

Comments on the Social Security Administration's Operating Procedures for Determining Disability for Persons Whose Drug Addiction or Alcoholism (DAA) May be Material to Disability [Docket No. SSA-2009-0081]

Thank you for the opportunity to submit comments on the Social Security Administration's operating procedures for determining disability for persons whose drug addiction or alcoholism may be a contributing factor material to their disability. The National Health Care for the Homeless Council is a membership organization comprised of health care professionals and agencies that serve homeless people in communities across America. Our members serve patients who are affected by this SSA procedure and frequently provide medical and functional documentation of disability to SSA on behalf of their patients.

Disability Precipitates and Prolongs Homelessness

Physical and cognitive impairments are among the factors that increase the likelihood of becoming (and remaining) homeless if services to meet basic needs are not available.^{1, 2} People who have disabling physical and cognitive impairments are at risk of becoming homeless from unemployment, loss of family support, severity of symptoms, and inadequate supports after institutional discharge. Indeed, people with disabilities represent over 40% of the homeless population and constitute the entire "chronically homeless" population in America. ^{3, 4, 5}

Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) constitute a critical safety net for persons with disabilities, providing cash assistance and, usually, eligibility for public health insurance (Medicaid/Medicare). For many people living in poverty, the income from SSI entitlements prevents homelessness and assists in meeting basic needs. For people who are already homeless, SSI benefits can improve opportunities for finding and maintaining housing, including supportive housing. ⁶ By increasing access to housing and health care, people who are disabled and homeless have a greater chance at achieving stability and resuming productivity.

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¹ HCH Clinicians' Network. (Oct. 2002). Dealing with Disability: Physical Impairments & Homelessness. Healing Hands. http://www.nhchc.org/Network/HealingHands/2002/hh.10_02.pdf

² HCH Clinicians' Network. (Mar 2003). Dealing with Disability: Cognitive Impairments & Homelessness. Healing Hands. http://www.nhchc.org/Network/HealingHands/2003/hh-0303.pdf

³ According to the Federal definition, a chronically homeless person is defined as "an unaccompanied homeless individual with a disabling condition who has either been continuously homeless for a year or more OR has had at least four (4) episodes of homelessness in the past three (3) years." A disabling condition is defined as "a diagnosable substance use disorder, serious mental illness, developmental disability, or chronic physical illness or disability, including the co-occurrence of two or more of these conditions." (Notice of Funding Availability for the Collaborative Initiative to Help End Chronic Homelessness/Federal Register, Vol. 68, No. 17/Monday, January 27, 2003, 4019. This definition is shared by the U.S. Department of Housing and Urban Development, the U.S. Department of Health and Human Services, and the U.S. Department of Veterans Affairs.]

⁴ HUD. (2008). Annual Homeless Assessment Report. http://www.hudhre.info/documents/4thHomelessAssessmentReport.pdf
⁵ Brault, M. (2008). Disability Status and the Characteristics of People in Group Quarters

http://www.census.gov/hhes/www/disability/GQdisability.pdf

Rosenheck, R., Frisman, L., and Kasprow, W. (1999). Improving access to disability benefits among homeless persons with mental illness: an agency-specific approach to services integration. Am J Public Health, 89(4): 524-528.

Currently, only a small proportion of the homeless population in America receives Federal disability assistance. In a national study of homeless assistance providers and their clients conducted in 1996, only 11 percent of homeless service users received SSI and 8 percent had qualified for SSDI. Local studies conducted since that time suggest that homeless disability claimants are denied benefits at significantly higher rates than others, often for failure to negotiate the intricate application process, rather than for lack of severe medical impairments that meet SSA disability criteria. Case managers working in Health Care for the Homeless programs have reported that as many as 80 percent of their uninsured clients should have qualified for SSI or other disability assistance but were instead denied. People experiencing homelessness often fail to qualify for Federal disability assistance due to a variety of system barriers — lack of access to health services, insufficient documentation of functional impairment, remote application offices, complex application processes, lack of transportation, scattered medical records— despite the high likelihood that they would meet eligibility requirements. These obstacles are exacerbated by mental impairments and the lack of stability necessary to see a complex application process through to completion.

The Link Between Disability and Addiction

During the last 25 years, scientific research has begun to reveal the biochemical mechanisms by which mood-altering drugs — including caffeine, nicotine, alcohol, opiates, stimulants, and sedatives — change brain structure and function, thereby triggering addiction and dependence in persons with particular neurological vulnerabilities. There is evidence that the biological changes persist long after drug use has ceased. From these findings has evolved the current view of addiction as a chronic brain disorder with intrinsic behavioral and social-context components, similar to other forms of mental illness. ¹⁰ Indeed, substance use has for decades been categorized as a mental disorder in the Diagnostic and Statistical Manual of Mental Disorders (DSM IV), the standard psychiatric reference used by mental health professionals worldwide.

The co-occurrence of mental illness with substance use disorders is not unusual, regardless of housing status, but individuals with co-occurring disorders who are homeless are particularly vulnerable. Estimates of the number of homeless people with co-occurring behavioral health disorders vary, depending on the population studied and the definition of co-occurring disorders employed. In a national sample, 75% of homeless clients with a past-year drug disorder had a comorbid nonsubstance related mental illness. The National Alliance on Mental Illness (NAMI) cites an estimated 50% of homeless people have co-occurring disorders. AMHSA's Co-Occurring Center for Excellence (COCE) cites

http://www.nami.org/Template.cfm?Section=By_Illness&template=/ContentManagement/ContentDisplay.cfm&ContentID=13693

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⁷ Burt MR, Aron LY, Douglas T, Valente J, Lee E, Iwen B. (1999). Homelessness: Programs and the People They Serve: Summary Report – Findings of the National Survey of Homeless Assistance Providers and Clients, HUD Technical Report. Washington, DC: The Urban Institute. http://www.huduser.org/Publications/pdf/home_tech/tchap-05.pdf

⁸ A review of disability claims submitted to the Disability Determination Services in Boston, 2002 – 2006, revealed that SSI/SSDI denials were 2.3 times more common than approvals for homeless individuals, while denials for housed claimants were only 1.5 times more common than approvals. An earlier study by the Homeless Subcommittee of the Massachusetts DDS Advisory Committee had found that over one-third of unsuccessful disability claims submitted by homeless persons (over a nine month period in 1998–99) were denied for lack of sufficient medical evidence or failure to keep appointments for a consultative examination (see reference 10).

⁹ Post, PA. (2001). Casualties of Complexity: Why Eligible Homeless People Are Not Enrolled In Medicaid. Nashville, TN: The National Health Care for the Homeless Council. http://www.nhchc.org/Publications/CasualtiesofComplexity.pdf
¹⁰ World Health Organization (WHO). (2004). Neuroscience of Psychoactive Substance Use and Dependence.

http://www.who.int/substance_abuse/publications/en/Neuroscience_E.pdf

11 Kertesz, S. G., Madan, A., Wallace, D., Schumacher, J.E., Milby, J.B. (2006). Substance abuse treatment and psychiatric comorbidity: Do benefits spill over? Analysis of data from a prospective trial among cocaine-dependent homeless persons. Substance Abuse Treatment, Prevention, and Policy, 1(27), 1–8. www.substanceabusepolicy.com/content/1/1/27

12 National Alliance on Mental Illness (NAMI). (2003). Dual diagnosis and integrated treatment of mental illness and substance abuse disorder.

32% of homeless men and 37% of homeless women have comorbid mental illness and substance abuse disorders. 13

Medical research suggests chronic distress as a central construct underlying the association of psychiatric disorders with substance use disorders. 14 Such findings shed light on the disproportionate numbers of people who are homeless who have co-occurring mental illness and substance use disorders. On a daily basis, people who are homeless deal with discrimination, violence, inadequate access to health care, and constant stress in trying to meet basic needs such as shelter and food. Moreover, we know that most people who are homeless have experienced significant trauma from severe physical, sexual, or emotional abuse at some point in their lives.

Systemic Barriers Created by the DAA Policy

The 1996 termination of SSI and SSDI eligibility for individuals whose drug addiction or alcoholism is material to their disability was not intended to disqualify persons disabled by co-occurring impairments that include substance use disorders. Such denials have nevertheless been widely reported to occur at the initial stage of disability determination, many of which are reversed to allowances at the appeals level. Inconsistent interpretation and application of the DAA policy combined with the complexities of determining whether DAA is material to disability have prevented many people with severe disabilities from accessing assistance. One study found that over half of the people who lost their benefits due to the DAA policy had severe physical health disabilities that required hospitalization the year before termination. Another 15% of the population had been hospitalized for schizophrenia and psychosis unrelated to substance abuse. 15

The intent of the DAA policy was to reduce economic dependency on public programs and improve incentives to work. However, research shows that individuals who met DSM-IV criteria for addiction and who had their benefits terminated did not experience a significant change in their rates of employment; instead more disturbingly, arrest rates increased for this population. ¹⁶ Given these outcomes, we recommend that Congress and SSA repeal the DAA policy which has become a significant barrier to entitlements for people who have co-occurring physical or mental health and substance use disorders. The attached case example points out the difficulty homeless claimants have with proving their claims when substance abuse is woven into their life and their records. Until the policy is repealed, we offer the following recommendations in response to SSA's questions:

1. What should SSA consider to be medical evidence of DAA?

In most cases, symptoms of drug addiction or alcoholism are not the same for mental and physical impairment. However, inaccurate diagnoses are common. Misdiagnosis can occur when providers who do not have a longitudinal history with a patient make a determination based on a brief encounter. During brief encounters, symptoms of substance use may be more pronounced than symptoms from other disabling physical or mental impairment. Also, these encounters are not likely to distinguish between substance use and abuse and drug addiction or alcoholism.

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¹³ Substance Abuse and Mental Health Services Administration Co-Occurring Center for Excellence. (2007). Addressing cooccurring disorders in non-traditional service settings. http://coce.samhsa.gov/cod_resources/PDF/OP4-SpecialSettings-8-13-07.pdf Brady, K.T. and Sinha, R. (Aug 2005). Co-occurring mental and substance use disorders: the neurobiological effects of chronic

stress. *Am J Psychiatry*, 162(8):1483-93.

The stress of drug abuse or alcoholism disability. *Am J. Public Health*, 94(1): 46-47.

16 Chatterji, P., Meara, E. (in press, 2010). Consequences of eliminating federal disability benefits for substance abusers. *J. Health*

Econ.

Medical evidence of drug addiction or alcoholism for people who are homeless could and should be determined by providers who specialize in serving this population. Although most medical doctors and psychiatrists have the training necessary to determine addiction, they are not often found in high concentration in the programs that serve homeless populations. Instead, homeless patients receive much of their care from Nurse Practitioners, Physician Assistants, and Licensed Clinical Social Workers. These professions follow national standards of care and have the skills necessary to determine whether drug addiction or alcoholism is the source of functional impairment in their patients. We urge SSA to expand the list of acceptable medical sources to include Nurse Practitioners, Physician Assistants, and Licensed Clinical Social Workers in order to expedite and improve access to SSI/SSDI entitlements.

When an applicant is denied SSI/SSDI benefits due to drug addiction or alcoholism, the medical evidence of addiction should mirror the diagnostic criteria listed in the DSM-IV. Furthermore, impairment from physical and mental health conditions should be ruled out by a provider who has an established medical history with the applicant.

2. How should SSA evaluate claims of people who have a combination of DAA and at least one other physical impairment?

Our members observe a strong probability that drug addiction or alcoholism correlates to self-medication for lingering or severe pain issues. This is especially true for people who have limited access to health care services. In fact, one study found that people who had their SSI/SSDI benefits terminated under the 1996 law, increased their use of drugs and alcohol due to worsening health and economic circumstances. ¹⁷ For this reason, SSA should consider substance use and addiction as a probable indicator for underlying physical or mental impairment.

As noted earlier, most symptoms of drug addiction or alcoholism are not the same for physical impairment. Moreover, the consequences of the physical impairment will typically persist despite any addiction. Unless the provider indicates that the impairments are caused by the drug addiction or alcoholism, the assumption should be that the impairment is due to other physical or mental illness.

3. How should SSA evaluate claims of people who have a combination of DAA and at least one other mental impairment?

A hallmark of our members' provision of services is recognizing the importance of a continuing patient-provider relationship. In their experience, providers who know their patients are better able to recognize and distinguish symptoms resulting from addiction and non-addictive psychiatric disorders. The opinion of these providers should hold greater weight with SSA than the opinion of providers who have only had a brief encounter with a patient. In situations where a patient has not had a regular ongoing source of care, SSA should encourage providers and case managers to pull together all medical evidence that exists for that client, which may reside in multiple locations. The SSI/SSDI Outreach, Access, and Recovery (SOAR) program has been successful in training case managers on gathering medical evidence to assist SSI/SSDI applicants. Communities with designated SOAR workers have been most successful in gaining benefits for applicants. SSA should find opportunities to expand the SOAR program and invest in SOAR workers.

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¹⁷ Swartz, J., Lurigio, A., Goldstein, P. (2000). Severe mental illness and substance use disorders among former Supplemental Security Income beneficiaries for drug addiction and alcoholism. *Arch Gen. Psychiatry*, 57:701-07.

Instruments such as the Psychiatric Research Interview for Substance & Mental Disorders (PRISM)¹⁸, which was developed with support from the National Institutes of Heath and National Institute on Drug Abuse offers an explicit method for identifying psychiatric disorders that are separate from substance use disorders. The interview modules for this instrument are available online for free. The basic principles required to separate primary non-addictive psychiatric disorders from substance use disorders are logical in nature (i.e. if an individual had the primary non-addictive disorder symptoms during past periods of sobriety, that favors the existence of a separate nonaddictive psychiatric disorder). The PRISM interview modules have undergone validation in peerreviewed literature. 19 The developers (notably Professor Deborah Hasin of Columbia University, to whom we have no relationship) are certainly available to advise the Social Security Administration on this issue.

4. Should SSA include tobacco use in instructions?

SSA should not include tobacco use in the instructions. Research shows that people who have active psychiatric disorders are at increased risk for smoking and progression to nicotine dependence.²⁰ Tobacco use is generally not disruptive to people's ability to work and should not be considered in SSA instructions. Integrating tobacco use into the disability determination process would create additional barriers to accessing benefits (including smoking cessation programs) and may result in inappropriate decisions.

5. How long a period of abstinence should SSA consider in determining whether DAA is material to disability?

SSA should not require a period of abstinence. Requiring a period of abstinence would create a significant barrier to accessing entitlements for homeless persons who have co-occurring addiction and non-addictive psychiatric or medical disorders. Treatment programs for people who have limited incomes are in high demand and often have lengthy waiting lists. In addition, these programs are often ill-equipped to care for people who have co-occurring disorders. Academic literature is rich in evidence that proves abstinence and recovery to be extremely difficult and unlikely while living on the streets. Furthermore, our members have often found that people who abstain from drugs may initially see an improvement in symptoms, however, after a short "honeymoon period," symptoms of other underlying physical or mental health impairments become evident.

6. What guidance can SSA provide for people with DAA who are homeless?

Our members' experience is that their patients with DAA are often unable to negotiate the SSI/SSDI application process by themselves. SSA should require DDSs to employ a staff person who is knowledgeable of homelessness issues to work with homeless applicants. A designated staff person trained in homelessness issues would be better able to address systemic barriers occurring at the DDS level. Such a person could also act as a liaison and point person for homeless service providers who are acting on behalf of clients. DDSs, preferably though such a specialist, should track claims by homeless applicants. This data can be used to document the number of successful claims and reasons for denials. Such data can identify promising practices in expediting claims for homeless applicants.

⁰ Breslau N., Novak, S.P., Kessler R.C. (2004). Psychiatric disorders and stages of smoking. *Biol Psychiatry*, 55:69–76.

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¹⁸ http://www.columbia.edu/~dsh2/prism/

¹⁹ Hasin, D., Samet, S., Nunes, E., et al. (April 2006). Diagnosis of comorbid psychiatric disorders in substance users assessed with the Psychiatric Research Interview for Substance and Mental Disorders for DSM-IV. Am. J. Psychiatry, 163(4): 689-696.

Inconsistent interpretation and application of the DAA policy is widely reported by our members. SSA can make progress toward consistent application of this policy by instructing evaluators to:

- Consider drug addiction or alcoholism as a probable indicator of underlying physical or cognitive impairment
- Award claims when impairments are impossible to separate
- Consider long-term homelessness as an indicator of functional limitation
- Place greater weight on evidence coming from providers who have a longitudinal history with the claimant (including Nurse Practitioners, Physician Assistants, and Licensed Clinical Social Workers)
- Ensure that any determination where DAA is material to disability is based on documented
 evidence of addiction and alcoholism as listed in the DSM-IV, distinguishes addiction from
 substance use and abuse, and rules out impairments caused by a physical or mental health
 disorder
- When consultative exams are necessary, consider contracting clinicians who specialize in health care for people who are homeless

Respectfully submitted,

John Lozier, MSSW Executive Director

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In this case example SSA focused on the substance abuse issues which delayed the proper development in her case. Consequently, Ms.S has had to wait over 3 years for approval of her claim.

Ms. S first applied for SSI/SSDI in 2004 when she was living on the streets. Her claim was initially denied, and she did not appeal. She reapplied in March 2007, and that claim was denied in September 2007. Ms. S appealed, and the Federal Reviewing Official denied her request for reconsideration in September 2008. Her hearing before an ALJ was held in February 2010, and she is still waiting for a decision. Ms. S was born in Massachusetts, the youngest of four children. Her father was a fireman who suffered from severe schizophrenia and chronic alcoholism. When Ms. S was only six years old, he was hospitalized in the psychiatric ward of the local Veterans Administration Hospital. She has vivid memories of her father's emotional distress, and she and her siblings would frequently find him suicidal and holding a knife to his chest when they came home after school. As the primary provider for the family, Ms. S's mother was often away from the home. Her father's erratic behavior made it difficult for him to hold any employment. Ms. S quite despondently recalls her childhood as "just horrible." Her mother struggled to keep the family together and the household afloat. With barely a high school education, she was able to find only menial jobs at places such as Papa Gino's. The income she obtained from these jobs was barely enough to support four children and her ill and unemployed husband. The long hours her mother spent at work meant that she was rarely available for her children and was often exhausted and distant when at home. While her mother did not have any substances abuse issues, she did suffer from diabetes and eventually became disabled after poor circulation resulted in the amputation of one of her legs.

Ms. S struggled significantly through grammar school but was not held back. "I could not stand school; it was lucky I was not held back. She recalls disciplinary problems that started in junior high school, and she had several suspensions during high school in addition to "365 days in detention" during her high school years: "I never liked school." She did manage to get a high school diploma.

After graduating from high school, Ms. S worked in customer service at a flower shop that distributed flowers all over the country. Ms. S would take the orders that needed to be shipped. She stayed at this job a little over a year. Over the years Ms. S has had several jobs where she has stayed for a few weeks to a year but has always left because she found it difficult to get to work on time and she frequently called in sick. She would often quit jobs before being fired, but admits she was fired from her "fair share of jobs" as well. The longest position she held was as a customer service representative for a medical books distributor in MA. She was there for almost five years, from 1988 to 1993. Her position was terminated when the company's accounting department moved to Chicago.

Ms. S has been married once and lives separately from her husband and has little contact with him. They had no children together. While they met during childhood in grammar school, they began dating when she was age 26. They lived together for five years and then married when she was 31 years old. They drank alcohol frequently, if not daily, with each other and later began using heroin together. The relationship was volatile, and her husband was physically and emotionally abusive to her, although she does not recall ever having to go to an emergency room.

Ms. S tested positive for HIV in 2004, although she is not certain when she contracted the virus. She may have been infected during the 15 years she spent together with her husband. She tried many times to remain clean and sober, which distressed her husband. He successfully sabotaged her periods of sobriety and they continued to use drugs quite heavily. Ms. S also recalls multiple unsuccessful attempts to leave the relationship for her own good, but was frightened of her husband because he was violent and "too controlling." She ultimately was able to leave him in 2002. I should note that Ms. S and her husband had

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several apartments, but frequently were unable to pay rent and were often homeless during their time together and often stayed at Long Island Shelter.

Ms. S began drinking at age 12 and soon after was experimenting with marijuana. Her alcohol use escalated quickly over the next few years and she considers herself to have been "an alcoholic" by age 15. Alcohol remained her drug of choice until she began to use heroin around the age of 30. She underwent a dental procedure, became addicted to Percocet and rapidly escalated to heroin, which she shared with her husband. She now recalls dozens of detoxifications and attempts to gain sobriety, but most of the time she relapsed rapidly despite her efforts. Ms. S had no prolonged periods of sobriety until she was clean and sober for two years from 2000 through 2001. She was in a halfway house and then a sober house in Massachusetts.

Soon after relapsing in 2002, Ms. S entered a detox and a stabilization program which allowed her access to transitional housing. After completing the one-year transitional housing program, she relapsed and was back on the streets. During her time living on the streets, Ms. S slept on park benches, in alley ways, and on the sidewalk with little regard for her own safety. After five years of living this way, she was able to access housing through a Housing First program. As her doctor since 2004, I have grown increasingly concerned for her welfare and her seeming lack of concern about her own fate. I believe that her depression and her overwhelming sense of guilt and failure have left her without hope and without the will to live. She reports several instances of wanting to die, and once even drank an entire bottle of hairspray so "that I could end all this pain." I truly believe that her abuse of alcohol and drugs has been a cry for help and she has had repeated episodes of suicidal ideation when sober as well as intoxicated.

Ms. S has had no psychiatric hospitalizations. Ms. S admits to feeling depressed often and has little hope and no interest in her usual activities. She had been seen by psychiatrists in 1990 and again in 2005. She has been on Prozac and Paxil at different times, but she does not feel that they helped significantly. My observation and care of this patient over the past several years reveals significant signs and symptoms of a persistent affective disorder which has had devastating social consequences.

She has demonstrated a pervasive loss of interest in almost all activities, has been erratic in her sleep habits, is frequently agitated and unable to tolerate others, has difficulty concentrating, and has long been overwhelmed by feelings of guilt and worthlessness. I suspect much of these date to the isolation, neglect, and abuse she suffered as a child and clearly pre-date her problems with alcohol and drug use. Furthermore, she has shown marked difficulties in maintaining social functioning, has lost all friends and social supports, and openly admits to her inability to concentrate or keep up with a normal and persistent pace. I have personally witnessed the consequences of this disorder, as she was homeless and living on the streets for many years and was vulnerable to violence, weather, and exposure. If not for this housing first program, she would no doubt still be on the streets.

I firmly believe that Ms. S's affective disorder has been present before her chronic alcohol and drug abuse, and indeed is likely to be the reason that she has sought solace and self-medication through alcohol and drugs. I have no doubt that her chronic and persistent affective disorder will persist despite long-term sobriety, as evidenced by her relapse after two years of sobriety in 2002.

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