



AIDS Law Project of Pennsylvania

a non-profit, public interest law firm

October 18, 2021

Acting Commissioner
Social Security Administration
6401 Security Boulevard
Baltimore, MD 21235-6401

Submitted via www.regulations.gov

Re: Response to SSA's Agency Information Collection Activities: Proposed Request, 86 FR 46307 (August 18, 2021), Docket No: SSA-2021-0029

Dear Acting Commissioner Kilolo Kijakazi:

These comments are submitted on behalf of the AIDS Law Project of Pennsylvania. 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.

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 four 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.

We thank you for the opportunity to comment on the accuracy of SSA's burden estimate regarding the SSA-454-BK; its practical utility; ways to enhance its quality, utility, and ways to minimize the burden on respondents.

We think that SSA grossly underestimates the considerable burden SSA's current CDR review process places on claimants and the public, especially in its estimate that completing the SSA-454-BK form takes only 60 minutes. As described below, our experience is that it takes over ten (10) hours to properly review, collect information, complete the form, submit it and follow-up to make sure the forms were received and process. If there are any complications – such as SSA failing to process forms timely and erroneously suspending benefits for failure to cooperate - the burden is not just in additional time but places already vulnerable beneficiaries in risk of losing

housing, missing meals, and having utility shut-offs. We also suggest that form be streamlined and made more clear.

I. The Burden for Completing the SSA-454-BK is Greater than Sixty Minutes

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 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 60 minutes on average to complete the SSA-454, whether online or on paper. 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 information and records, following-up with field offices, talking to adjudicators, attending consultative exams, or appealing erroneous cessations.

When we complete the SSA-454-BK with a client, it usually takes 2 hours and the client has typically already spent at least 2 hours compiling information and reviewing the form beforehand (total of 6 hours). We also often rely on assistance with gathering medical provider information from medical case managers and hospital social workers and friends and family (an additional 4 hours). 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. We think a burden of at least ten hours – for a properly completed SSA-454-BK – is more accurate.

We have often seen field offices and disability determination services make costly and time consuming errors in processing CDRs, 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 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.

If beneficiaries try to complete the SSA-454-BK on their own and within a 60 minute time frame, they will likely be terminated. 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 (before the field offices were temporary closed due to COVID-19) 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 but only after the involvement of an attorney plus additional time and paperwork for the beneficiary, SSA, and our office.

II. Proposals on minimizing the burden on Respondents

We believe SSA could and should reduce the burden for claimants who need to complete form SSA-454 and adopt in full the recommendations by the Social Security Task Force of the Consortium for Citizens with Disabilities (CCD).

The SSA-454-BK is onerous and long. In Section 4, it requests very granular information about beneficiary's medical providers that is either irrelevant or easily answered by an adjudicator reviewing the medical record but difficult for beneficiaries to access (for example, first day a beneficiary visited a given medical provider). We have seen numerous occasions where beneficiaries were so intimidated by the sheer volume of the information requested that they gave up on completing the form or just gave cursory answers (both leading to costly cessations). We support streamlining the SSA-484-BK and eliminating superfluous requests for information.

Thank you for the opportunity to comment on this important matter.

Respectfully Submitted,

AIDS Law Project of Pennsylvania

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