AIDS Law Project of Pennsylvania
a non-profit, public interest law firm

January 31, 2020

The Honorable Andrew Saul
Commissioner of Social Security
6401 Security Boulevard
Baltimore, MD 21235-6401

Submitted via www.regulations.gov

Re: Notice of Proposed Rulemaking on Rules Regarding the Frequency and Notice of Continuing Disability Reviews, 84 Fed. Reg. 36588 (November 18, 2019), Docket No. SSA-2018-0026

Dear Commissioner Saul:

These comments are submitted on behalf of the AIDS Law Project of Pennsylvania and the undersigned individuals and organizations all of whom are knowledgeable, through personal or client experience, of the challenges facing people living with HIV who rely on Social Security disability benefits.

Founded in 1988, the AIDS Law Project of Pennsylvania is a nonprofit public-interest law firm providing free legal assistance to people living with HIV and AIDS and those affected by the epidemic. We are the nation's only independent public-interest law firm dedicated to HIV and AIDS. We serve all of Pennsylvania and Southern New Jersey from our offices in Philadelphia and Camden County, NJ, educating the public about AIDS-related legal issues, training case management professionals to become better advocates for their clients living with HIV, and working at local, state and national levels to achieve fair laws and policies.

We are one of the few organizations in the state that provide free legal representation to Title II and Title XVI beneficiaries undergoing continuing disability reviews (CDR). Due to changes in the CDR screening process for people living with HIV in 2017, our clients and our office have seen a large increase in CDRs in the last three years.

We represent and advise clients at every stage of the CDR process, including completing CDR mailer and full medical review forms, appealing initial cessations, requesting statutory benefits continuation, gathering medical records, and representing at both disability hearing officer and administrative law judge hearings. Our CDR clients were awarded benefits for meeting an HIV listing at step 3 or because of a combination of impairments at step 5.

The Social Security Administration (SSA) in its Notice of Proposed Rulemaking (NPRM) seeks to increase the frequency of CDRs for all beneficiaries by shortening the time period between CDRs and by creating a new diary classification (medical improvement likely) to try and detect medical improvement at its earliest possible moment. It also proposes to move most people awarded at step 5 into this new medical improvement likely (MIL) diary.

These changes add 2.6 million CDRs in the next ten years, increasing the already heavy burden placed on beneficiaries undergoing full medical review (FMR) CDRs who have continuing disabilities with no medical improvement. It fails, however, to address the current system's low overall cessation rate and poor appeal record on initial cessations. The NPRM suggest its attempting to time CDRs for accurate cessations, but it does not provide any meaningful data to support the agency's conclusions.

The NPRM also offers no evidence to support placing beneficiaries awarded at step 5 into the new CDR diary category nor does it address how multiple impairments affect a beneficiaries' likelihood of medical improvement.

The rule also misstates and misinterprets its own evidence regarding returning to work after time out of the work place. While it states that certain percentages of people return to a high level of work, the source data only discusses people earning a mere $1,000 per year.

Further, we concur with the comments submitted by the National Organization of Social Security Claimants' Representatives (NOSSCR) that show the NPRM is arbitrary and capricious and should be rescinded for lack of adequate relevant evidence for the changes.[1]

I. The goal of the agency should include more than identifying medical improvement at its earliest point; it should also consider the burden on beneficiaries and the accuracy of the process

In the NPRM, the agency states its goal as "identify[ing medical improvement] at its earliest point through the CDR process." This goal is not dictated by statute, which requires only that nonpermanent disabilities be reviewed every 3 years.[2] Consideration should be given to the burden placed on the vast majority of beneficiaries that have disabilities with no medical improvement who must undergo time-consuming, invasive FMR CDRs that have a low initial cessation rate and are frequently reversed on appeal.

[1] See https://www.regulations.gov/document?D=SSA-2018-0026-4837; also available at https://nosscr.org/wp-content/uploads/2020/01/NOSSCR-comments-continuing-disability-reviews-FINAL.pdf
[2] 42 USC §421(i)(1).

We recommend a new goal be formulated that aims to increase the efficiency of the CDR process by reserving full medical review (FMR) CDRs for beneficiaries with a high likelihood of medical improvement while decreasing the number of FMR CDRs on beneficiaries less likely to have medical improvement (e.g., by increasing the use of the mailer deferral process).

II. More CDRs will likely lead to more erroneous initial cessations that will require timely and costly appeals

The evidence shows that the current system of CDRs has a very low overall cessation rate. This suggests that identifying the very few beneficiaries with medical improvement is a burden borne by the many beneficiaries with ongoing disabilities.

For FY 2015, SSA estimated that only 94,666 beneficiaries would be terminated out of 683,298 FMR CDRs performed – a cessation rate of only 13.85%. Thus, that year, 530,300 disabled beneficiaries – over 85% of those undergoing a full medical review – were put through an intrusive, burdensome review, costing beneficiaries and SSA time and money. Of the 152,998 who were initially ceased that year, the SSA estimated 38.12% (58,332 beneficiaries) would successfully appeal the cessation and have their benefits continue, often after a years-long appeal process.[3]

If only adults are considered, SSA's poor record on FMR CDRs is more stark. A paltry 7.62% (33,939) of the 445,370 FMR CDRs performed on adults in FY 2015 will result in cessation. Of the 71,028 adult beneficiaries initially ceased, SSA estimated *more than half* - 37,089 beneficiaries - would successfully appeal.[4]

Through the AIDS Law Project's representation of people living with HIV, we have seen the inaccuracy of the current system. In the last three years, every CDR client that we have represented in appealing an initial cessation has won the appeal and maintained benefits.[5] We have not cherry picked cases. We have accepted all cessation cases in Philadelphia County for people who came to us for representation. We successfully represented 10 clients in requesting reconsideration of an initial cessation due to medical improvement. Six were resolved without a hearing, once we provided additional medical information. On average, we spent a little over forty hours on each of these reconsiderations. For the four that required a hearing before a disability hearings officer, we averaged almost 50 hours of work. In most of these cases, we

[3] These numbers were derived by subtracting Age 18 redeterminations from Total OASDI and SSI (initially centrally). *Social Security Administration, Annual Report on Medical Continuing Disability Reviews, Fiscal Year 2015 (2019). Available at: https://www.ssa.gov/legislation/FY%202015%20CDR%20Report.pdf. Appendix A.* We subtracted age 18 redeterminations because they use a more stringent medical standard for determining continuing disability.

[4] These numbers were derived by subtracting the Disabled Children (under Total SSI Only) row from Total OASDI and SSI (initiated centrally) row in Appendix A of *CDR FY15*.

[5] This excludes the 8 FMR CDR cases in which we have appeals pending.

worked closely both with our clients and their medical case managers, funded through the federal Ryan White HIV/AIDS program, who also spent many hours challenging these erroneous cessations.

Unfortunately, not everyone undergoing a CDR has access to legal representation. We have seen limited interest in the private bar to take CDR cases, especially when the beneficiary opts for statutory benefit continuation, while the appeal is pending. Without retroactive benefits, claimants often have no resources to pay a fee for legal service. The Government Accountability Office has found that having legal representation is one of the most determinative factors in whether a person successfully appeals an initial denial.[6] If beneficiaries appealing a CDR cessation had access to attorneys, the already high appeal success rate would likely rise significantly.

We recommend SSA study and publish its results on how the diary classification system could be improved to increase efficiency while reducing unnecessary burdens. The NPRM fails to explain how increasing CDRs will result in a higher overall cessation rate. Considering that many initial cessations are overturned on appeal even without attorney representation, SSA should study ways to encourage private bar representation in CDR appeals to help ensure an accurate and fair process.

We also recommend that SSA revise its calculation of the NPRM's cost to the public. SSA does not credit any time or money spent by beneficiaries, family, friends, social workers, medical providers or lawyers in appealing erroneous initial cessations. SSA estimates that over 50% of initial cessations for adults will be successfully appealed, yet factors in no costs for these thousands of successful appeals. SSA should also factor in how erroneously ceased benefits cost beneficiaries in terms of late fees for bills, evictions, utility shutoffs, increase in SNAP benefits, and many other secondary and tertiary expenses.

II. The NPRM fails to properly estimate the burden and expense of CDRs

Everyone undergoing a CDR, by definition, has already been found to have a disabling condition meeting the more stringent medical standard for initial determinations. They have demonstrated to SSA through medical records that they have a disabling condition that is either terminal or will last for more than a year and that prevents them from significant employment. In many cases, the impairments that prevent beneficiaries from working also prevent them from accurately completing CDR forms. Due to our clients' significant impairments, we receive frequent requests

[6] U.S. Gov't Accountability Off., GAO-18-37, *Social Security Disability: Additional Measures and Evaluation Needed to Enhance Accuracy and Consistency of Hearings Decisions* 24 (2017) (finding that claimants with a representative were 2.9 times likely to be awarded benefits than those without).

for help even with the two-page CDR mailer (SSA-455-OCR-SM). For clients undergoing a full medical review, we assist in completing the 15-page Continuing Disability Report (SSA-454-BK).

In our practice, we see clients struggle to complete forms on their own, whether from problems with concentration, memory, physical limitations or other disabling conditions. Our clients struggle the most in completing information about their medical providers – the most important part of the form for showing continuing disability. When clients come to us following a notice of cessation, the underlying issue is rarely whether the client's disability is continuing, but whether they were able to successfully convey necessary information through the lengthy form.

In calculating the cost to the public, SSA estimates it will take 15 minutes to complete the short CDR mailer and 60 minutes to complete a FMR form. Our experience is not consistent with SSA's estimates. Based on our experience, the SSA fails to consider the tasks beneficiaries must undertake before and after completing the form, such as gathering medical records, talking to adjudicators, attending consultative exams, or appealing (see above). A typical CDR mailer case takes 1 hour of attorney time and an hour of client time (assuming it does not progress to a FMR). When we complete forms for a FMR in our office with a client, it usually takes 2 hours and the client has typically already spent 2 hours compiling information and reviewing the form beforehand. We also often rely on assistance with gathering medical provider information from medical case managers and hospital social workers. SSA does not count the time spent by attorneys, friends, or social workers in completing these documents in its estimate. It also does not consider any time spent by beneficiaries or others on gathering medical records, talking to disability determination services, attending consultative exams, resolving failure to cooperate suspensions, or appealing decisions. As a result, the cost to the public is grossly underestimated in the NPRM.

We have also seen field offices and disability determination services make costly and time consuming errors in processing CDRs, often resulting in interruptions and delays of both medical and financial benefits that our clients rely on to live. On several occasions, our clients' benefits have been suspended for failure to cooperate, despite responding and submitting the forms to a local field office. After three to four hours of attorney time (not including filling out the forms for a second time if necessary), we usually get the suspension lifted and move the CDR process forward. Unfortunately, however, our clients frequently will have already suffered financial consequences such as missed rent or utility payment with resulting late fees, evictions, and utility shut-offs. We have also seen at least two occasions where a beneficiary undergoing a FMR CDR changed their address at a field office but disability determination services continued to send mail to the previous address. Both cases resulted in failure to cooperate cessations which were successfully appealed after wasting beneficiaries' and attorneys' time. An increase in frequency of CDRs will only exacerbate these problems and drive up the cost to the public.

Clients who appeal within ten days of an initial cessation (or of a Notice of Reconsideration) can opt to continue their benefits while their appeals are considered. However, the necessary appeal forms are not included with the Notice of Cessation. Many of our clients call the number provided in the notice and the appropriate (or sometimes inappropriate) forms are mailed to the client, which do not arrive until after the ten days elapse. Clients also go to their local office within ten days and wait for hours to meet with a claims representative who then fails to accept their appeals and requests for statutory benefits continuation on the spot. Instead, our clients have been sent away with a stack of forms – including the appeal – without being told they had not yet appealed or that they have to return the written request for an appeal within the ten day deadline. As a result, the client's benefits are terminated for failure to appeal timely. These cases are usually resolvable through arguing for a good cause extension[7] but only after the involvement of an attorney plus additional time and paperwork for the beneficiary, SSA, and our office.

An increase in CDRs will only exacerbate these problems. We recommend that if SSA increases the number of CDRs performed, they also provide beneficiaries assistance in effectively completing the forms. This would reduce the number of initial cessations that would subsequently be reversed. The rule should also include requirements for SSA to revise its process for accepting appeals and send necessary appeal paperwork with all notices. SSA should also adjust its public cost estimate to more accurately show the time beneficiaries, family, friends, social workers, medical providers and attorneys spend on completing CDRs, particularly FMR CDRs. [8]

IV. The NPRM fails to consider how multiple impairments affect likelihood for medical improvement, particularly in beneficiaries approved at step 5

The NPRM assigns most cases awarded at step 5 of the sequential evaluation process to the new medical improvement likely (MIL) diary with reviews every two years. This proposal is not supported by evidence. By law, meeting a listing at step 3 or having a combination of medical and vocational factors that preclude work at step 5 are equivalent for demonstrating disability. Many people approved at step 5 have multiple impairments that in combination make it impossible to sustain meaningful employment.

Our experience working with people living with HIV suggests that people with multiple impairments are less likely to medically improve. While antiretroviral therapies have helped transform HIV into a chronic condition, comorbidities remain an issue and a danger. People

[7] 20 CFR § 404.1597a (f)(2); § 416.996 (c)(2).
[8] For example, whether a beneficiary received help and from whom is recorded on the SSA-454-BK. The SSA should publish statistics on this information and reissue the NPRM.

living with HIV and comorbidities are more likely to be hospitalized than those who do not.[9] Because people with multiple impairments have a harder time accessing and maintaining consistent treatment, based on our experience, they have greater challenges to sustaining the ability to work.

We recommend the agency eliminate placing almost all step 5 beneficiaries into the MIL diary as many of those beneficiaries have multiple impairments that make medical improvement less likely. We also recommend the agency clarify how the rule will be applied to people with multiple impairments, regardless of which step in the sequential evaluation process they were allowed.

V. The NPRM misinterprets evidence of the connection between length of time out of workplace and return to substantial gainful activity

The NPRM misstates evidence in bolstering its questionable claim that more frequent CDRs would mean some beneficiaries would be more likely to return to substantial gainful activity (SGA) because they would be out of the workplace for a shorter period. The relevant sections read:

> [I]n 2013, 35.5 percent of the 40-year-old adults who had been out of the work force for 1 year returned to work at *an SGA level*. The percentage of the 40-year-olds who returned to work at an SGA level dropped to 27.1 percent after 2 years out of the work force, 17 percent after 3 years, and to only 7.4 percent after 7 years. In the same year, 30.7 percent of the 50-year-old adults out of the work force for 1 year returned to work *at an SGA level*, 23.5 percent after 2 years, 14 percent after 3 years, and only 5.5 percent after 7 years out of the work force.[10]

To support these claims, the NPRM cites a document – SSA Office of Research, Evaluation, and Statistics (ORES) analysis of data from the Continuous Work History Sample, Likelihood of Returning to Employment by Age and Time Out of the Labor Market - that is attached to the NPRM under supporting documentations.[11]

The cited document, however, does not support the NPRM claims. The largest discrepancy is that the cited ORES data provides statistics on people who return to employment, with

[9] Cammarota, et. al., "Impact of comorbidity on the risk and cost of hospitalization in HIV-infected patients: real-world data from Abruzzo Region," CLINICOECONOMICS AND OUTCOMES RESEARCH, VOLUME 2018:10, 389-398, available at https://www.dovepress.com/impact-of-comorbidity-on-the-risk-and-cost-of-hospitalization-in-hiv-i-peer-reviewed-fulltext-article-CEOR.

[10] Notice of Proposed Rulemaking on Rules Regarding the Frequency and Notice of Continuing Disability Reviews, 84 Fed. Reg. 36588 (November 18, 2019), Docket No. SSA-2018-0026. (Emphasis added).

[11] SSA Office of Research, Evaluation, and Statistics (ORES) analysis of data from the Continuous Work History Sample, Likelihood of Returning to Employment by Age and Time Out of the Labor Market. Available at regulations.gov as supporting and related material for docket SSA-2018-0026.

employment defined as having earnings above *$1,000 per year*. The document provides no information about work at SGA levels, which in 2013, the year of the data, was *$1,040 per month.* Additionally, none of the percentages listed for 40 and 50 year olds in the NPRM match the chart in the source document provided.

The financial outlook for people terminated for medical improvement is bleak. Four out of five people terminated for medical improvement fail to earn at the SGA level for the five years following termination.[12] This indicates that SSA is terminating people whose impairments still prevent them from working at SGA levels, SSA's very definition of disability.

We recommend the NPRM be rescinded and that any new proposed rules be supported by adequate data and evidence. Additionally, we recommend more study on the employment outcomes of people ceased for medical improvement to see whether or not medical improvement has actually occurred, considering the poor work outcomes.

Conclusion

CDRs are burdensome and can be harmful to beneficiaries. We urge the agency to consider a different goal that strives to lower the burden on beneficiaries with continuing disabilities while at the same time more accurately identifying beneficiaries likely to improve medically. Benefits should only be ceased if there is proof of medical improvement, not because beneficiaries are unable to comply with the CDR process. Additionally, the agency should adjust its calculations on the cost to public to more accurately reflect the heavy burden of increased CDRs. It should also rescind the current rule because it is arbitrary and capricious because it is not backed by a coherent rationale or evidence.

Thank you for the opportunity to comment on these proposed regulations.

Respectfully submitted,

AIDS Law Project of Pennsylvania

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[12] Hemmeter, J., Bailey, M.S. Earnings after DI: evidence from full medical continuing disability reviews. *IZA J Labor Policy* 5, 11 (2016) doi:10.1186/s40173-016-0066-9 available at https://izajolp.springeropen.com/articles/10.1186/s40173-016-0066-9.

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