDS definition based on information from health care providers, “AIDS” as a diagnosis was shaped by who had access to health care to begin with. Not surprisingly, the individuals with readiest access to health care were white men (in particular gay white men). This had the effect of making invisible the particular ways HIV presents in men of color and in women. Since many HIV manifestations in women are not unique to HIV (even though they may be profoundly more severe or resistant to therapy when HIV is present), women were consistently misdiagnosed. This inherent bias in the AIDS definition was then adopted into SSA’s disability evaluation, through the use of the CDC’s AIDS definition.

In December 1991, SSA released proposed HIV Listings, which were adopted as an interim regulatory scheme²⁶. The Interim Regulations set up a remarkably complex methodology for meeting a Listing. Although the Interim Regs were theoretically “decoupled” from the CDC AIDS definition, the interim scheme continued to privilege conditions that, at that time, constituted formal AIDS diagnoses, by treating them as disabling per se. For the remainder of HIV conditions, claimants had to make additional showings in order to meet a Listing. To many, this seemed to reveal SSA’s deep, institutional disbelief in the physically disabling nature of HIV disease.

In July 1993, SSA released final Listings for HIV disability²⁷. These new regulations, incorporated as §§ 14.08 (adults) and 114.08 (children) of the Listings, replace the Interim Regulations as the standard for proving disability based on HIV disease. For a useful summary of adult HIV Listings, look at SSA Form 4814-F5, “Medical Report on Adult with Allegation of Human Immunodeficiency Virus (HIV) Infection,” included as Appendix C of this chapter. Children’s HIV Listings are summarized in Form 4815-F6, included as an appendix to Chapter 9: Family Law.

²⁵ See 50 Fed. Reg. 5573 (Feb. 11, 1985).

²⁶ 56 Fed. Reg. 65498 *et seq.* (December 17, 1991) and 56 Fed. Reg. 65702 *et seq.* (December 18, 1991).

²⁷ 58 Fed. Reg. 36008 *et seq.* (July 2, 1993).

The 1993 HIV Listings are a significant improvement over all the regulatory schemes that preceded it. Nonetheless, many SSA disability evaluators have remained caught in their old methods, and have been known to require showings of HIV claimants that are not necessary under the new regulations. It is important for advocates to be vigilant of this problem, so that claims can be decided as rapidly and smoothly as possible.

Under the final HIV regulations, an adult who demonstrates she is HIV-positive can go on to meet the Listings in one of two ways:

- A diagnosis of any one of 41 “stand alone” conditions; or
- A series of “repeated manifestations” of HIV disease accompanied by functional impairment.

“Stand-alone” conditions

The first means of meeting the HIV Listings entails providing medical documentation of one of 41 severe HIV conditions, present in the particular way described in the Listing. Although some conditions have no qualifiers (for instance pneumocystis carinii pneumonia is considered disabling per se), others must be located at particular body sites, be resistant to therapy, or involve particular symptoms in order to be considered automatically disabling (see Appendix C: Medical Report Form 4814-F5). One noticeable improvement in the final HIV Listings is the inclusion of more conditions that are specific to women.

“Repeated manifestations” and functional impairment

Although 41 items certainly constitute a substantial list, many of the conditions are described quite restrictively. Manifestations of HIV conditions that don’t quite meet the qualifications of this stand-alone list may still be found to be disabling using the “repeated manifestations” method. Using this method, the claimant must provide a list of other manifestations of HIV infection she’s experienced within the last year, along with evidence of functional impairment.

This method of proving HIV disability creates an open ended opportunity for an individual with HIV to report on the many conditions she is experiencing. As SSA notes in its preamble to the new regulations:

“We decided that instead of expanding the list of manifestations, we could respond to the commentators’ concerns by abandoning the finite list of HIV-related manifestations and referring instead to “manifestations of HIV infection” in general. This allows for consideration of any manifestations, whether identified in the listing or not. . . . We had hoped to include in the listings [by means of this provision] a group of individuals whom we believed would be very difficult to describe in strictly medical terms – individuals who become ill then improve, only to repeatedly become ill again, either with the same manifestation of HIV infection or with different manifestations.”²⁸

²⁸ 58 Fed. Reg. 36016-17 (July 2, 1993).

The “repeated manifestations” approach constitutes, at least on paper, a significant achievement in SSA’s recognition of what HIV disability often looks like: an endless series of different medical problems, none of which would be disabling in and of itself, but which, in combination and rapid succession, make it impossible to do just about anything.

Under the first prong of the “repeated manifestations” analysis, the claimant must provide evidence of repeated manifestations of HIV infection. These manifestations can include conditions listed in the “stand-alone” section whose exact terms were not met, or any other condition attributable to HIV. To be sufficient, the claimant must document the following severity:

- At least three episodes within one year, each episode lasting at least two weeks;
- Substantially more than three episodes within one year, each episode lasting less than two weeks; or
- Less than three episodes within one year, each episode lasting substantially more than two weeks.

These episodic occurrences of HIV conditions, although referred to in the regulations as “repeated manifestations,” do not have to be recurrences of the same condition over and over. Instead, three distinct HIV manifestations will suffice. For instance, two episodes of diarrhea each lasting two weeks and one episode of a bacterial infection lasting two weeks should meet the requirement.

Although the formula above represents the minimum number of episodes necessary to prove disability, there is no limit on how many manifestations may be included in the disability claim. The claimant’s physician should be encouraged to list as many manifestations of HIV disease as possible and to submit additional paperwork if necessary. (You may use the supplemental manifestation sheet included as Appendix D to this chapter.)

The second prong of the “repeated manifestations” analysis is a functional limitations inquiry. The claimant must show marked functional impairment in one of three categories of life function: activities of daily living, social functioning, or completing tasks in a timely manner. In evaluating functionality, SSA should take into consideration “symptoms, such as fatigue and pain; characteristics of the illness, such as the frequency and duration of manifestations or periods of exacerbation and remission in the disease course; and the functional impact of treatment for the disease, including the side effects of medication.”

Relevance of T-cell counts

Another significant factor of the new regulations is that they exclude T-helper lymphocyte (CD4 or “T-cell”) counts from direct consideration as an indicator either of HIV infection or of disability. T-cells are the white blood cells that are taken to be a marker of the body’s immune function. Although a T-cell count of 200/mm³ or less

constitutes an AIDS diagnosis, as defined by the CDC (since January 1993), many individuals with low T-cells remain asymptomatic.

Despite this decision by SSA, many evaluators look at T-cell counts informally. A claimant can bring a period of falling T-cells to the evaluator's attention by including it in her laundry list of "repeated manifestations."

(d) Disability based on drug addiction or alcoholism

The SSA regulations regarding drug addiction and alcoholism (DAA) reveal a disbelief in the potentially disabling nature of addiction. To meet the Listings based on DAA, the effects of a claimant's chemical dependency or alcoholism must be manifested in one of several diagnosable physical or behavioral conditions: organic mental disorder, depressive syndrome, anxiety disorder, personality disorder, peripheral neuropathy, liver damage, gastritis, pancreatitis, or seizures.²⁹

Federal courts, however, have taken the view that alcoholism or drug addiction can in itself be severe enough to make it impossible for a person to engage in substantial gainful activity. Severe addiction therefore can make a claimant eligible for disability benefits³⁰. Under the case law, the relevant inquiry in DAA cases is two-fold:

- Has the claimant lost the voluntary ability to control his or her drug or alcohol use?
- If so, does the claimant's drug or alcohol use prevent him or her from engaging in sustained work?

The second prong of the inquiry is essentially a reformulation of the "Past Relevant Work" and "Other Work" steps of the 5-Step sequential evaluation. Note, however, that the threshold question of "substantial gainful activity" still precedes the inquiry above. Illegal activities engaged in to obtain drugs may be considered "substantial gainful activity."³¹

Individuals found to be disabled based materially or entirely on DAA face a number of restrictions on their eligibility for benefits. First, they must undergo drug or alcohol treatment that is available, that is appropriate for alcoholism or substance addiction, and that is appropriate for the stage of his or her rehabilitation, at an "approved facility." The individual must comply with the terms, conditions, and requirements of the treatment. The exact requirements and timelines for treatment differ for SSI recipients and SSDI beneficiaries. If the individual does not comply with the treatment requirement, she risks suspension, and ultimately termination, of benefits.

Second, individuals with DAA claims will not be permitted to receive their SSI or SSDI checks directly, but rather only through a representative payee. SSA must approve the

²⁹ 20 C.F.R., Pt. 404, Subpt. P, App. 1, § 12.09.

³⁰ Pub. L. No. 103-296 (1994), codifying the holdings of *Corrao v. Shalala*, 20 F.3d 943 (9th Cir. 1994) and *Dotson v. Shalala*, 1 F.3d 571 (7th Cir. 1993).

³¹ Pub. L. No. 103-296; POMS DI 90001.001-90095.001. See also Ethel Zelenske, *The Social Security Administrative Reform Act of 1994*, 28 Clearinghouse Rev. 897, 898-902 (Dec. 1994).

payee, and find one if the individual cannot. In approving representative payees, SSA will give preference to “qualified organizations” including community-based non-profit social service agencies, government social service or health care agencies, or state or local government agencies with fiduciary responsibilities, unless there is a determination that a family member would be more appropriate.

Finally, there is a 36-month limit on payment of SSDI and SSI benefits on DAA claims. If retroactive benefits are due at the time of the determination, they will be paid to the recipient over time, instead of in a lump sum, unless the recipient is homeless or at risk of becoming homeless if the full amount is not received.

(e) Practice pointers

Although Social Security is a public entitlement program, it is, for all intents and purposes, inaccessible to the public. The process itself is complicated, and the documentation required is nearly impossible to compile without professional support of some sort. For this reason it is crucial for claimants to work with benefits counselors from the beginning of the process. It is also crucial for their advocates to have access to as much help and technical support as possible.

Representing a claimant in an SSDI or SSI appeal can be as complicated and tricky as it is rewarding. We suggest that if you intend to do this representation, you obtain a copy of the AIDS Legal Referral Panel’s *Social Security Appeals for HIV Disability: An Advocate’s Manual* (ALRP 1995), and read through its practice pointers section. You should also attend a training in this subject. There are other resources that can be of use to you, including local groups of Social Security claimants’ representatives which meet periodically to discuss cases, local ALJs, and changes in the law, as well as national organizations. There are technical support centers available to pro bono lawyers. (See the list of Additional Resources, Appendix A.) The AIDS Legal Referral Panel also has mentor attorneys who can give you guidance.

Notes:

(f) Citizenship and Alienage

The SSI eligibility requirements and the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA) and the Balanced Budget Act of 1997 (BBA):

To qualify for SSI, a claimant must fit into one of the following citizenship/alienage categories:

1. a U.S. citizen or;

2. a non-citizen “qualified alien” (e.g., such as a permanent legal resident) who was not receiving SSI on August 22, 1996 but was residing in the U.S. lawfully at that time may be eligible for SSI on the basis of blindness and disability only (not eligible to receive SSI solely based on being aged); or;
3. a non-citizen “qualified alien” (e.g., such as a legal permanent resident) who was receiving SSI as of August 22, 1996 (this does NOT include immigrants with PRUCOL status); or;
4. SSI recipients who were receiving SSI on August 22, 1996 based on an application filed before January 1, 1979; or;
5. American Indians born in Canada who are members of certain federally-recognized tribes.

The Balanced Budget Act of 1997 (BBA), in essence “grandfathered” the following individuals, changing how PRWORA applies to them:

- All SSI recipients who were already receiving SSI as of August 22, 1996 are not subject to the provisions of the PRWORA which require a claimant to demonstrate citizenship or to fit within one of the limited exceptions to citizenship.
- Non-citizen “qualified aliens” who were residing lawfully in the U.S. as of August 22, 1996, but may not have been receiving SSI at that time may be eligible for SSI on the basis of blindness and/or disability without meeting the citizenship requirements of the PRWORA. In these cases, there is no requirement that the onset of disability occur after entry to the U.S.
- Those who are “qualified aliens” and were residing lawfully in the U.S. on August 22, 1996 and are 65 years or older may NOT apply for SSI solely on the basis of age, but instead must prove that they are either blind or disabled.
- Those recipients who were receiving SSI as of August 22, 1996 based on an SSI application filed before January 1, 1979 (before SSA tracked citizenship/immigration status), and for whom SSA lacks “clear and convincing evidence” that the recipient is ineligible based on his/her immigration status, are also grandfathered into SSI under the BBA.

However, if a claimant does not fit into one of the categories mentioned above, (i.e., is not a citizen, is not a “qualified alien” and was not residing lawfully in the U.S. on August 22, 1996) these individuals may be eligible for SSI only if they meet one of the following exceptions as outlined in the PRWORA:

1. claimant or her/his spouse is a veteran or on active duty in the U.S. Armed Forces (or claimant is the unmarried dependent child of a veteran or serviceman); or
2. claimant is a legal permanent resident and claimant or claimant's spouse (or claimant's parents when claimant was a minor child) has worked the equivalent of 10 years (40 qualifying quarters) at an income level that is credited for coverage under Social Security. For a quarter of work to count after December 31, 1996, claimant must not have received any means-tested federal public benefit during that quarter; or
3. claimant is a refugee, (an) asylee, (an) immigrant whose deportation is being withheld, or a Cuban/Haitian entrant, but only for the first seven years since her/his admittance, grant of asylum or withholding date. (Refugees, asylees, and immigrants whose deportation is being withheld who gained that status before 1990 are no longer eligible.)

This area of the law is complicated and subject to a variety of recent changes. If you have a question as to whether your client is eligible to apply for SSI benefits based on his/her citizenship or immigration status, please consult with a legal expert or an ALRP attorney.

Notes:

C. Veterans Administration disability benefits

Many people with HIV served in the military at some point and may be eligible for a disability benefit from the Veterans Administration. Often, people do not realize that these programs might be open to them, especially in light of the military's ban on participation of people with HIV. Whenever working with a client on disability issues, inquire whether the client ever served in the Armed Forces.

A veteran, for purposes of disability benefits, is a person who served in the active military, naval or air service and who was discharged under conditions other than dishonorable.³² The discharges that qualify as "other than dishonorable" are "honorable," "general," and "under honorable conditions." If an individual who served has a dishonorable discharge, she may undertake an official discharge upgrade from the military itself, or (the easier alternative) request the Veterans Administration to make a "Character of Service Determination." The determination would only be binding on the VA, but that would be sufficient to potentially qualify her for benefits.

³² 38 U.S.C. § 101.

Entitlement programs for disabled veterans are either service or nonservice-connected.

1. Service connected compensation³³

Monthly service connected compensation payments are available for a disability incurred or aggravated in the line of duty in the active military, naval or air service. The disabling condition does not need to be the result of an injury. A disability due to VA health care also qualifies.

The amount of the benefit is calculated on a percentage basis to compensate the veteran to the degree she is disabled by the service connected condition. (The minimum is 10% disabled.) These benefits are tax free, and are available regardless of the veteran's financial status.

2. Nonservice-connected pension³⁴

This is the VA's equivalent to the SSI program. It is a monthly payment for veterans who are permanently and totally disabled, financially eligible, and who have served for at least 90 days during wartime.³⁵ Actual combat is not required. The disability does not have to be related to the military service. Financial eligibility involves falling within both income and net worth limits. In evaluating income, VA will deduct unreimbursed "unusual medical expenses," those which exceed 5% of claimant's annual income.³⁶ For monthly benefit information, go to <http://www.appc1.va.gov/pubaff/fedben/Fedben.pdf>. The annual benefit level for a veteran without a dependant as of 2003 is \$9690.

Veterans entitled to both service connected compensation and nonservice-connected pension may receive only one. The VA will award whichever benefit is greater.

3. Special monthly pension³⁷

There are some additional, supplementary benefits that may be available upon request. The VA will grant them automatically if a veteran is rated at 100% disabled. The benefits include "housebound benefits," available to pension recipients who are permanently housebound, and "aid and attendance," available to pension recipients when the veteran needs the regular assistance of another person to perform the functions required by everyday living. "Aid and attendance" benefits require a greater degree of disability than "housebound" benefits. The standard is met per se if the veteran is in a nursing home.

³³ 38 U.S.C. § 1110.

³⁴ 38 U.S.C. § 1521; 38 C.F.R. § 3.3.

³⁵ See 38 U.S.C. § 101 for dates of qualifying wartimes. They currently include World War II, Korea, Vietnam, and the Gulf War. Veterans of the conflicts in Grenada and Panama would not be eligible for nonservice-connected pensions.

³⁶ 38 C.F.R. § 3.262(1) and § 3.271.

³⁷ 38 U.S.C. § 1502.

4. Special issue of HIV and “willful misconduct”³⁸

Disabilities arising during military service are presumed to be service-connected, unless they arise out of a veteran’s “willful misconduct.”³⁹ “Willful misconduct” has been held to be “an act involving ...[a] known prohibited action.”⁴⁰ The most common disabilities for which the VA denies service-connected compensation are drug/alcohol addiction and venereal disease.

HIV infection and AIDS-related conditions may be service connected, if there is evidence that the exposure occurred during military service. HIV-related symptoms need not have appeared during active service, as long as evidence indicates the exposure did.⁴¹ The U.S. Court of Veterans Appeals has been asked, and has declined, to establish a specific presumption that an HIV-related disability arising within 15 years of separation from the military is necessarily service connected.⁴²

Although HIV exposure during military service is generally not considered to be the result of “willful misconduct,” a “concurring” opinion in *ZN v. Brown* argues that HIV exposure stemming from same-sex sexual contact during military service must be considered to be the result of willful misconduct since “Congress has clearly stated that homosexual acts of sodomy are proscribed conduct within the military.”⁴³ Although this dissenting view is dictum in the *ZN* case, it may reflect a growing viewpoint. Advocates should be vigilant around this issue.

Substance addiction could be compensable if it is service connected; for instance, if the veteran can prove it is the result of post-traumatic stress disorder.

5. Relationship of VA income to SSDI/SSI

Social Security Disability Insurance or Retirement Benefits are not reduced on receipt of VA compensation. VA benefits are, however, considered income for SSI accounting purposes. These federal agencies share information; one should presume that information reported to Social Security is reported to the VA. Be careful to advise SSI recipients about the impact of VA income. Offsets can be confusing and may result in overpayment to the recipient, which would have to be repaid.

6. Claim processing

For disability benefits, veterans apply to the Department of Veterans Affairs, Regional Office (1-800-827-1000). However, it is advisable to speak first with a VA benefits counselor⁴⁴ or with a service organization, such as Disabled American Veterans or

³⁸ 38 U.S.C. § 101, § 1110.

³⁹ 38 U.S.C. § 105(a); 38 C.F.R. § 3.1(m), § 3.301(a) - (b).

⁴⁰ *Smith v. Derwinski*, 2 Vet.App. 241, 243-44 (1992).

⁴¹ *ZN v. Brown*, 6 Vet.App. 183, 194 (1994).

⁴² *Kern v. Brown*, 4 Vet.App. 350, 352 (1993).

⁴³ *ZN v. Brown*, 6 Vet.App. at 196.

⁴⁴ The VA’s regional HIV benefits counselor is Paula Bender, LCSW, at (415) 221-4810, ext. 2805.

Swords to Plowshares. Since benefits vest as of the application date, it is important to apply as early as possible.

There is no official expedited track for HIV disability evaluations. It is at the discretion of the local authority. Also, no presumptive benefits are available. During the evaluation, it is useful to be in contact with the VA medical examiners. The ratings board that makes the ultimate determination, however, is not accessible.

The veteran most likely has a copy of her discharge papers (DD 214). If not, service records should be obtained when applying for benefits. Use Standard Form I80 (available at Swords to Plowshares and other service organizations) to obtain military records from the National Archives. Obtaining DD 214's can be expedited if the veteran is homeless. Note that a special medical release is required to obtain military records regarding HIV, drug addiction or sickle cell anemia.

If benefits are denied, one should appeal the denial. To appeal an adverse decision about income benefits, appeal to the Regional Office. To appeal a denial of medical care, get the denial in writing and appeal to the Director of Medical Services at the medical center where benefits were denied (although one may wish to simultaneously file protective notice with the regional office).

The sources of law useful in handling an appeal include: Title 38, United States Code; Title 38, Code of Federal Regulations; Veterans Appeals Reporter (West's); VA General Counsel Opinions; and M21-1, VA's internal Adjudication Manual.

Notes:

III. Health Care Programs

Access to medical care is crucial for someone with a life-threatening disease like HIV. The cost of life-saving medical treatment, HIV drugs in particular, is costly even for those people healthy enough to work. Two popular HIV drugs, Norvir and Kaletra, cost about \$7,100 and \$6,500 respectively. The RAND research institute in Santa Monica, Calif., coordinated the largest examination ever of the economics of HIV treatment. The researchers interviewed 2,864 HIV patients. Between 1996 and 1998, the patients' average annual medical costs cost from \$18,300 to \$20,300. Despite these exorbitant costs, medical care and HIV drug therapy has increased expected lifespan of individuals living with HIV and improved the quality of their lives. For most clients you will be assisting, access to health care benefits will be one of the most important services you can provide.

A. Medi-Cal

Medi-Cal is California's Medicaid. Despite the name-game confusion, it functions within the rules of the federally developed program to provide medically necessary care. Medi-Cal offers a comprehensive system of care, covering institutional care, treatment by medical professionals, and prescription drugs. Its major limits are in its coverage of experimental and preventive care, although people with HIV can often obtain this type of treatment through special programs. Medi-Cal's payment scales also tend to be lower than the amount private insurers pay, and thus some private health care providers refuse to treat the lower-paying Medi-Cal card holders. Despite these difficulties, Medi-Cal is the most important source of care for many people with HIV.

1. Eligibility

- Individual must meet Social Security's definition of disability
- Assets must be less than \$2000⁴⁵
- "Qualified Immigrants and PRUCOL can receive full-scope Medi-Cal
- Undocumented immigrants are eligible for restricted Medi-Cal (Emergency, pre-natal care, labor, and delivery, family planning, long-term care and renal dialysis.)

A note on exempt resources

"Available" resources must be under the amount shown in Figure 2. Medi-Cal has a fairly generous list of "exempt" resources, i.e. resources that by their nature are not considered "available" and therefore are not counted: a home (as long as the Medi-Cal recipient lives in it or intends to return to it), a car of any value, clothing, household goods, musical instruments, work tools, wedding rings or heirlooms. It also does not consider burial funds, burial trusts, or burial contracts up to \$1,500 in value, or burial trusts of any value if they are irrevocable.

- CalWORKS (previously known as AFDC or TANF)
- Supplemental Security Income (SSI)
- Entrant Cash Assistance (ECA)
- Refugee Cash Assistance (RCA)
- In-Home Supportive Services

The majority of ALRP clients who receive Medi-Cal do so because they receive SSI. Included among the SSI-linked recipients of Medi-Cal are those who no longer receive

⁴⁵ There is an exception: if the client owns her home, she must live in it. If your client owns her car, the value must be less than \$4,500 or used for medical purposes.

SSI because the cost of living increases on their Social Security Disability Insurance benefits have pushed their incomes too high, as well as those who receive SSI despite high earned incomes under SSI's "\$1619(b)" work incentive program (see below).

If an individual's entitling benefits stop for any reason, the state must continue the person's Medi-Cal until it makes a determination of whether the individual qualifies for Medi-Cal on another ground (such as medically needy).⁴⁶

Social Security's 1619(b) provision 🌈

If an individual has earnings that reduce a monthly SSI cash benefit to zero, he or she may be eligible to continue Medi-Cal at no cost if the following requirements are met:

- Received Supplemental Security Income in the past twelve months;
- Continues to meet medical disability requirements;
- Continues to meet non-disability requirements;
- Needs Medicaid health coverage to continue to work; and
- Has income (wages) that are below the 1619(b) threshold amount of \$26,837 annually (as of 2003 in California).

*An individual with earnings higher than the threshold amount can apply for an individual threshold amount through Social Security if the individual's situation includes any of the following:

- Medi-Cal expenses above the average state amount;
- Personal attendant whose fees are publicly funded;
- Impairment-related work expenses;
- Blind work expenses; or
- A plan for achieving self-support.

Aged, Blind or Disabled Program

Aged, Blind or Disabled is a Medi-Cal *eligibility category* (program) for California residents under age 65 who meet disability and financial eligibility requirements. An individual may consider applying for this eligibility category when the sum of monthly unearned income and Countable Earned Income is not more than \$999 for an individual or \$1,340 for a couple during the year 2003.

Medically needy

Medically Needy Medi-Cal is an eligibility category (program) for California residents under 65 who meet disability and financial eligibility requirements. An individual may consider applying for this eligibility category when the sum of monthly unearned income and countable earned income is above the levels needed to be eligible in the SSI-linked

⁴⁶ The AFDC rule is found in *Edwards v. Myers*, 167 Cal. App. 3d 1070 (1985); the SSI rule is established by the consent decree in *Ramos v. Myers*, No. C 80 0332 WHO (N.D. Cal. Dec. 18, 1981).

and the Aged, Blind or Disabled categories of Medi-Cal. This coverage may require the individual to incur a monthly co-payment known as a share of cost. An individual under age 65 must meet Social Security's medical rules for disability.

Under Medically Needy Medi-Cal, the individual is the initial payer for health services, up to a fixed limit called the *share of cost*. The share of cost incurred by an individual in a given month is the amount by which the sum of the individual's unearned and countable earned incomes exceeds \$620 (\$954 for a couple). Payment of the monthly share of cost amount is a financial arrangement between the individual and the provider, not Medi-Cal. Medi-Cal pays for all other approved Medi-Cal services that month.

Individuals applying for Medically Needy Medi-Cal with unpaid medical bills may be able to reduce future share of cost expenses. This reduction is authorized by case law known as *Hunt v. Kizer*.

Program enrollees living with HIV/AIDS may be eligible to have the AIDS Drug Assistance Program (ADAP) cover the share of cost amount if they meet ADAP requirements and use ADAP approved prescriptions.

Handling a share of cost

A "medically needy" Medi-Cal recipient is responsible for paying her share of cost. Many recipients think this is a prerequisite to receiving Medi-Cal. It is not. Rather it is merely a deductible. The amount of countable income over the maintenance need is the amount that Medi-Cal will not pay. Whether the individual pays it or not is between her and her health care providers. Some providers waive the share of cost amount. Others are willing to set up a payment plan. A third party can pay the share of cost directly to the provider, as long as the money does not pass through the Medi-Cal recipient's hands (in which case it would have to be counted as income).

Individuals with a high share of cost may be able to reduce their share of cost by submitting old unpaid bills to Medi-Cal to count against the share of cost, so that their current treatment gets paid for fully. They may also submit bills for health care related costs that Medi-Cal itself does not cover, like occupational therapy, psychotherapy beyond what Medi-Cal covers, non-prescription drugs and health aids that a doctor thinks are medically necessary. Arguably, alternative and experimental therapies not covered by Medi-Cal also might be used to reduce the share of cost.

250% Working Disabled Medi-Cal Program

This program allows disabled workers to buy into Medi-Cal health coverage by paying a monthly premium. An individual must be working, meet Social Security's medical definition of disability, and meet the program's asset and income requirements. Workers not enrolled in any disability benefits program can be eligible for this program if they meet the medical definition of disability. Work activity is not considered in the medical

definition of disability in this Medi-Cal category. Working disabled individuals who do receive disability income, such as Social Security Disability Insurance or State Disability Insurance, may also be eligible for this program.

The program uses Medi-Cal's Countable Income Calculation to determine a worker's financial eligibility and the program's monthly premium. Because of this, an individual in 2003 can earn up to \$3,827 per month or \$45,924 annually (gross wages) and use this program.

Medi-Cal's In-Home Supportive Services Program (IHSS)

In-Home Supportive Services (IHSS) provides personal assistance services an individual can use to live at home or maintain employment safely. IHSS can be an alternative to living in an institution if the individual is found eligible for these services by means of a *needs assessment*. The individual must also meet Social Security's medical eligibility rules for disability, have limited assets, and live at home. IHSS is a Medi-Cal program.

An individual under age 65 must meet Social Security's medical rules for disability and show he or she can live at home safely with the assistance of an IHSS worker.

In addition to meeting the medical eligibility rules, a separate needs assessment is conducted by IHSS.

To qualify for no-cost In-Home Supportive Services, the sum of the individual's *unearned* and *countable earned income* (using the *Countable Earned Income calculation*) can be up to \$777 for an individual and \$1,364 for a couple for 2003.

Application, intake, and the IHSS Needs Assessment

The application and IHSS needs assessment are two separate procedures for eligibility. The process can take 30 days or longer depending on county caseloads and other factors.

An IHSS application can be taken over the telephone. (Call the Beneficiary Unit for Medi-Cal, 916-636-1980 to get the number of the closest IHSS office near you.) Once the initial IHSS application has been received, the individual will be assigned a caseworker who conducts the IHSS needs assessment. After IHSS approves your client for the program, she will be responsible for hiring, supervising, and firing their IHSS worker from the general labor market.

IHSS workers may be located through the county IHSS Public Authority, county home maker program, or county contract agency. Some community-based organizations, such as independent living centers, have personal assistant worker registries. Screening or background check procedures on IHSS workers varies from county to county.

2. Coverage and scope of services

Medi-Cal covers a broad range of medical services. Services include but are not limited to:

- inpatient hospital services, including tests, surgeries, special procedures and care that is medically necessary;
- outpatient hospital services;
- physician services;
- medical and surgical dental services;
- nursing facility (NF) services for individuals aged 21 or older;
- home health care for persons eligible for nursing facility services;
- family planning services and supplies;
- rural health clinic services and any other ambulatory services offered by a rural health clinic that are otherwise covered under the state plan;
- laboratory and x-ray services;
- pediatric and family nurse practitioner services;
- federally-qualified health center services and any other ambulatory services offered by a federally qualified health center that are otherwise covered under the state plan;
- nurse-midwife services;
- early and periodic screening, diagnosis and treatment (EPSDT) services for individuals under age 21;
- prenatal care and delivery services for pregnant women;
- ambulatory services to individuals under age 18 and individuals entitled to institutional services;
- home health services to individuals entitled to nursing facility services;
- clinic services;
- nursing facility services for persons under age 21;
- intermediate care facility/mentally retarded services;
- optometrist services and eyeglasses;
- prescribed drugs;
- TB-related services for TB infected persons;
- prosthetic devices; and
- dental services.

In general there are no limitations placed on basic services provided by Medi-Cal. Some procedures, treatments or care may require advanced screening or approval. If you are unsure whether or not a specific service is covered by Medi-Cal, speak with the prescribing and/or treating physician or practitioner. Service providers who accept Medi-Cal are typically well informed about care access provisions as well as whether or not pre-authorizations are required for specific treatments and procedures.

On November 1, 1994, California's Medi-Cal program instituted a policy of limiting prescription medications to six prescriptions per client per month. Because there are a substantial amount of HIV drugs and cancer medications that are exempt from this limit, most HIV-positive Medi-Cal recipients are not affected by this policy.

Experimental treatments

Although Medi-Cal doesn't cover experimental treatments, it covers "investigational" treatments that meet certain criteria. In order to be covered, it must be shown that conventional therapy is inadequate, the provider has a record of safety and success, and the treatment is likely to succeed.⁴⁷ For HIV-positive clients, Medi-Cal will cover medications classified by the FDA or DHS as an Investigational New Drug.⁴⁸

Retroactivity

Medi-Cal covers care received up to three months prior to the application for Medi-Cal, provided the individual would have been eligible in those months. Medi-Cal must receive the request for retroactive coverage within one year of the application. Old bills not covered by Medi-Cal can always be used against the share of cost, as long as they are still due.

3. Medi-Cal processing

(a) Disability determination

State law requires Medi-Cal disability determinations to be completed within 90 days of the application.⁴⁹ Medi-Cal disability determinations are done by the Department of Social Services Disability Evaluation Division, the same state agency that performs SSI/SSDI disability determinations. It has been observed, however, that the DED personnel making Medi-Cal disability determinations tend to make somewhat more favorable decisions on the whole.

SSI/SSDI disability determinations take precedence over Medi-Cal determinations. If someone applies for Medi-Cal at the same time she applies for SSI or SSDI, an SSI/SSDI rejection will result in a Medi-Cal rejection. In some instances, the fact that there is an SSI/SSDI claim pending will cause the state agency to hold off making a Medi-Cal disability determination. This violates the 90-day rule mentioned above, but there have been widespread reports of this happening.⁵⁰

For this reason, if Medi-Cal benefits are more important to your client than the SSI or SSDI benefit, it might be advantageous for your client to apply for Medi-Cal only. The decision will have to be made within 90 days, and then your client can apply for SSI/SSDI. If she is determined not to be disabled for SSI/SSDI purposes, Medi-Cal must keep her on the Medi-Cal rolls as long as the SSI/SSDI claim is being appealed.

(b) Fair hearing rights

Any adverse decision by Medi-Cal must be appealed within 90 days. There is no "reconsideration" level of appeal, but only a fair hearing before an Administrative Law Judge.

⁴⁷ Cal. Welf. & Inst. Code § 14137.8.

⁴⁸ Cal. Welf. & Inst. Code § 14137.6.

⁴⁹ 22 Cal. Code Regs. § 50177(a)(2).

⁵⁰ 45 C.F.R. § 435.541(c)(2); *see also Radcliffe v. Kizer*, San Francisco Superior Court, Docket No. 910-804. If you have questions, call Mike Keys at SFNLAF, (415) 627-0200.

4. Penalties for transfers of assets

Transfer of non-exempt assets for less than their fair market value triggers penalties under federal Medicaid law. The penalty consists of Medi-Cal refusing to cover certain types of care for periods of time, depending on the value of the transferred assets. It is not yet clear whether individuals who receive Medi-Cal based on categorical linkage via SSI are also subject to the penalties, but one should presume that they will be affected also.

(a) Care affected

The penalty affects care received in long-term care nursing facilities, and care received through home and community-based “waivers.” Other than long-term nursing home care, the regulations are not yet specific regarding what types of home care or “waiver” care is affected, although it is reasonable to assume that In-Home Supportive Services (IHSS) will be affected. The penalty does not affect the receipt of standard Medi-Cal care and home care.

(b) Calculating the duration of the penalty

Under federal Medicaid law, upon entering a long-term care facility, Medi-Cal will “look back” 36 months for transfers of assets for less than their fair market value. (They will look back 60 months for transfers involving trusts.) The amount of the transfers (or amounts of under-value) will be divided by the state’s monthly Medi-Cal cost for nursing homes. The result will be the number of months Medi-Cal will not cover long-term care. There is no outside limit to how long a penalty may last.

There are exceptions to the penalty: transfers made to certain people, undue hardship, or transfers not made in order to qualify for Medi-Cal will not be penalized. Therefore, transfers of exempt assets such as a home – by definition – will not trigger a penalty.

(c) Trusts

Trusts in which an individual has discretion over how funds are used, as well as trusts that are revocable, will be considered “available” resources. Transfers of assets into irrevocable trusts are considered transfers of assets that will give rise to penalties. Only special needs trusts set up for a person with a disability and funded by parents or by a court⁵¹ (e.g., out of a personal injury settlement) are not counted as available resources, although Medi-Cal may recover against the trust upon the individual’s death.

(d) Liens and claims

Medi-Cal maintains the right to claim against a Medi-Cal recipient’s property upon death if it paid for long-term care, or for any care after age 55.⁵² Under federal law, estate recovery can even include reaching joint tenancy property.

⁵¹ State law permits courts to establish special needs trusts for the purpose of maintaining eligibility for public benefits. Cal. Prob. Code § 3600 *et seq.*

⁵² 42 U.S.C. § 1396p(b)(1)(B), as amended by COBRA 1993, § 13612.

5. Special programs

(a) Medi-Cal/HIPP

For Medi-Cal recipients lucky enough to have private health insurance, Medi-Cal may pay those private insurance premiums through its Health Insurance Premium Payment (HIPP) program. To be eligible for this plan the following requirements must be met:

1. There must be a private health insurance plan in force which covers the high cost medical condition. It may be an individual policy or a group health plan on self-pay through COBRA or a conversion policy. HIPP does not purchase new policies for persons. NOTE: HIPP will not pay the premiums for the California Major Risk Medical Insurance Plan (MRMIP).
 2. There must be current Medi-Cal eligibility either with full Medi-Cal or with a Share of Cost less than \$200. Share of Cost equals total income less health insurance premiums, child support, alimony and the Medi-Cal maintenance need of \$600 (\$620 for persons who are disabled). For example, someone who is disabled with an income of \$950 and insurance premiums of \$250 would be eligible for HIPP as their Share of Cost would be less than \$200 ($\$950 - \$250 - \$620 = \80 Share of Cost).
 3. The applicant must have a disability resulting in high medical costs, such as HIV/AIDS. Proof may be requested that medical bills exceed twice the monthly premiums, but this is usually waived with a diagnosis of AIDS.
 4. The applicant must not be enrolled in a Medi-Cal related pre-paid health plan, the San Mateo County Health Plan, the Santa Barbara County Health Initiative or a Medicare HMO.
 5. HIPP will NOT pay premiums for plans written by the California Major Risk Medical Insurance Plan (MRMIP).
- To apply for the Medi-Cal HIPP program you should submit:
 - A completed Health Insurance Premium Payment (HIPP) Referral Form (DHS 6172).
 - Copy of a doctor's statement of diagnosis, signed and dated.
 - Proof of Medi-Cal eligibility (photo of Medi-Cal Card, Share of Cost form, etc.).
 - Copy of the latest premium payment notice or a signed COBRA election form.
 - Copy of insurance policy booklet (which describes benefits).
 - Documents should be sent to: Department of Health Services, HIPP Coordinator Premium Payment Unit, P.O. Box 1287, Sacramento, CA 95812-1287.

6. Serostim

The government has tried to reduce the overall spending in the area of Medicaid over the past few years. Due to budget deficits, and the fact that California provides the highest amount of Medi-Cal (California's Medicaid) funding in the country, it is ripe for budget cuts in the eyes of some government officials. Another reason that spending on

Medi-Cal is the subject of scrutiny is due to the fact that Medi-Cal spent \$175 million in a four-year period on a drug called Serostim which helps AIDS patients with wasting syndrome to build muscle mass and prolong their lives.

Wasting syndrome causes the body to consume fat, organ, and muscle tissue, sometimes at the alarming rate of one pound per day. Serostim is one of the drugs found to help reverse or prolong this process.⁵³ However, Serostim also has a black market value because it is a hormone that increases muscle mass and thus is highly sought after by bodybuilders. The drug costs about \$7,000 a month and it is estimated that, until recent legislation, one-third of Medi-Cal's drug program was funding this lucrative black market trade.⁵⁴

Recent legislation makes it more difficult for some AIDS patients to get the medication they need in order to live. It is highly debatable as to whether this Serostim legislation helps AIDS patients by restricting the use of the drug to those in need, or if the new laws actually decrease the life expectancy of certain patients at the benefit of saving money and helping to lessen the fraud and illegal trade of Serostim. As of June 1, 2003, all new prescriptions for Serostim must be state-approved prior to being filled and initial prescriptions of the drug will be limited to four weeks. This means that the patient's physician must complete a Treatment Authorization Request (TAR) containing all specified information before Medi-Cal will consider paying for Serostim.⁵⁵ Also, since the prescription is limited to 28 days, a new TAR must be submitted every month.

Some healthcare providers are very aware of these requirements for AIDS patients (like positive healthcare) yet many are in the dark about the necessary requirements and thus do not complete and submit all the proper paper work. This makes the drug inaccessible to the patient, which is life threatening when the patient is losing muscle and organ mass. Litigation is on the rise as to what can and should be done for these patients. For an attorney, doctor, and patient, there are some places to look for information regarding the rules that must be followed in order to receive the prescribed medication. Some of this information can be found at <http://www.hcfa.gov/medicaid>.

7. ADAP

Another area of Medi-Cal litigation that involves people with HIV who are not disabled but were not eligible for Medi-Cal benefits. These people were and are eligible for the AIDS Drug Assistance Program (ADAP) as long as they: are an HIV-positive California resident over the age of 18, make less than \$50,000 per year, and have a valid prescription from a doctor licensed in this state. This was the only aid available to non-disabled HIV patients until bill AB 2197 was signed into legislation in 2002.

This bill is codified in the California Welfare and Institutions Code and allows for non-disabled persons with HIV to receive Medi-Cal benefits as long as they are enrolled in ADAP (because ADAP subrogates the costs) and would, if disabled, qualify for Medi-

⁵³ Serostim is one of the few FDA-approved drugs to treat wasting syndrome. Other drugs like Megestrol Acetate are FDA approved but have varying effects.

⁵⁴ See Tim Reiterman's article *California: Tighter Controls Set for AIDS Drug* (*LA Times*, April 4, 2003). The \$7,000 figure comes from the California Department of Health Services. It is important to note that the article also states, "You don't stop fraud by denying people who need the medicine."

⁵⁵ See Cal. Wel. & Inst. Code §14133; See also www.alpa.org

Cal benefits.⁵⁶ This program is supposed to be instituted on a voluntary basis and was scheduled to begin in January 2003; however, issues of funding are making this a slow implementation process.⁵⁷

B. Medicare

Medicare is a health insurance program sponsored by the Social Security Administration. It is available to seniors as well as younger adults if they are disabled and have been receiving Social Security Disability Insurance benefits for two years. There is no way for young people to purchase Medicare if they are not entitled through SSDI.

Medicare is made up of two parts: Hospitalization (Part A) and Medical (Part B). Entitlement to Part A is automatic after 24 months of SSDI. The SSDI beneficiary cannot opt out of Part A coverage. Part B, however, is optional. If the individual decides to accept Part B, it will entail a small monthly premium. If an individual is entitled to Medi-Cal as well, Medi-Cal will pay the Medicare Part B premium.

Medicare's coverage is much more limited than Medi-Cal's. Medicare pays only 80% of its approved costs for medically necessary treatment. The beneficiary must pay the remaining 20%, unless the health care provider takes "Medicare assignment." Medicare Part A covers costs of inpatient treatment, including hospital care, skilled nursing facilities, home health care and hospice care. Part B covers physician's services, durable medical equipment and supplies, psychiatric social services, chiropractic care and ambulance service.

Neither Medicare Part A nor Part B covers outpatient pharmaceuticals. For people with HIV, this is Medicare's greatest limitation. If an individual has Medi-Cal as well, Medi-Cal will pay for drugs. Otherwise, a Medicare recipient must use other programs such as the California AIDS Drug Assistance Program (ADAP), or private Medicare Supplemental Insurance (not available on the market to young individuals, but only as "conversion" policies from certain group or individual health insurance plans).

C. Veterans Administration Health Care⁵⁸

Some HIV-positive individuals may be eligible for health care through Veterans Administration hospitals and clinics. Discrimination against HIV-infected veterans is prohibited at VA health care facilities.⁵⁹

1. Hospital care

Hospital care must be provided (and nursing home care may be provided) by the Veteran's Administration to certain categories of veterans, including:

⁵⁶ Cal. Wel. & Inst. Code §14149; *see also* Cal. Health and Safety Code §120960 and Cal. Wel. & Inst. Code §14149.3.

⁵⁷ A program along these same lines is being considered by the federal government and is called the Early Treatment for HIV Act (ETHA) which would allow states to amend the Medicaid eligibility requirements for people with HIV.

⁵⁸ 38 U.S.C. § 1710, § 1712.

⁵⁹ 38 U.S.C. § 7333; 38 C.F.R. § 17.48.

- (a) Veterans who have a service-connected disability;
- (b) Veterans who have a disability resulting from VA medical care;
- (c) Veterans who have a nonservice-connected disability who are unable to pay for care and who meet a limited income and assets test; or
- (d) Any other veterans, on a fee-for-service basis, if “resources and facilities are available.”

“Service connected” and “nonservice-connected” have the same meanings as they do in the disability program context. (*See above.*)

2. Outpatient care

Outpatient care must be provided to certain categories of veterans, including:

- (a) Veterans with service-connected disability (for treatment of that disability);
- (b) Veterans with service-connected condition rated at 50% or more, for treatment of any disability; or
- (c) Veterans with disability resulting from VA care.

The VA may furnish outpatient care to certain other veterans on limited basis. The VA may charge some of those veterans a fee for its services. Veterans with discharges under less than honorable conditions may receive VA care for any disability incurred or aggravated in the line of duty (unless there is a statutory bar to benefits).⁶⁰ The VA will make reimbursement for non-VA care in some emergency situations, if the veteran has a service connected disability rating 50% or more.⁶¹ To apply for medical benefits, veterans should contact a VA hospital, medical center or outpatient clinic.

D. California HIV-specific programs

1. AIDS Drug Assistance Program (ADAP)⁶²

The AIDS Drug Assistance Program (ADAP) is a state program funded by federal Ryan White “CARE” funds. It provides certain prescription drugs free of charge or on a sliding scale for people with HIV who have no other drug coverage.

⁶⁰ 38 C.F.R. § 3.360.

⁶¹ 38 C.F.R. § 17.80, § 17.50.

⁶² RAMSELL handles most public inquiries about the ADAP program. Provides or clients needing more specific policy information should contact the California State Office of AIDS (SOA) at 919/445-0553. SOA can also be reached via the Internet at www.dha.ca.gov/ps/ooa/ooaindex.htm. Interested parties are also encouraged to contact the HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA). HRSA’s HIV/AIDS Bureau is the federal office responsible for implementing and overseeing the Ryan White Care Act. HRSA’s HIV/AIDS Bureau can be reached via the Internet at www.hab.hrsa.gov.

The program is administered through the counties' Departments of Public Health. In some counties, such as San Francisco, individuals can enroll in the program through any city health clinic, and can obtain drugs through any pharmacy. In other counties, the program is limited to a public health office or public hospital.

In California, ADAP was established soon after the national initiation of the benefit. Currently, California has one of the most generous ADAP plans in the country. The California ADAP formulary (list of available drugs) covers over 140 medications. This formulary includes medications for the treatment of depression, diabetes and anxiety as well as for the management of HIV infection.

The Ramsell Corporation administers the California ADAP program and is under contract with the California Department of Health Services. RAMSELL is responsible for payment and coordination of services as well as client enrollment and inquiries. RAMSELL can be reached toll free at 1-888-575-ADAP (2327). RAMSELL can also be reached via the web at www.Ramsellcorp.com.

To be eligible for the California ADAP program applicants must:

- Be living in California. Special note applicants are not required to be United States citizens or U.S. legal permanent residents. Legal residency in the United States is not required for participation in the ADAP program;
- Be at least 18 years of age;
- Be HIV positive; and
- Have a federal adjusted gross income of less than \$50,000 a year. See levels of coverage for more information.

Documentation

The following documents are required in order to apply for ADAP.

- Proof of California residency – utility bills, rental agreements, leases or mortgages will suffice as proof.
- Picture identification- California drivers license or ID, passport, school ID or disabled bus pass are all acceptable.
- Proof of income – copies of federal and state income tax returns, most recent pay stubs, public assistance benefits verification letters or social security award letters.
- Letter of diagnosis – a letter from a licensed physician is required as verification of HIV infection. Not required for ADAP but the state of California likes to see current CD4 counts and viral load.

* If the above documents are not available at the time of application, RAMSELL is authorized to provide a 30-day temporary supply of medications.

Levels of Coverage

- Participants with federal adjusted gross incomes of less than \$35,440 (or 400% of federal poverty level) are eligible for full coverage. Full coverage provides access to all medications on the ADAP formulary free of charge. Medications must be prescribed by a licensed physician and must be purchased at an ADAP participating pharmacy. Contact RAMSELL to find out if a participating pharmacy.
- Applicants with federal adjusted gross incomes of between \$35,441 and \$50,000 may be eligible for partial assistance with the cost of their HIV medications. Participants with incomes in this range are required to pay a monthly co-payment towards the costs of their medications. Co-payments are calculated based on income, number of dependents (if any), whether or not the applicant has other private health insurance, and other qualifying factors. Certain restrictions may apply and are explained at the time of application by the ADAP enrollment counselor.
- Participants with federal adjusted gross incomes of greater than \$50,000 are not eligible for ADAP assistance in California.

HOW ADAP WORKS WITH OTHER PROGRAMS:

- Medi-Cal & ADAP – persons with Medi-Cal are able to use ADAP to absorb share of cost as long as they meet eligibility requirements. ADAP works in conjunction with Medi-Cal to reduce monthly out-of-pocket expenses for needed medications. Clients with Medi-Cal and no other source of drug assistance are able to use their ADAP coverage to eliminate their monthly share of cost. This service is handled through a billing procedure and does not require the ADAP participant to apply for this benefit separately. Clients with Medi-Cal should simply advise their pharmacy that they have both ADAP and Medi-Cal.
- However, clients with Medi-Cal and private health insurance coverage are not able to have their share of cost met through ADAP. Clients with Medicare HMO coverage are also excluded from this service if their Medicare HMO provides a drug benefits.
- Medi-Cal with no share of cost makes one ineligible for the ADAP program.
- Clients with VA benefits are ineligible for the ADAP program.
- Clients with private health insurance who also meet ADAP program eligibility requirements are able to access a service that pays for co-payments for the prescription medications listed on the ADAP formulary. Using ADAP services in conjunction with private health insurance can eliminate any out of pocket expenses related to an HIV medications regimens. Clients with private health insurance are encouraged to apply for ADAP assistance.
- ADAP & CARE HIPP (Comprehensive AIDS Resources Emergency ACT, Health Insurance Premium Payment Program)- CARE HIPP pays for health

insurance premiums for eligible HIV infected individuals. People who receive CARE HIPP assistance are eligible for ADAP services. If clients are receiving CARE HIPP, they are most likely enrolled in a private health insurance program. This means that they are eligible for the co-payment assistance only.

2. CARE/HIPP

CARE/HIPP (Health Insurance Premium Payment) is another state program funded by federal Ryan White “CARE” funds. It is designed to pay private health insurance premiums for low-income people with HIV for up to 29 months per lifetime. CARE/HIPP has more generous financial eligibility than Medi-Cal/HIPP, and is intended to bridge people with HIV into that program. In order to be eligible, one must be disabled due to HIV/AIDS and unable to work full-time, must have prescription drug coverage, must have an income less than 400% of the federal poverty level (\$2,953 a month for an individual in 2002), and their assets must not exceed \$6,000—the individual must apply for Medi-Cal /HIPP when and if assets go below \$2,000.

Enrollment in the CARE/HIPP program is through community-based AIDS service providers, who have been trained by the California Department of Health Services. An individual can find out where to enroll by calling a local AIDS service provider or by contacting the State Office of AIDS.

IV. Special Needs Trusts⁶³

INTRODUCTION

A special needs trust (SNT) is a special kind of trust that permits a disabled person to qualify for needs-based public benefits like Supplemental Security Income (SSI), Medicaid (Medi-Cal in California), In-Home Support Services (IHSS), and, in some cases, Section 8 housing while enjoying benefits of assets and income that exceed program income and resource limitations. Assets of a disabled person under age 65 placed in an SNT are also exempt from the Social Security transfer penalties.⁶⁴

There are two main types of special needs trusts, distinguished primarily by the source of assets used to fund the trust. These two types are generally referred to as “first-party” and “third-party” SNTs. First-party SNTs are established with the assets of the disabled individual. Third-party SNTs are established with anyone else’s funds. Third-party SNTs are relatively easy and inexpensive to establish and maintain. Some first-party SNTs can only be established by a court, require ongoing court supervision, and are therefore more costly to establish and maintain.

Depending on multiple variables, then, an SNT may be an option for an individual with a severe impairment to qualify for needs-based public benefits when that individual has personal savings or has received or anticipates receiving an otherwise disqualifying windfall such as an award from a personal injury claim, an inheritance, or a life insurance benefit.

This article, intended as an overview of SNT law and procedure, is divided in six parts: Part I, “How SNTs Work,” treats the theoretical underpinnings of SNTs, summarizing SSI income and resource rules in the process. Part II, “What are Special Needs?,” distinguishes “basic” from “special” needs, illustrating the latter. Part III, “First-Party versus Third-Party SNTs,” compares the two SNTs types and their subtypes. Part IV, “Is an SNT Appropriate for Your Client?,” helps assess whether an SNT is advisable in a given case. Part V, “Pooled SNTs,” recognizes a variation on standard SNTs. Part VI, “Where to Get Help,” gives referral sources for attorneys who counsel, prepare, and administer SNTs.

I. HOW SNTS WORK

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⁶⁴The main source of federal law governing special needs trusts is at 42 U.S.C. § 1382(b) and 42 U.S.C. § 1396p(d)(4)(A). These code sections are interpreted for use by Social Security personnel in the Social Security Programs Operations Manual (POMS) at SI 01120.200 *et seq.* Social Security POMS, including those pertaining to SNTs and SSI income, resource, and reporting rules, are accessible at <http://policy.ssa.gov>. The main sources of California law governing SNTs are found at 22 C.C.R. § 50489.5 and California Probate Code § 3600 *et seq.*

Social Security exempts assets placed in a properly formed and administered special needs trust from its income, resource, and asset transfer rules for two broad reasons: (1) the trust, if properly drafted, is fully discretionary, meaning the beneficiary either never acquires or else irrevocably relinquishes all ownership and control over the assets that fund the trust; and (2) the SNT, if properly administered, “supplements, without supplanting” public benefits.

Trustee’s Absolute Discretion Versus Beneficiary’s Ownership and Control

In the process of creating an effectively drafted SNT, the trustmaker will give ownership of assets to a trustee and grant the trustee sole and absolute discretion over distributions of income and principle consistent with the purpose of the trust to supplement not supplant the beneficiary’s public benefits. As a result, the trustee, not the beneficiary, has power to decide the time, purpose, and amount of all such distributions, and even whether any distributions ever are made from the trust.⁶⁵ While the trustee usually can revoke or at least amend an SNT, all SNTs are irrevocable by the beneficiary.

Because trust assets are given irrevocably to a trustee who has sole and absolute discretion over distributions, the beneficiary cannot direct the assets and use them to satisfy his or her basic needs for food, clothing, or shelter. Hence, Social Security and other benefit agencies exempt assets placed in a properly drafted SNT in determining program eligibility. (POMS SI 01120.200.D.2.)

SSI Income and Resource Rules - A Brief Overview

Theoretically, SSI provides for basic living needs (food, clothing, and shelter) of a financially needy, disabled person. Medicaid (Medi-Cal in California) provides for the beneficiary’s medical needs. Because SSI is available only to the financially needy, almost any income that a beneficiary receives besides the SSI monthly cash payment results in a reduction in the beneficiary’s payment level, and most resources the beneficiary owns beyond a basic minimum needed for subsistence preclude or eliminate program eligibility.

Under SSI income rules, generally an SSI beneficiary can receive up to \$20.00 a month of unearned income and up to \$65.00 a month of earned income without affecting his or her SSI payment. After that, the beneficiary’s payment is reduced by one dollar for every two dollars of earned income and one dollar for every one dollar of unearned income. An SSI beneficiary in California is entitled to Medi-Cal if he or she is eligible for at least one dollar of SSI.

If the beneficiary receives income one month and retains it into the next calendar month, Social Security considers the retained income as a “resource” subject to its resource limits. While Social Security excludes many assets in determining a beneficiary’s

⁶⁵ While a trustee has complete discretion over SNT distributions, a trustee also has a fiduciary duty to its beneficiary to disburse SNT funds only to fulfill the trust purpose.

resources, it permits a single person up to \$2,000.00 and a married couple up to \$3,000.00 in resources without affecting program eligibility.

Social Security enforces its strict income and resource rules by requiring a beneficiary to report any income besides SSI by the 10th of the month following receipt, whether that income is received in cash or “in kind.” (In-kind income is goods or services that meet the beneficiary’s needs for food, clothing or shelter.) Some two months after income is reported, Social Security reduces the beneficiary’s SSI payment level by at least 10 percent until the amount or value of reported income is repaid.

“Supplement, Not Supplant” Public Benefits

Under these income and resource rules, a third party can “supplement without supplanting” an SSI/Medi-Cal beneficiary’s benefits. The first example that follows illustrates a distribution that would “supplant” public benefits:

In January, Mom (a “third party”) gives an SSI beneficiary (“Jack”) \$2,021.00 in cash. Jack has an obligation to report that income to Social Security by the 10th of February. Social Security would then consider Jack overpaid for the month of January for the full amount of the SSI benefit, because, even overlooking the first \$20.00 of this unearned income, Jack received an amount of unearned cash that exceeds the value of his SSI payment (in late 2003, that is \$778.00 a month for an unmarried person living in his or her own household).⁶⁶ If Jack retained the income he received in January into February, Social Security would consider him to have countable resources in February that exceed the program’s allowable limits. Consequently, he would be disqualified from SSI and Medi-Cal altogether.

Here, income Jack received one month, and retained as a resource into the next calendar month, *supplanted* his public benefits. Jack will not requalify for SSI and Medi-Cal until he spends down his resources to below \$2,000.00. He also must repay any SSI received during any month of ineligibility.

The following example illustrates a distribution that supplements without supplanting public benefits:

Here, instead of giving him cash, Mom places in Jack’s home and allows Jack to use a washer and dryer which she purchased with \$2,021.00 of her own funds and which she continues to own, perhaps even listing as an asset of her living trust. Here, Jack has received an item or service that is not cash and that he cannot convert to cash and use to satisfy his basic needs for food, clothing and shelter. Hence, this distribution is not “income.” Jack has acquired only a beneficial interest in appliances owned by a third party. He has nothing to report. He has nothing to repay. His payment level is

⁶⁶ The SSI payment consists of up to two components: the Federal Benefit Rate (FBR) and, in some states, a State Supplement. SSI payment levels differ from state to state, depending on whether and by what amount a state supplements the FBR. Payment levels also differ according to whether or not a beneficiary is married or single, according to the beneficiary’s living arrangement (i.e., living independently or not, etc.) and according to whether the beneficiary’s disabling impairment includes blindness or not.

unaffected. Mom's payment to a third-party "vendor" (the appliance dealer) *supplemented, without supplanting*, Jack's public benefits.

A properly drafted and administered SNT works like a third-party vendor payment. Distributions from the trust that provide for "special," rather than basic, needs, are not income and do not affect the beneficiary's SSI payment level or entitlement to Medi-Cal or most public benefits.

Trustee Discretion and the Presumed Maximum Value (PMV) Rules

Social Security has a complex set of income rules called the presumed maximum value (PMV) rules. These rules allow a third party or an SNT to pay for some basic needs without supplanting the SSI beneficiary's public benefits. Here in a nutshell is how the relevant PMV rules work:

The relevant PMV rules set a limit to the value of in-kind support and maintenance (ISM) a beneficiary receives from outside source. ISM is reportable. Once reported, Social Security will reduce the beneficiary's SSI payment by the presumed maximum value of such in-kind support and maintenance. That PMV is one third of the federal benefit rate (FBR) or, in late 2004, \$184.00. For example, a third party or an SNT can, for instance, pay an SSI beneficiary's (let's call her "Rose") monthly rent of \$500.00. Rose will report the income, then receive a lower monthly SSI payment. However, none of her SSI need go toward rent. She will have more cash to spend on food and clothing. (If the trust also paid Rose's telephone, books, entertainment, and transportation costs, she could begin to "get by" on her SSI monthly benefit.)

One of many possible exceptions to the example provided arises in the case of the beneficiary who receives Social Security Disability Insurance (SSDI) as well as SSI and whose SSI payment level is less than the presumed maximum value of in-kind support and maintenance. For example, David receives \$680.00 a month in SSDI and \$118.00 in SSI. He cannot benefit from the PMV rule discussed because his SSI payment level is less than one-third of federal benefit rate. Rather, the value of any ISM distributions to David must be at least one dollar less than his SSI payment. Otherwise, the distribution would supplant his entitlement to SSI and Medi-Cal.

II. WHAT ARE SPECIAL NEEDS?

The preceding section identifies "basic" needs as food, clothing, shelter, and very basic medical care - needs critical to survival. These needs are supposed to be satisfied by SSI and, in California, Medi-Cal. "Special" needs are any other needs. In a black-and-white world, we would say that special needs pertain not to survival but to quality of life. Thus, "special needs" comprise a broad category that may include but is not limited to the following:

- Supplemental, nonessential, sophisticated, preventative, and alternative medical, dental, vision, and mental health care, equipment, and rehabilitation;
- Supplemental nursing, attendant and custodial care;
- Educational programs and equipment;
- Dietary supplements;
- Personal care, including hair, skin and nail care products and services;
- Exercise classes or equipment;
- Membership fees for health and other clubs and associations;
- Fees for contests, workshops;
- Residential expenses beyond basic rent and utilities (gas, electricity, water and garbage⁶⁷);
- Home furnishings;
- Access and repair services for telephone, television, and computer;
- Transportation needs;
- Costs for travel, camping, athletic programs and events;
- Radios, compact discs, television sets, and computer equipment;
- Books, magazine subscriptions;
- Movies, concerts;
- Other items, services, and activities that enhance the beneficiary's quality of life.

If the beneficiary requires an attendant or is unable to travel, his or her special needs may extend to include the reasonable expenses of an attendant or the reasonable costs to bring a loved one to visit the beneficiary.

III. FIRST-PARTY VERSUS THIRD-PARTY SNTS

As noted above, there are two main types of special needs trusts; these are distinguished primarily by the source of the funds going into the trust. SNTs established with the beneficiary's own funds go by many names, including "first-party," "self-settled," "(d)(4)(A)," "litigation," and "grantor" special needs trusts. Here I refer to these interchangeably as first-party and d4A trusts. SNTs established with someone else's funds are referred to as "third-party" SNTs.

First and third-party SNTs have the common features discussed above: assets placed in any properly formed SNT are given up to a trustee who has absolute discretion over distributions of income and principal. In turn, Social Security exempts trust assets from its transfer restrictions and resource limitations. Also, proper distributions from the SNT do not run afoul of SSI income rules to supplant SSI and Medi-Cal. Beyond these common features, first and third-party SNTs have important differences, and there are multiple subtypes of each basic type. This section overviews the subtypes and distinguishing features of first and third-party SNTs.

⁶⁷ The PMV rules discussed in the previous section may apply to such expenditures.

First-Party SNTs

Federal law at 42 U.S.C. § 1396p(d)(4)(A) exempts the following from SSI income, resource, and transfer penalty rules and so describes a qualifying first-party or “d4A” SNT:

A trust containing the assets of an individual under age 65 who is disabled [within Social Security guidelines] and which is established for the benefit of such individual by a parent, grandparent, legal guardian of the individual, or a court if the State will receive all amounts remaining in the trust upon the death of such individual up to an amount equal to the total medical assistance paid on behalf of the individual under a State plan under this subchapter.

This provision identifies six critical components of such a trust:

1. “A trust containing the assets of an individual...” The d4A trust is established with “the assets of an individual,” that is, with the beneficiary’s own funds. These may be assets that the beneficiary saved or received before becoming disabled, or they may be the result of a windfall the beneficiary received after the onset of disability, for instance, from a gift, inheritance, personal injury award, insurance proceed or the like. Under the concept of constructive receipt, an inheritance or insurance award may be considered “assets of” the disabled individual before he or she actually receives the funds. As a result, the beneficiary may lose one or several months of SSI and Medi-Cal before the trust is established and funded.
2. “An individual under age 65...” For a first-party SNT to qualify as an exempt resource, it must be established and funded before the beneficiary reaches age 65. However, as long as the trust is established and funded before the beneficiary’s 65th birthday, the assets in the SNT and any accumulated but undistributed income will remain exempt for the beneficiary’s lifetime.
3. “Who is disabled within [the Social Security guidelines]...” For trust assets to be considered exempt for purposes of determining eligibility for SSI, the beneficiary must meet Social Security’s medical criteria. However, the SNT may be appropriate even if the beneficiary has not yet established medical eligibility or even if his or her condition improves after a qualifying period. This is true for at least two reasons. First, Medi-Cal uses the same criteria for determining disability as Social Security. However, the state in determining Medi-Cal eligibility may find that the individual meets the medical criteria although Social Security, looking at the same record, does not. If so, the SNT will qualify the beneficiary financially for Medi-Cal even if he or she is not receiving SSI. Second, the SNT can function to protect assets of an individual from the individual and his or her creditors even if he or she is not receiving public

benefits. If the beneficiary is not receiving benefits, the trustee can operate the SNT as a support trust and pay for basic needs because there are no public benefits to protect.

4. “And which is specifically for the benefit of such individual...” While a d4A trust can and definitely should name remainder beneficiaries, or persons who will receive any assets remaining in the trust on the death of the SNT beneficiary, the SNT beneficiary must be the sole primary beneficiary, and the trust must be drafted to benefit only that individual during his or her lifetime. Hence, a gift from the trust to the child of the beneficiary would probably be considered as a transfer for less than fair market value and result in a period of ineligibility for the beneficiary.
5. “By a parent, grandparent, legal guardian, or a court...” Only four potential persons or entities can establish a first-party SNT: a parent, grandparent, legal guardian of the beneficiary, or a court of law. An individual cannot personally create a special needs trust with his or her own funds.⁶⁸

If the beneficiary is mentally competent and has a parent or grandparent alive, then he or she can execute a power of attorney authorizing the relative to create the trust. In that case, no court need be involved, and the trust can be established relatively simply and inexpensively. However, if the proposed SNT beneficiary has no living parent or grandparent and/or if the beneficiary lacks mental capacity to authorize establishment of the trust, then only a court can establish the trust.

California Probate Code § 3600 *et seq.* provides the primary procedure under which a California court may authorize establishment of a d4A SNT. Where the beneficiary is under guardianship or conservatorship, the procedure may require substituted judgment under Probate Code § 2580. Where the proposed beneficiary is a competent adult, some jurisdictions will authorize establishment of a d4A SNT under a power of attorney as provided under Probate Code § 4541. Which procedure is opted for depends on whether or not the proposed beneficiary is mentally competent or conserved and the policies and practices of the local jurisdiction.

If a court must be involved, the cost of establishing the trust increases substantially. If the trust is established under Probate Code § 3600, then the court retains jurisdiction over the trust and supervision as determined by the court. Typically, courts require a first accounting after one year and subsequent accountings biennially thereafter. The requirement of court accountings adds significantly to the cost of administering a trust.

⁶⁸ Social Security POMS blur the distinction between “creating” and “establishing” an SNT. It is generally believed, however, that while a mentally competent disabled individual can transfer his or her own assets into an SNT once it is established or, alternatively, execute a power of attorney to authorize a third party to establish and fund an SNT with the beneficiary’s funds, such individual cannot under any circumstances be the maker or creator of his or her own trust. Gregory Wilcox, Esq., “A (d)(4)(A) Q&A,” CANHR Legal Network News, Part I, spring 2002.

Whereas a trust established by a parent or grandparent may be drafted, executed, and funded in as little as one to two weeks, notice and calendaring requirements generally extend the time required to establish a court-ordered SNT to a minimum of two months. (In the rare jurisdictions where a petition may be brought ex parte under Probate Code § 4541, the time required to establish a court-approved SNT may be reduced by half.)

6. “If the State will receive all amounts remaining in the trust upon the death of such individual up to an amount equal to the total medical assistance paid on behalf of the individual under a State plan.” All first-party SNTs must incorporate language that requires the trustee, on the death of the beneficiary, to reimburse “the state” for services the state provided the beneficiary during his or her lifetime. California law extends the payback requirement to trusts terminated for any reason. Currently in California, the Department of Health Services is the only agency that makes claims against SNTs. Its claims are for Medi-Cal services provided during the life of the beneficiary.

If the beneficiary has private medical insurance or minimal medical costs, then the payback is probably not a significant issue. However, if the trust is relatively small or the beneficiary receives substantial Medi-Cal services, the payback requirement may preclude him or her from passing assets on to heirs. In such cases, the payback may be the deciding factor in considering whether to utilize a first-party SNT.

Where the payback is an obstacle, the beneficiary should carefully consider alternatives to the SNT. For instance, the beneficiary might instead spend down assets on exempt resources, such as a personal residence or a car, and the costs of maintaining these assets. Where funds are sufficient, the beneficiary might spend some assets on the exempt resources and set aside sufficient assets in an SNT maintain to them.⁶⁹

Alternatively, if the beneficiary has significant medical needs and a reasonably long life expectancy, it is sometimes instructive to view the SNT as a contingent interest-free loan from the state for the cost of medical services to the beneficiary. The contingency is this: whatever assets remain in the trust on the death of the beneficiary (or early termination of the trust) must be paid back to the state up to an amount equal to the medical assistance the state has provided. However, if there is nothing left in the trust on the beneficiary’s death, the state recovers nothing. If the remaining assets are less than the amount of the state claim, then

⁶⁹ In deciding whether to place assets in an SNT, the beneficiary should know that, unless a narrow exception applies, the state will recover on the death of a Medi-Cal beneficiary against the house or other assets in the name of the beneficiary for the amount of skilled nursing care services provided at any age and for medical services provided after age 55. Hence, avoiding recovery against the SNT does not preclude other recovery by the Department of Health Services against other assets.

the state either makes no recovery or recovers only to the extent the trust has assets to satisfy the claim.

Third-Party SNTs

Third-party SNTs have the same general purpose as first-party SNTs – to supplement, not supplant public benefits – but they are created by and funded with the assets of someone besides the trust beneficiary.

Third-party SNTs grew out of the estate planning context as a means for parents to leave assets to benefit a disabled child without jeopardizing the child's entitlement as an adult to public benefits. Before the development of third-party SNTs, such parents had multiple unsatisfactory choices: leave nothing to their disabled child; leave the child's share to a third party and ask that person to manage the funds for the child; or leave assets outright (or in conservatorship) for the child. In the first case, the child received no support for special needs. In the second case, the child became dependent on the good graces of a third party who might not have a good relationship with the disabled child, or the skills or desire to carry out the parents' wishes. In the last case, the child lost public benefits, often having to spend down his or her inheritance on medical and attendant care, and then reapply for benefits when he or she was impoverished. Third-party SNTs grew up to provide an infinitely better solution in most cases than any of these alternatives.

Third-party SNTs have the benefits of first-party SNTs but not the following disadvantages:

1. No constructive receipt; no interruption of benefits. Whereas the beneficiary gives up ownership and control of his assets to fund a first-party special needs trust, the beneficiary never acquires ownership of the assets that fund a third-party SNT. Rather in the third-party trust, ownership transfers directly from the third-party source to the trustee charged with managing the assets. Because the beneficiary never owns the assets, there is no constructive receipt. As a result, the beneficiary should not suffer any interruption of benefits when the trust funds.
2. No payback requirement. Because the beneficiary never possesses assets that fund a third-party SNT, assets remaining in the trust when the beneficiary dies (or on earlier termination) are not subject to state payback but distribute directly to the residual beneficiaries whom the trustmaker names in the trust.
3. No age limitations. Whereas federal law provides that a first-party d4A SNT can be established only before the beneficiary reaches age 65, there is no age limit for third-party SNTs. Thus, an adult child could establish a third-party SNT to benefit her 85 year-old father without jeopardizing his SSI or Medi-Cal eligibility.

4. Accountings and other protection but no required court involvement. The court need never be involved in establishing or supervising a third-party SNT. However, the beneficiary typically is entitled at least to annual accountings of the receipts, disbursements, assets and liabilities of the trust. If the trust is mismanaged, the beneficiary can bring an action to remove and replace a trustee or recover losses due to the trustee's breach of fiduciary duties.

Established privately without court involvement or age limitation, not requiring payback to the state, and providing built-in protections for the beneficiary, third-party special needs trusts are the generally preferred means to leave assets to individuals with disabilities of any kind.

There are two ways to establish a third-party SNT. In most cases, the trust can be created as a subtrust in a will or revocable living trust.⁷⁰ So created, the SNT becomes effective only on the death (or, if created in a living trust, potentially on the incapacity) of the trustmaker.

Alternatively, a third-party SNT can be set up and funded during the life of the trustmaker. The advantage of the so-called "standalone" third-party SNT is that once established, individuals besides the trustmakers may leave assets to the beneficiary in that same trust. Another advantage is that the standalone can be tried and tested with Social Security while the trustmakers are still alive to defend it. The standalone third-party SNT is also an option for trustmakers who anticipate a contest of their estate plan on their death. By gifting to and then administering an SNT for their disabled child before they pass, the trustmakers clarify their intent to leave the assets in question to the disabled child. (There are potential gift tax consequences to funding an SNT during the lives of the trustmakers.)

A disadvantage to the standalone, if established to receive funds from other bequestors, is that the other bequestors must agree to the management personnel and the ultimate distribution plan selected up by the trustmakers. Hence, this mechanism often is not suitable for divorced parents; however, it may well work for intact families who would leave assets ultimately to the beneficiary's children, if any, or to his or her intestate heirs.

Third-party SNTs established as a subtrust in a will or other trust are fully revocable and amendable by the trustmaker. A standalone third-party SNT may but need not be revocable by the trustmaker. As noted above, SNTs are always irrevocable and unamendable by the beneficiary. At the same time, California law does provide other means for modification and termination of irrevocable trusts. (California Probate Code § 15400 *et seq.*)

⁷⁰ Federal law permits a spouse to leave assets in an SNT for the benefit of his or her spouse only through a will.

IV. IS AN SNT APPROPRIATE FOR YOUR CLIENT?

Whether an SNT is appropriate for your client depends on many factors, including the source and amount of funds, the availability of parents or grandparents and a knowledgeable trustee, and the age, competence, goals and overall health and needs of the beneficiary. The following analysis will help make an initial assessment of such factors in a given case.

The first consideration is always the source of the funds. If the funds have not yet been received, but are anticipated to be inherited from an individual who is still living and has mental capacity or an authorized agent, then a third-party SNT may be appropriate. The prospective benefactor should be advised to contact an appropriate estate planning/elder law attorney to draft a third-party SNT and assist with transferring assets to the SNT.

If the client has actually or constructively received the funds, or if the funds will result from litigation, then federal law will permit only a first-party SNT with the requisite payback provision. In such cases, the threshold issue is the age of the beneficiary. If he or she is age 65 or older, then a first-party d4A trust is not available. The beneficiary should contact a qualified estate planning/elder law attorney to explore other options, including a pooled trust, for managing the funds.

If the beneficiary is under age 65, then the next issues are the beneficiary's mental capacity and the availability of a parent or grandparent to create the trust. If the beneficiary has capacity and a parent or grandparent alive to create the trust, then a first-party SNT can be created relatively simply and inexpensively. Possible impediments may still remain if the trust is small and the beneficiary has no nonprofessional to serve as trustee. Before electing the SNT, the beneficiary should also consider the relative merits of a spenddown.

If the beneficiary is under age 65 and has mental capacity but no parent or grandparent alive to create the trust, then federal law mandates that a d4A SNT can be established only by a court. In addition to considering the relative merits of a spenddown versus the payback requirement and the availability and importance of a nonprofessional trustee, the beneficiary needs to consider the cost of the court proceedings to establish and supervise the trust over time against the size of the trust. Consideration should also be paid to the policy of the local jurisdiction regarding the possibility of establishing the trust under Probate Code § 4541, which could be quicker and less costly over time than establishment by the more conventional Code § 3600 *et seq.*

If the beneficiary is not legally or mentally competent, then the only legal means to establish the trust is through a court order even if a parent or grandparent survives. Here again, critical issues are then the amount of funds at issue versus the likely cost to establish and administer the trust. If the beneficiary is not legally competent and has assets beyond public benefits, a conservatorship will probably be required if not an SNT.

(The costs of establishing and maintaining a conservatorship are comparable to those of a court-ordered and supervised SNT.)

V. POOLED TRUSTS

Federal law at 42 U.S.C. § 1396p(d)(4)(C) allows for yet another kind of special needs trust referred to as a “pooled” trust. “Pooled trusts,” described at 42 U.S.C. § 1696p(d)(4)(C), allow an individual’s own assets to be “pooled” with those of a number of persons with disabilities if managed by a non-profit organization. There are no age restrictions on pooled trusts, and they are potentially less costly to enter into and administer than court-ordered third-party SNTs. Thus, pooled trusts provide an alternative for disabled individuals for whom age or the amount of funds in question precludes establishment of a d4A trust. Within the next five years, pooled trusts are likely to become available in California. At the time of this writing, however, there are few (if any) pooled trusts in California although some, operational in other states, are available to Californians.

VI. WHERE TO GET HELP

The following organizations provide referrals to attorneys who are able to evaluate the propriety in given cases and prepare and administer special needs trusts:

CALIFORNIA ADVOCATES FOR NURSING HOME REFORM

1610 Bush Street, San Francisco, CA 94101, (415) 474-5171, www.CANHR.org

NATIONAL ACADEMY OF ELDER LAW ATTORNEYS

1604 North Country Club Road, Tucson, AZ 85716, (520) 881-4005, www.NAELA.org

Appendix A: Additional Resources

I. Books and Manuals

An Advocate's Guide to the Medicaid Program, rev. ed., 1993. National Health Law Program. (310) 204-6010.

Getting it and Keeping It: The Impact of Monetary Awards on Clients Who Also Receive Government Benefits, published by the State Bar of California and the Western Center on Law and Poverty. Call (415) 561-8243 or (213) 487-7211 to order.

Guide to Alien Eligibility for Federal Programs, 2d Ed., 1993. National Immigration Law Center. Call (213) 487-2531 to order.

Medi-Cal: Service Rights and Entitlement Programs Affecting Californians with Disabilities, (Rev. Ed. 1994). Protection and Advocacy, Inc. (510) 251-6270.

Social Security Advisory Service (a loose-leaf technical support manual for more experienced practitioners). Call (415) 388-2400 to order.

Social Security Appeals for HIV Disability, rev. ed., 1995. AIDS Legal Referral Panel of the San Francisco Bay Area. (415) 291-5454.

SSI Non-disability Issues, 3d Ed. 1993. Covers income and resource rules, overpayments, work incentives, representative payee issues and more. Contact the National Senior Citizens Law Center at (202) 887-5280 to order.

When 45 Days is Too Long to Wait (Resource book on emergency benefits), published by Western Center on Law and Poverty, (213) 487-7211.

II. Organizations

Bay Area Social Security Claimants' Representatives (BASSCR). Holds monthly update meetings in Oakland. (510) 848-7200.

California Advocates for Nursing Home Reform (CANHR) provides technical support and attorney referrals on issues of long-term care and Medi-Cal assets issues. (415) 474-5171.

Coalition of California Welfare Rights Organizations (CCWRO) does technical support and organizing on poverty issues, including benefits. (916) 736-0616.

National Organization of Social Security Claimants' Representatives (NOSSCR) is a membership organization. It sponsors a newsletter and advice line, as well as national conventions. (800) 431-2804.

National Senior Citizens Law Center is a technical support center on Social Security and Medicare issues. (213) 236-3890.

National Veterans' Legal Services Project is a technical support center on veterans' issues. (202) 265-8305.

Social Security Claimants' Representatives. Holds monthly update meetings in San Francisco. Organized through San Francisco Neighborhood Legal Aid Foundation (SFNLAF). (415) 627-0200.

Western Center on Law and Poverty is a technical support center on poverty law, including welfare benefits (AFDC, SSI, Food Stamps, etc.) Call (213) 487-7211.

Appendix B: List of Social Security Forms

You may order these forms in bulk from SSA. You can also get single copies from the local SSA office.

SSA-7004:	Request for Earnings and Benefits Estimate Statement
SSA-827:	Authorization to Release Information to the Social Security Administration
SSA-4814-F5:	Medical Report on Adult with Allegation of HIV Infection
SSA-4815-F6:	Medical Report on Child with Allegation of HIV Infection
SSA-3368:	Disability Report
SSA-3369:	Vocational Report
SSA-821:	Work Activity Report – Employee
DEP 2059:	Daily Activities Questionnaire (California)
DEP 1002s (14)(AIDS)	HIV Assessment Form for Adults and Children (California)
SSA-1696:	Appointment of Representative
SSA-561:	Request for Reconsideration
SSA-3441:	Reconsideration Disability Report
SSA-795:	Statement of Claimant or Other Person
HA-501:	Request for Hearing by ALJ
HA-4486:	Claimant's Statement When Request for Hearing is Filed and the Issue of Disability
HA-520:	Request for Review of Hearing Decision/Order
Publ. 64-030	Red Book on Work Incentives

Appendix C: Social Security Form 4815-F5

MEDICAL SOURCE INSTRUCTION SHEET FOR COMPLETION OF ATTACHED SSA-4814-F5 (Medical Report On Adult With Allegation Of Human Immunodeficiency Virus (HIV) Infection)

Your patient, identified in section A of the attached form, has filed a claim for Supplemental Security Income disability payments based on HIV Infection. **MEDICAL SOURCE:** Please detach this instruction sheet and use it to complete the attached form.

I. PURPOSE OF THIS FORM:

IF YOU COMPLETE AND RETURN THE ATTACHED FORM PROMPTLY, YOUR PATIENT MAY BE ABLE TO RECEIVE PAYMENTS WHILE WE ARE PROCESSING HIS OR HER CLAIM OR ONGOING DISABILITY PAYMENTS.

This is not a request for an examination. At this time, we simply need you to fill out this form based on existing medical information. The State Disability Determination Services will contact you later to obtain further evidence needed to process your patient's claim.

II. WHO MAY COMPLETE THIS FORM:

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 based on your records may complete and sign the form.

III. MEDICAL RELEASE:

An SSA medical release (an SSA-827) signed by your patient should be attached to the form when you receive it. If the release is not attached, the medical release section on the form itself should be signed by your patient

IV. HOW TO COMPLETE THE FORM:

- If you receive the form from your patient and section A has not been completed, please fill in the identifying information about your patient.
- You may not have to complete all of the sections on the form.
- **ALWAYS COMPLETE SECTION B.**
- **COMPLETE SECTION C, IF APPROPRIATE.** If you check at least one of the items in section C, go right to section E.
- **ONLY COMPLETE SECTION D IF YOU HAVE NOT CHECKED ANY ITEM IN SECTION C.** See the special information below which will help you to complete section D.
- **COMPLETE SECTION E IF YOU WISH TO PROVIDE COMMENTS ON YOUR PATIENT'S CONDITION(S).**
- **ALWAYS COMPLETE SECTIONS F AND G. NOTE:** This torn Is not complete unto It Is signed.

V. HOW TO RETURN THE FORM TO US:

- Mail the completed, signed form, as soon as possible, in the return envelope provided.

- If you received the form from your patient without a return envelope, give the completed, signed form back to your patient for return to the SSA field office.

VI. SPECIAL INFORMATION TO HELP YOU COMPLETE SECTION D
HOW WE USE SECTION D:

- Section D asks you to tell us what other manifestations of HIV your patient may have. It also asks you to give us an idea of how your patient's ability to function has been affected.
- We do not need detailed descriptions of the functional limitations imposed by the illness; we just need to know whether your patient's ability to function has been affected to a "marked" degree in any of the areas listed. See below for an explanation of the term "marked."

SPECIAL TERMS USED IN SECTION D

WHAT WE MEAN BY "REPEATED" MANIFESTATIONS OF HIV INFECTION: (See Item 42.a)

"Repeated" means that a condition or combination of conditions:

- Occurs an average of 3 times a year or once every 4 months, each lasting 2 weeks or more; or
- Does not last for 2 weeks, but occurs substantially more frequently than 3 times in a year or once every 4 months; or
- Occurs less often than an average of 3 times a year or once every 4 months but lasts substantially longer than 2 weeks.

WHAT WE MEAN BY "MANIFESTATIONS OF HIV INFECTION": (See Item 42.a)

- "Manifestations of HIV infection" may include:

Any condition listed in section C, but without the findings specified there (e.g., carcinoma of the cervix not meeting the criteria shown in item 22 of the form, diarrhea not meeting the criteria shown in item 33 of the form); or any other condition that is not listed in section C (e.g., oral hairy leukoplakia, myositis).

- Manifestations of HIV must result in significant, documented, symptoms and signs (e.g., fatigue, fever, malaise, weight loss, pain, night sweats).

WHAT WE MEAN BY "MARKED" LIMITATION OR RESTRICTION IN FUNCTIONING: (See Item 42.b)

- When "marked" is used to describe functional limitations, it means more than moderate, but less than extreme. "Marked" does not imply that your patient is confined to bed, hospitalized, or in a nursing home.
- A marked limitation may be present when several activities or functions are impaired or even when only one is impaired. An individual need not be totally precluded from performing an activity to have a marked limitation, as long as the degree of limitation is such as to seriously interfere with the ability to function independently, appropriately, and effectively.

WHAT WE MEAN BY "ACTIVITIES OF DAILY LIVING": (See Item 42.b)

- Activities of daily living include, but are not limited to, such activities as doing household chores, grooming and hygiene, using a post office, taking public transportation, and paying bills.
- **EXAMPLE:** An individual with HIV infection who, because of symptoms such as pain imposed by the illness or its treatment, is not able to maintain a household or take public transportation on a sustained basis or without assistance (even though he or she is able to perform some self-care activities) would have marked limitation of activities of daily living.

WHAT WE MEAN BY "SOCIAL FUNCTIONING": (See Item 42.b)

- Social functioning includes the capacity to interact appropriately and communicate effectively with others.
- **EXAMPLE:** An individual with HIV infection who, because of symptoms or a pattern of exacerbation and remission caused by the illness or its treatment, cannot engage in social interaction on a sustained basis (even though he or she is able to communicate with close friends or relatives) would have marked difficulty maintaining social functioning.

WHAT WE MEAN BY "COMPLETING TASKS IN A TIMELY MANNER": (See Item 42b)

- Completing tasks in a timely manner involves the ability to sustain concentration, persistence, or pace to permit timely completion of tasks commonly found in work settings.
- **EXAMPLE:** An individual with HIV infection who, because of HIV-related fatigue or other symptoms, is unable to sustain concentration or pace adequate to complete simple work-related tasks (even though he or she is able to do routine activities of daily living) would have marked difficulty completing tasks.

PRIVACY ACT NOTICE: The Social Security Administration is authorized to collect the information on this form under sections 205(a), 223(d) and 1633(e)(1) of the Social Security Act. The information on this form is needed by Social Security to make a decision on the named claimant's claim. While giving us the information on this form is voluntary, failure to provide all or part of the requested information could prevent an accurate or timely decision on the named claimant's claim. Although the information you furnish is almost never used for any purpose other than making a determination about the claimant's disability, such information may be disclosed by the Social Security Administration as follows: (1) to enable a third party or agency to assist Social Security in establishing rights to Social Security benefits and/or coverage; (2) to comply with federal laws requiring the release of information from Social Security records (e.g., to the General Accounting Office and the Department of Veterans Affairs); and (3) to facilitate statistical research and audit activities necessary to assure the integrity and improvement of the Social Security programs (e.g., to the Bureau of the Census and private concerns under contract to Social Security).

We may also use the information you give us when we match records by computer. Matching programs compare our records with those of other federal, state, or local government agencies. Many agencies may use matching programs to find or prove that a person qualifies for benefits paid by the federal government. The law allows us to do this even if you do not agree to it.

Explanations about these and other reasons why information you provide us may be used or given out are available in Social Security offices. If you want to learn more about this, contact any Social Security office.

TIME IT TAKES TO COMPLETE THIS FORM

We estimate that it will take you about 10 minutes to complete this form. This includes the time it will take to read the instructions, gather the necessary facts, and fill out the form. If you have comments or suggestions on this estimate or on any other aspect of this form, write to the Social Security Administration, ATTN: Reports Clearance Officer, 1-A-21 Operations Bldg., Baltimore, MD 21235-0001, and to the Office of Management and Budget, Paperwork Reduction Project (0960-0503), Washington, D.C. 20503. **SEND ONLY COMMENTS RELATING TO OUR ESTIMATE OR OTHER ASPECTS OF THIS FORM TO THE OFFICES LISTED ABOVE. ALL REQUESTS FOR SOCIAL SECURITY CARDS AND OTHER CLAIMS-RELATED INFORMATION SHOULD BE SENT TO YOUR LOCAL SOCIAL SECURITY OFFICE, WHOSE ADDRESS IS LISTED IN YOUR TELEPHONE DIRECTORY UNDER THE DEPARTMENT OF HEALTH AND HUMAN SERVICES.**

MEDICAL REPORT ON ADULT WITH ALLEGATION OF HUMAN IMMUNODEFICIENCY VIRUS (HIV) INFECTION	DO/BO CODE:
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The individual named below has filed an application for a period of disability and/or disability payments. If you complete this form, your patient may be able to receive early payments. (This is not a request for an examination, but for existing medical information.)

MEDICAL RELEASE INFORMATION

- ☐ Form SSA-827, "Authorization to Release Medical Information to the Social Security Administration," attached.
- ☐ I hereby authorize the medical source named below to release or disclose to the Social Security Administration or State agency any medical records or other information regarding my treatment for human immunodeficiency virus (HIV) infection.

CLAIMANT'S SIGNATURE (<i>Required only if Form SSA-827 is NOT attached</i>)	DATE
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A. IDENTIFYING INFORMATION

MEDICAL SOURCE'S NAME	CLAIMANT'S NAME
CLAIMANT'S SSN	CLAIMANT'S DATE OF BIRTH

B. HOW WAS HIV INFECTION DIAGNOSED?

- ☐ Laboratory testing confirming HIV infection
- ☐ Other clinical and laboratory findings, medical history, and diagnosis(es) indicated in the medical evidence

C. OPPORTUNITISTIC AND INDICATOR DISEASES: *Please check if applicable.*

BACTERIAL INFECTIONS

1. ☐ **MYCOBACTERIAL INFECTION** (e.g., caused by *M. avium*-intracellulare, *M. kansasii* or *M. tuberculosis*), at a site other than the lungs, skin, or cervical or hilar lymph Nodes
2. ☐ **PULMONARY TUBERCULOSIS**, resistant to treatment
3. ☐ **NOCARDIOSIS**
4. ☐ **SALMONELLA BACTEREMIA**,

11. ☐ **HISTOPLASMOSIS**, at a site other than the lungs or lymph nodes

12. ☐ **MUCORMYCOSIS**

PROTOZOAN OR HELMINTHIC INFECTIONS

13. ☐ **CRYPTOSPORIDIOSIS, ISOSPORIASIS, OR MICROSPORIDIOSIS**, with diarrhea lasting for 1 month or longer
14. ☐ **PNEUMOCYSTIS CARINII PNEUMONIA OR EXTRAPULMONARY**

- recurrent non-typhoid
5. ☐ **SYPHILIS OR NEUROSYPHILIS**
(e.g., meningovascular syphilis)
resulting in neurologic
or other sequelae

6. ☐ **MULTIPLE OR RECURRENT
BACTERIAL INFECTION(S)**,
including pelvic inflammatory
disease, requiring hospitalization or
intravenous antibiotic treatment 3 or
more times in 1 year

FUNGAL INFECTIONS

7. ☐ **ASPERGILLOSIS**
8. ☐ **CANDIDIASIS**, at a site other than
the skin, urinary tract, intestinal tract,
or oral or vulvovaginal mucous
membranes; or candidiasis involving
the esophagus, trachea, bronchi, or
lungs
9. ☐ **COCCIDIOIDOMYCOSIS**, at a
site other than the lungs or lymph
nodes
10. ☐ **CRYPTOCOCCOSIS**, at a site
other than the lungs (e.g.,
cryptococcal meningitis)

PNEUMOCYSTIS CARINII INFECTION

15. ☐ **STRONGYLOIDIASIS**, extra-
intestinal
16. ☐ **TOXOPLASMOSIS** of an organ other
than the liver, spleen, or lymph nodes

VIRAL INFECTIONS

17. ☐ **CYTOMEGALOVIRUS DISEASE**,
at a site other than the liver, spleen, or
lymph nodes
18. ☐ **HERPES SIMPLEX VIRUS** causing
mucocutaneous infection (e.g., oral,
genital, perianal) lasting for 1 month or
longer; or infection at a site other than
the skin or mucous membranes (e.g.,
bronchitis, pneumonitis, esophagitis, or
encephalitis); or disseminated infection
19. ☐ **HERPES ZOSTER**, disseminated or
with multidermatomal eruptions that
are resistant to treatment
20. ☐ **PROGRESSIVE MULTIFOCAL
LEUKOENCEPHALOPATHY**

21. ☐ **HEPATITIS**, resulting in chronic liver disease manifested by appropriate findings (e.g., persistent ascites, bleeding esophageal varices, hepatic encephalopathy)
- MALIGNANT NEOPLASMS**
22. ☐ **CARCINOMA OF THE CERVIX**, invasive, FIGO stage II and beyond
23. ☐ **KAPOSI'S SARCOMA**, with extensive oral lesions; or involvement of the gastrointestinal tract, lungs, or other visceral organs; or involvement of the skin or mucous membranes with extensive fungating or ulcerating lesions not responding to treatment
24. ☐ **LYMPHOMA** of any type (e.g., primary lymphoma of the brain, Burkitt's lymphoma, immunoblastic sarcoma, other non-Hodgkins lymphoma, Hodgkin's disease)
25. ☐ **SQUAMOUS CELL CARCINOMA OF THE ANUS**
- SKIN OR MUCOUS MEMBRANES**
26. ☐ **CONDITIONS OF THE SKIN OR MUCOUS MEMBRANES**, with extensive fungating or ulcerating lesions not responding to treatment (e.g., dermatological conditions such as eczema or psoriasis, vulvovaginal or other mucosal candida, condyloma caused by human papillomavirus, genital
31. ☐ **OTHER NEUROLOGICAL MANIFESTATIONS OF HIV INFECTION** (e.g., peripheral neuropathy), with significant and persistent disorganization of motor function in 2 extremities resulting in sustained disturbance of gross and dexterous movements, or gait and station
- HIV WASTING SYNDROME**
32. ☐ **HIV WASTING SYNDROME**, characterized by involuntary weight loss of 10 percent or more of baseline (or other significant involuntary weight loss) and, in the absence of a concurrent illness that could explain the findings, involving: chronic diarrhea with 2 or more loose stools daily lasting for 1 month or longer; or chronic weakness and documented fever greater than 38°C (100.4°F) for the majority of 1 month or longer
- DIARRHEA**
33. ☐ **DIARRHEA**, lasting for 1 month or longer, resistant to treatment, and requiring intravenous hydration, intravenous alimentation, or tube feeding
- CARDIOMYOPATHY**
34. ☐ **CARDIOMYOPATHY** (chronic heart failure, or cor pulmonale, or other severe cardiac abnormality not responsive to treatment)

ulcerative disease)

HEMATOLOGIC ABNORMALITIES

27. ☐ **ANEMIA** (hematocrit persisting at 30 percent or less), requiring one or more blood transfusions on an average of at least once every 2 months
28. ☐ **GRANULOCYTOPENIA**, with absolute neutrophil counts repeatedly below 1,000 cells/mm³ and Documented recurrent systemic bacterial infections occurring at least 3 times in the last 5 months
29. ☐ **THROMBOCYTOPENIA**, with platelet counts repeatedly below 40,000/mm³; with at least one spontaneous hemorrhage, requiring transfusion in the last 5 months; or intracranial bleeding in the last 12 months.

NEUROLOGICAL ABNORMALITIES

30. ☐ **HIV ENCEPHALOPATHY**, characterized by cognitive or motor dysfunction that limits function and progresses

NEPHROPATHY

35. ☐ **NEPHROPATHY**, resulting in chronic renal failure

INFECTIONS RESISTANT TO TREATMENT OR REQUIRING HOSPITALIZATION OR INTRAVENOUS TREATMENT 3 OR MORE TIMES IN 1 YEAR

36. ☐ **SEPSIS**
37. ☐ **MENINGITIS**
38. ☐ **PNEUMONIA** (non-PCP)
39. ☐ **SEPTIC ARTHRITIS**
40. ☐ **ENDOCARDITIS**
41. ☐ **SINUSITIS**, radiographically documented

NOTE: If you have checked any of the boxes in section C proceed to section E if you have any remarks you want to make about this patient's condition. Then proceed to section F and G and sign and date the form.

If you have not checked any of the boxes in section C, please complete section D. See part VI of the instruction sheet for definitions of the terms we use in section D. Proceed to section E if you have any remarks you want to make about this patient's condition. Then, proceed to sections F and G and sign and date the form.

D. OTHER MANIFESTATION(S) OF HIV INFECTION

- 42. a. REPEATED MANIFESTATIONS OF HIV INFECTION**, including diseases mentioned in section C, items 1-41, but without the specified findings described above, or other diseases, resulting in significant, documented, symptoms or signs (e.g., fatigue, fever, malaise, weight loss, pain, night sweats).

Please specify:

1. The manifestations you patient has had;
2. The number of episodes occurring in the same 1-year period; and
3. The approximate duration of each episode.

Remember, your patient need not have the same manifestation each time to meet the definition of repeated manifestations; but, all manifestations used to meet the requirement must have occurred in the same 1-year period. (See attached instructions for the definition of repeated manifestations.)

If you need more space, please use section E.

MANIFESTATIONS:	NO. OF EPISODES IN THE SAME 1-YEAR PERIOD:	DURATION OF EACH EPISODE:

AND

b. ANY OF THE FOLLOWING:

- ☐ Marked restriction of **ACTIVITIES OF DAILY LIVING**; or
- ☐ Marked difficulties in maintaining **SOCIAL FUNCTIONING**; or
- ☐ Marked difficulties in completing tasks in a timely manner due to deficiencies in **CONCENTRATION, PERSISTENCE, OR PACE**.

E. REMARKS: *(Please use this space if you lack sufficient room in section D or to provide any other comments you wish about your patient.)*

F. MEDICAL SOURCE'S NAME AND ADDRESS *(Print or type)*

TELEPHONE NUMBER
(Area Code)

DATE

KNOWING THAT ANYONE MAKING A FALSE STATEMENT OR REPRESENTATION OF A MATERIAL FACT FOR USE IN DETERMINING A RIGHT TO PAYMENT UNDER THE SOCIAL SECURITY ACT COMMITS A CRIME PUNISHABLE UNDER FEDERAL LAW, I CERTIFY THAT THE ABOVE STATEMENTS ARE TRUE.

G. SIGNATURE AND TITLE (e.g., physician, R.N.) OF PERSON COMPLETING THIS FORM

FOR ☐ **FIELD OFFICE DISPOSITION**

OFFICIAL USE ONLY ☐ **DISABILITY DETERMINATION SERVICES DISPOSITION**

**Appendix D: Form 4814-F5, Question 42a.
Supplemental Information**

MANIFESTATIONS	No. of episodes in 1-yr period	Dates or duration of each episode

Note: This is not an official SSA form. It may be used, at the physician’s discretion, to supplement Part D (“repeated manifestations”) of Form SSA-4814-F5 (Medical Report). Please refer to the instructions included with Form SSA-4814-F5.