

**BEFORE THE UNITED STATES SOCIAL SECURITY ADMINISTRATION**

**Rules Regarding the Frequency and Notice of Continuing Disability Reviews** ) **Docket No. SSA-2018-0026**  
)

*Submitted via [regulations.gov](https://www.regulations.gov)*

**COMMENTS OF WHITMAN-WALKER HEALTH**

Whitman-Walker Health (WWH or Whitman-Walker) submits these comments in response to the Social Security Administration’s (SSA) notice of proposed rulemaking (hereinafter Proposed rule or NPRM) (84 Fed. Reg. at 63588) published on November 18, 2019. We are opposed to the proposed rule, because it is inadequately explained and justified, will generate confusion, and threatens considerable harm to SSDI and SSI beneficiaries and to persons applying for benefits. It also threatens to undermine the Administration’s initiative to End the HIV Epidemic.

**EXPERTISE AND INTEREST OF WHITMAN-WALKER HEALTH**

Whitman-Walker Health (hereinafter referred to as WWH or Whitman-Walker) is a community-based Federally Qualified Health Center committed to bringing high-quality, culturally sensitive care to the Washington, DC metro area, with a special mission to lesbian, gay, bisexual, and transgender (LGBT) communities and to people living with or at risk for HIV. We offer a wide range of services, including primary medical care, HIV specialty care, transgender health care, mental and behavioral health services, oral health care, medical adherence case management, HIV and Sexually Transmitted Infections testing and counseling, community health services, and legal services and public benefits assistance. In our four health care sites in the District of Columbia, WWH served more than 20,700 patients in 2018.

For almost 40 years, Whitman-Walker has been a major provider of care, treatment, and prevention of HIV in the DC metropolitan area, and a national leader in HIV treatment and

prevention. Approximately 25% of DC residents diagnosed with HIV use WWH as their primary medical home.

In 1986 WWH established our Legal Services Program to provide *pro bono* legal assistance to people with HIV on matters related to their diagnosis. One our first practice areas – which continues to be one of our core areas of specialization – was assisting individuals too sick to work in obtaining, and keeping, SSDI and SSI benefits. Over the decades, our staff and volunteer attorneys and paralegals have represented many hundreds, if not thousands, of individuals in applications for benefits and appeals of denials, Continuing Disability Reviews, and other SSDI- and SSA-related matters. We also have worked with SSA staff and leadership on individual cases, to improve the timely and accurate processing of cases, and on policy initiatives. Since the onset of the HIV/AIDS epidemic, we have been deeply involved in SSA’s guidelines for evaluating HIV-related disability claims. Our attorneys and health care providers offered expert advice on HIV and disability in SSA-convened public forums in 2003 and 2004, and offered extensive comments on proposed regulations in 2003, 2005, 2008 and 2014. We are proud of our longstanding partnership with SSA to secure quality service for people living with HIV and other disabilities, and to strengthen the integrity of our disability benefit system. In calendar year 2019, we opened 90 new SSDI- and SSI-related cases, including 23 new CDR cases, and continued to work on many more cases opened in earlier years.

#### **COMMENTS ON THE NOTICE OF PROPOSED RULEMAKING**

**Whitman-Walker fully endorses the detailed comments submitted on January 6 by the National Organization of Social Security Claimants’ Representatives (NOSSCR). We submit these additional comments to emphasize areas of particular concern to our thousands of**

health care patients and legal clients who are SSDI or SSI beneficiaries, or who may need those benefits in the future if their health deteriorates.

**The proposed increase in the frequency of CDRs for persons with HIV-related disabilities will exacerbate the distress, and harm the health, of many SSDI and SSI beneficiaries.** Even without the changes proposed in the current rulemaking proceeding, our clients living with HIV have experienced an increase in CDRs over the past several years, which has increased their anxiety and impaired their health, because the CDR process is poorly explained, the requests for information that they receive are quite burdensome, and the review process all too often is filled with errors. It appears that SSA plans to reclassify most HIV-related disabilities into the new MIL (Medical Improvement Likely) category, and subject them to more frequent CDRs – every 2 years instead of every 3 years.<sup>1</sup> This change would impose substantial unjustified harm.

As NOSSCR points out (January 6 comments at 3-4), CDRs are enormously burdensome for many individuals who are already sick or otherwise impaired, and ill-equipped to navigate a complex, confusing and anxiety-generating process. Whitman-Walker's experience underscores this concern – many if not most of our patients and clients receiving disability benefits simply cannot effectively handle the review without the assistance of a lawyer or other trained and experienced advocate. We regularly have clients who contact their medical providers for assistance filling out the paperwork because they are not able to answer the numerous questions involved. Our medical providers are able to refer their patients to our Legal Services program for assistance, but many beneficiaries without access to Whitman-Walker's resources are left

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<sup>1</sup> Docket SSA-2018-0026, *Supplementary Document: Impairment Placements in CDR Categories*, <https://www.regulations.gov/document?D=SSA-2018-0026-0003>, page 4.

without help and lose benefits due to these administrative challenges. Even with our assistance, the process is time-consuming and quite challenging. For instance:

- **Example 1.** A Whitman-Walker patient had been receiving SSDI benefits for several years, based on bipolar disorder and HIV, when he attempted to return to part-time work. He reported his earnings to SSA and received a notice that he was no longer eligible for benefits as a result of his earnings. His parent, who was his representative payee, contacted SSA for additional information, and received conflicting information from multiple SSA staff. In the meantime, the patient had been hospitalized when he suffered a manic episode after Medicare stopped paying for his medications. When his parent contacted SSA again, she was told that a letter had been sent saying he was “medically well.” Neither the patient nor his parent/representative payee received a copy of this letter, or any paperwork related to a CDR. The patient and his parent went to the SSA office in person and submitted an appeal. When they tried to follow up, they were told that they had filled out the wrong paperwork and had to submit a new appeal, which they did. Due to a number of errors by SSA representatives, the agency did not know whether to process his paperwork as an Expedited Reinstatement request or as a Request for Reconsideration of the CDR/medical cessation. At one point, the beneficiary’s parent was blamed by SSA staff for the delays for asking too many questions (while her son was struggling to access care).

After more delay, the patient’s psychiatrist referred him to a Whitman-Walker lawyer. Even with the attorney’s help, it took several weeks, and multiple phone calls and other communications with SSA supervisors, to receive accurate information. Throughout this time, the beneficiary remained without income or medical coverage and was suffering from a severe decline in his condition requiring multiple hospitalizations. Once the claim was finally processed correctly and forwarded for review, a DDS examiner found that disability was continuing, and that SSA had not gathered the necessary evidence from the beneficiary during the initial CDR. It took several more weeks for a decision to be finalized. Since Medicare had been terminated, once benefits were reinstated the beneficiary and his parent had to contact numerous hospitals and medical providers to try to resolve the multitude of bills, totaling thousands of dollars, for care that he received while without coverage.

- **Example 2.** A Whitman-Walker patient was undergoing medical review of his Social Security disability benefits, which he had received based on HIV and mental health conditions. During his review he had to move out of state, and he properly notified SSA of the move. He suddenly stopped receiving his benefits and received notice of a large overpayment. He attempted to appeal on his own, but the anxiety and stress from the process was causing a decline in his mental health. He was unable to maintain

employment, and he and his partner were struggling to pay rent and incurring growing amounts of debt. His medical provider at Whitman-Walker referred him to Legal Services for assistance and the lawyer was able to determine that SSA has given him the incorrect paperwork so an appeal was not actually being processed in his case. Upon further discussion with a DDS supervisor, the lawyer discovered that the initial CDR review had not correctly considered the comparison point decision with respect to his HIV. The supervisor agreed that benefits should in fact have been continued. Even once this happened, however, it took several months to unwind SSA's administrative errors. More than one year later, the beneficiary continued to receive conflicting notices from SSA.

These examples underscore SSA's confusion about its own processes and the errors that occur even with the current volume of CDRs. SSA should not increase the frequency of CDRs without clear evidence that this action is likely to result in benefits for the disability system – such as a substantial decrease in the number of persons continuing to receive benefits when they actually are able to work, and a substantial increase in persons re-entering the workforce after their benefits are terminated – that outweigh the substantial additional burdens on beneficiaries and the additional administrative costs of processing more CDRs. As the NOSSCR comments note, the record contains no such evidence.

**Confusions over the timing of CDRs threatens to exacerbate harms to people living with HIV and other disabilities.** Whitman-Walker wholeheartedly endorses the concerns expressed by NOSSCR on page 11 of its January 6 comments:

The proposed rule does not explain the start date for each CDR diary. It is unclear whether, for example, people placed in the MIE category will face their first CDRs 6-18 months from application, onset, effectuation, or other event. Depending on which start date is selected, it could be possible for people to receive CDRs before they ever receive any benefits.

The proposed rule also does not explain how subsequent CDRs will be scheduled. Given that more than 23% of CDRs in calendar years 2014 through 2016 took more than six months solely for the pre-hearing case review stage [citing <https://oig.ssa.gov/sites/default/files/audit/full/pdf/A-07-18-50391.pdf>], let alone the additional

years required for appeals, it is likely that many people ... may be due for a new CDR while a previous review is still pending. This will be confusing and inefficient for beneficiaries and SSA, and places people at grave risk of having their benefits suspended if they fail to properly elect benefit continuation or are terminated for failure to cooperate.

The clock for an initial CDR should run from the date when the beneficiary began to receive benefits, not from the disability onset date, which often is considerably earlier. The clock for a subsequent CDR should run from the date of decision of the previous CDR.

**The proposed more frequent scheduling of CDRs will stretch SSA resources considerably and threatens to exacerbate already unacceptable backlogs, and further delay processing of initial applications for benefits.** The SSA should make sure that increase in the frequency of CDRs does not negatively affect processing of new applications for SSDI and SSI benefits. There is already a significant backlog in the processing and disposition of initial applications for benefits and requests for reconsideration. Increasing the rate of CDRs will exacerbate this problematic result, since the same SSA offices that handle these cases also handle CDRs. Shifting staff to hiring and training new SSA and state agency employees, or to performing additional CDRs, can be expected to increase other backlogs, such as processing of initial claims and reconsiderations in disability claims, implementing decisions that award benefits, and processing changes reported by beneficiaries.

As noted by NOSSCR, “SSA has extensively documented difficulties adhering to its current CDR scheduling policy. ... These problems will only be multiplied if SSA expands its CDR process in the way it has proposed” (NOSSCR January 6 comments at 13-14).

**Any CDR must take account of the whole person at the time that the CDR is conducted, not just look narrowly at whether the symptoms initially documented have improved.** Whitman-Walker underscores NOSSCR’s concern that

[t]he proposed rule does not explain how people with multiple impairments will be placed into CDR categories. Most disability claimants have multiple impairments, but SSA's systems allow a maximum of two impairments to be recorded and the choices of which impairments are selected and which is labeled as primary are haphazard at best. The proposed rule also does not explain whether or how beneficiaries will be moved to different CDR categories as their ages change or if they develop new conditions, though the former circumstance is inevitable and the latter is likely.

NOSSCR January 6 comments at 11-12 (citations omitted). These concerns are particularly acute for our patients and clients. Many if not most of those receiving SSDI or SSI suffer from multiple morbidities, not just their HIV diagnosis; their disability determinations often fail to accurately reflect all their disabling conditions. Moreover, many of our patients and clients experience new medical problems with time – such as newly-diagnosed mental health challenges, cardiovascular disease, or complications from advancing hepatitis infection. A CDR that focuses narrowly on the specific conditions listed in the initial determination, without taking account of the individual's full range of conditions at the time the review is conducted, will often result in an erroneous conclusion.

A holistic, contemporary evaluation of whether a beneficiary remains disabled is particularly critical for long-term survivors living with HIV, and for persons aging with HIV more generally. Even in patients whose HIV is well controlled (in the sense that they have a low or even undetectable viral load), the virus frequently produces multiple complications as they age. As HHS notes:

While effective HIV treatments have decreased the likelihood of AIDS-defining illnesses among people aging with HIV, HIV-associated non-AIDS conditions are more common in individuals with long-standing HIV infection. These conditions include cardiovascular disease, lung disease, certain cancers, HIV-Associated Neurocognitive Disorders (HAND), and liver disease (including hepatitis B and hepatitis C), among others.

In addition, HIV appears to increase the risk for several age-associated diseases, as well as to cause chronic inflammation throughout the body. Chronic inflammation is associated with a number of health conditions, including cardiovascular disease,

lymphoma, and type 2 diabetes. Researchers are working to better understand what causes chronic inflammation, even when people are being treated with ART for their HIV disease.

HIV and its treatment can also have profound effects on the brain. Although AIDS-related dementia, once relatively common among people with HIV, is now rare, researchers estimate that more than 50 percent of people with HIV have HAND, which may include deficits in attention, language, motor skills, memory, and other aspects of cognitive function that may significantly affect a person's quality of life. People who have HAND may also experience depression or psychological distress. Researchers are studying how HIV and its treatment affect the brain, including the effects on older people living with HIV.

Department of Health and Human Services, *Aging With HIV*, <https://www.hiv.gov/hiv-basics/living-well-with-hiv/taking-care-of-yourself/aging-with-hiv> (visited January 15, 2020).

See also National Institutes of Health, National Institute on Aging, *Aging with HIV: Responding to an Emerging Challenge*, Sept. 30, 2013, <https://www.nia.nih.gov/news/aging-hiv-responding-emerging-challenge>.

**The proposed rule threatens to undermine the Administration's End the HIV Epidemic Initiative.** In his State of the Union Address on February 5, 2019, President Trump announced an ambitious initiative to end the HIV epidemic in the United States in 10 years. The initiative initially will target specific communities – 48 counties, seven states, the District of Columbia and San Juan, Puerto Rico – where HIV incidence and prevalence are particularly high – and subsequently expand across the nation. The initiative's announced strategies are:

- Diagnose all individuals with HIV as early as possible.
- Treat people with HIV rapidly and effectively to reach sustained viral suppression.
- Prevent new HIV transmissions by using proven interventions, including PrEP and syringe services programs (SSPs).
- Respond quickly to potential HIV outbreaks to get needed prevention and treatment services to people who need them.

What is “Ending the HIV Epidemic: A Plan for America”? <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview> (visited Aug. 9, 2019). These strategies all depend on the targeted individuals having access to affordable, comprehensive health care. The Medicaid and Medicare programs are essential to the success of the Initiative. Individuals on SSI, and many SSDI beneficiaries, depend on those programs for their continued entitlement to Medicaid or Medicare, and for the income that those programs provide, which make it possible for many of them to look after their health and engage with the health care system. Terminating their disability benefits is likely to result in loss of Medicaid or Medicare coverage, which will make it much more difficult for them to access health care. Loss of income will also threaten them with loss of housing and difficulty keeping access to adequate food and other necessities of life, all of which will create additional barriers to looking after their health. Persons living with HIV are likely to be forced to interrupt their antiretroviral treatment, which will not only harm them but may make it more likely that they will be able to transmit the virus to others. Persons who are HIV-negative and on PrEP may be forced to interrupt that regimen. Individuals living with HIV but unaware of their status will be less likely to be tested and then engage with the health care system once diagnosed.

### **CONCLUSION**

The proposed rule is inadequately explained and justified, will generate confusion, and threatens considerable harm to SSDI and SSI beneficiaries and to persons applying for benefits. It also threatens to undermine the Administration’s initiative to End the HIV Epidemic. All these effects should be considered in evaluating the costs and benefits of the proposed rule; SSA has failed to even note them.

The proposed rule should be rescinded – or at a minimum, substantially modified to address the many concerns listed here and in NOSCCR’s January 6 comments. Whitman-Walker would be happy to participate in additional discussions to identify ways in which SSA can improve the CDR process to more accurately and fairly administer our disability benefits system.

Respectfully submitted,



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