



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

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 undersigned members of the Social Security Task Force of the Consortium for Citizens with Disabilities (CCD). CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. Since 1972, CCD has advocated on behalf of people of all ages with physical and mental disabilities and their families.

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

We agree that the Social Security Administration (SSA) is required by Congress to perform periodic Continuing Disability Reviews (CDR) on recipients of Supplemental Security Income (SSI) or Title II Social Security benefits awarded on the basis of disability. We also are concerned about the considerable burden SSA's current CDR review process, including its use of the SSA-454-BK form, places on claimants and the public. Not only do we think that SSA grossly underestimates that burden (discussed below), but because SSA does not adequately consider the burden each inquiry places on claimants, it seeks some information for which the burden on the claimant far outweighs the utility of the answer. We hope SSA will revise their burden estimate and take steps to reduce the Time Tax¹ this process imposes on claimants. We believe

¹ Annie Lowrey, *The Time Tax*, The Atlantic (July 27, 2021), <https://www.theatlantic.com/politics/archive/2021/07/how-government-learned-waste-your-time-tax/619568/> (describing the often underappreciated time tax imposed on recipients of government programs).

the burden created by the CDR process should receive heightened scrutiny because this is a process that is being imposed exclusively on a population that has already been identified to have severe impairments.

I. SSA Underestimates the Burden Related to Completing the SSA-454

SSA grossly underestimates the burden that responding to SSA-454-BK places on claimants and the public when it suggests the average burden is 60 minutes. Anecdotally, we believe that if you consider the complete time burden spent by the claimant and third parties to review SSA-454-BK, collect documentation, complete and transmit this form, it would take an average of 15-20 hours. This would include:

- times spent by the claimant receiving and reviewing the letter;
- time spent by assisters (neighbors, family, community assisters and sometimes SSA claims representatives) helping the claimant understand the SSA-454-BK form, and the steps required to respond (particularly in cases where SSA knows the claimant has intellectual, cognitive, behavioral or language deficits);
- time spent to collect information or documentation needed to complete the form;
- time spent by medical, behavioral health, and other providers furnishing documentation and or fielding specific questions necessary to complete the form;
- time spent securing assistance from advocates or lawyers;
- time spent to actually complete form;
- and the time required to transmit the SSA-454-BK to SSA.

Everyone undergoing a CDR, by definition, has already been found to have a severe condition that is disabling for at least a year, if not terminal. In many cases, the impairments that prevent beneficiaries from working also prevent them from accurately completing the SSA-454-BK (either on paper or online). In addition, disability beneficiaries are often older and have lower income, less stable housing, and less education than the general population, providing additional challenges when they need to fill out the SSA-454-BK and submit supporting documents like medical records. For children undergoing CDRs, the burden on families and service providers is substantial – adults must take time off of work and children must take time out of school for medical appointments in response to the form.

Just completing the SSA-454-BK form is burdensome in and of itself. It is 15 pages long and requires multiple stamps to be mailed back to SSA. It requires beneficiaries to write short essays in response to questions, report all the medication they take and all of the medical treatment and providers they attend, and all of their daily activities. For adults and children with disabilities, this is usually a huge amount of information. The SSA-454-BK form asks for detailed summaries of the medical treatment received over the last 12 months, including the dates of first and last appointments, information that the individual themselves is unlikely to know in the detailed required to respond, and necessitating assistance from health care professionals and other service providers. While it would be challenging and time-consuming for anyone to fill out, many of those who will need to fill it out have disabilities that will add additional complexity.

It is hard to give a precise estimate of what the real burden of completing an SSA-454 is because so many people completing it are doing so unassisted. Community Legal Services (“CLS”) of Philadelphia, one of the few organizations in Pennsylvania that provides free legal representation to Title II and Title XVI beneficiaries undergoing CDRs, estimates that it takes a minimum of 1.5 hours of attorney or paralegal time with the client (so 3 hours total) to just fill out the form, if all the underlying information has already been collected. Because CLS completes these forms regularly, this three hour estimate reflects a process that is uniquely efficient due to their familiarity and expertise with the SSA-454-BK form. It no doubt takes other assisters who are less familiar with this form, and certainly unrepresented claimants, far longer.

CLS’s three-hour estimate does not include the additional time the claimant already spent compiling information and reviewing the form beforehand. It does not account for the time the claimant spends receiving and trying to read the forms, or the time of friends, relative, case workers, and other assisters who they reach out to help them read the forms if they do not understand due to literacy or limited English proficient status. Many claimants report calling SSA to get assistance from claims representatives understanding these forms, which often includes getting through long-wait times on the phone. It also does not account for the time claimants and their community assisters spend collecting information to complete the form, or the staff time from medical offices who field questions about what medication has been prescribed, what tests were given, and the dates of first and last appointments.

Most claimants are unassisted and have huge challenges completing these forms due to symptoms of their impairments including poor memory, poor concentration or other limitations. It is often most challenging for clients to remember specific details about their medical treatment called for by the form (date of first or last appointment and each test performed) which is concerning because it is the most important part of the forms showing continued disability.

CDRs are also costly to beneficiaries, who often need to pay for medical records or appointments with doctors and other providers to fill out the forms (and any transportation required to get to and from these appointments). Although some states require medical records to be provided free to Social Security disability claimants, this does not extend to beneficiaries undergoing CDRs. Beneficiaries may need to hire representatives to assist them in completing the CDR paperwork.

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.

A. Ensure the SSA-454-BK is as accessible as possible.

The SSA-454-BK form is being sent exclusively to claimants who have already been adjudicated to have a severe disability, and thus, it is paramount that SSA take steps to ensure that the SSA-454-BK is as accessible as possible. Some recommendations to improve this form include, SSA ensuring that the form written in as clear and concise language as possible and analyzing the form for literacy level. We also recommend SSA make this form available in multiple languages. SSA collects information about literacy and limited-English proficiency status as part of its disability adjudications. SSA is aware that many of its claimants who have been found eligible for SSA benefits are limited English proficient, or lack literacy, and are not able to read these critical forms. Because the ability to respond to this form could lead to a cessation of benefits, it essential that SSA provide these in a language the claimant can read, whenever possible. For claimants that SSA is aware are illiterate, they should also be doing telephonic outreach.

B. Streamline the SSA-454-BK by eliminating unnecessary questions.

We recommend SSA take steps to reduce the burden on claimants by truncating and streamlining the SSA-454-BK. Specific consideration should be paid to the utility to each piece of information solicited as well as the burden it places on the claimant. Although detailed medical information is no doubt useful to evaluating ongoing disability claims, some of this information is not absolutely necessary to adjudicating the claim but may place a large burden on the responder. We recommend removing any questions that are not absolutely necessary to initiate a CDR review, or including modifiers to make clear that this information is not required if it is not known. Some specific examples include, but are not limited to:

Section 4: One of the longer sections of the form, Section 4, where the form asks for details about Medical Treatment, should be streamlined and truncated. We speculate that SSA is requesting information about recent medical treatment in order to solicit medical records, but Section 4 requests far more information than is necessary to complete this task.

First, we recommend significantly streamlining this section. Instead of asking for medical information in response to the same question three separate times in 4(C), 4(D), and 4(E) (“Tell us who may have medical records covering the last 12 months about any of your physical or mental conditions(s) . . .”), we recommend including only one question seeking treatment information stating: “Have you gone to see any doctors, psychiatrists, nurse practitioners, therapists, physical therapists, or other medical professionals in the last 12 months?” followed by a check box for yes or no. In a second question, ask, if yes, where? Under the “if yes, where,” we recommend SSA provide a few lines asking for the name of the institution, address and telephone number. This will allow SSA to get the necessary information it needs regarding recent treatment in a much more streamlined fashion. It will also significantly reduce the overall length of the form.

Whether SSA takes our recommendation to reformat and streamline Section 4, we recommend SSA remove the request for the claimant to identify the first, last, and next appointment with each provider throughout the form. *See* SSA-454-BK at 5, 6, 8, 10. We find that most claimants

do not know their scheduled appointments with this level of detail. Many claimants get upset when they do not know this information, and some get deterred and stop completing the form (leading to cessation of eligible individuals) when facing these obstacles. Others spend a significant amount of time contacting medical offices or pouring through their medical records to try to find these dates, creating additional burden. Although knowing dates of treatment may be helpful to SSA in making targeted medical requests, it is not necessary. Most medical record requests only require the name of the institution. Thus, any benefit garnered by getting responses to these specific questions is outweighed by the burden it puts on the claimant.

We also request SSA either remove, or add the modifier “(if known)” after all questions soliciting the name of the healthcare professional that provided treatment in Section 4. We find that many claimants do not know the name of who treated them, sometimes because providers serve them as a team, or the claimant cannot recall their name(s). Many claimants experience stress when they realize they cannot provide this information and in some cases may stop completing the form. In other cases, they may spend a significant amount of time collecting this information. We find that this level of details is not required for medical records requests; thus, the burden caused to claimants outweighs its utility to SSA.

We recommend revising the question about hospital and emergency room visits (*see* Section 4(D)) to say the following: “Have you been treated at a hospital, an emergency room, or urgent care in the past twelve months?” followed by a yes/no check box. Following this question, “if yes, where?” followed by lines asking for the name and address of the institution. At the end of each line there should be check box for – “overnight stay.”

We further recommend SSA revise and consolidate their questions about medical testing. Right now the SSA-454-BK asks claimants to report testing in multiple places. We recommend keeping the check boxes where claimants can indicate what sort of testing they have had or have scheduled, but think asking it multiple times can be overwhelming for claimants. Instead, we recommend including it only one time on the form. We recommend removing the solicitation for the dates of these tests, because many claimants struggle with that information, and instead use that space to ask “where test occurred (if known).”

We think removing questions about the dates of testing, would be an important improvement. As noted above, many claimants are not aware of this information. When confronted by these questions claimants experience anxiety, sometimes stop completing the form, or spend considerable time trying to learn it. While treatment dates have some utility, we do not believe having these testing dates is particularly important to SSA’s reviewing efforts and their utility is outweighed by the burden they put on claimants. We recommend you remove the sentence “Please give the dates for past and future tests” from the instructions (See, p. 6), or at a minimum, include the modifier “(if known).” We would further add the same modifier, “(if known)” after the phrase “Date of Test(s)” so it is clear that claimants do not need to provide that information if that question is not removed.

Section 5: For Section 5, we understand the need to know what medications that claimants are taking. Many claimants are unaware of which doctors prescribe certain medications, or their use. Some claimants spend considerable time trying to collect this information, but this information is easily gleaned from medical records and is not necessary for records request. We recommend adding the modifier “(if known)” after “If Prescribed Give Name of Doctor” and “Reason for Medicine.”

Section 9: We understand that information about daily activities, solicited in Section 9, is essential to understanding ongoing disability. That said, we recommend revising this section. First, we recommend SSA remove question 9(A), because essay questions are very burdensome for claimants to complete. We also think that question 9(A) is unnecessary because it is duplicative of 9(C). We recommend keeping the check box responses to “Do you ever have difficulty doing any of the following” in 9(C) but find them under-inclusive. We recommend adding a box for “Sometimes” to accommodate those claimants who have intermittent problems completing activities of daily living.

We further think you should add a 9(D) where you ask “Do you ever need or get help doing any of the following” and include the same list of activities, followed by check boxes: Yes, No, or Sometimes. We find claimants frequently report they do not need have difficulty completing certain tasks, even if they require assistance to do them, if that assistance is already in place (i.e., I don’t difficulty cooking because my partner does all the cooking). In order to ensure SSA is capturing complete Daily Activity information, this additional question may be helpful.

C. We recommend SSA revisit and improve processes related to ensuring that claimants diaried for CDR reviews receive the proper paperwork regarding their review.

Many claimants report that they do not receive CDR paperwork in a timely manner, or at all. SSA sometimes sends these forms to an incorrect address because the claimant has moved or SSA has not properly updated the address in its numerous databases. This causes considerable problems, because if someone does not respond to the SSA-454-BK, it can lead to benefit cessation.

CLS clients have reported that SSA does not always receive and process the SSA-454-BK when the claimant sends them in. Some claimants will send in forms repeatedly, and others will have their benefits terminated because they do not realize SSA did not receive their SSA-454-BK. Other client-facing agencies including Benefits Data Trust have also identified receipt of the form as a common pain point.² The fact that beneficiaries do not receive the CDR forms is also supported by SSA data that shows 40,000 beneficiaries are terminated from SSI each year because their “whereabouts [are] unknown: (e.g. returned mail) or because the “failed to

² Keith Barnes, Benefits Data Trust Comment in Opposition to the SSA’s Rules Regarding the Frequency and Notice of Continuing Disability Review (Feb. 2, 3030) at 2, <https://www.regulations.gov/comment/SSA-2018-0026-124466>.

furnish [a CDR] report.”³ We recommend SSA revisit and improve processes related to ensuring that claimants identified for CDR reviews receive their proper paperwork.

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

Respectfully submitted,

American Association on Health and Disability and Lakeshore Foundation
Association of People Supporting Employment First (APSE)
Epilepsy Foundation
Justice in Aging
Lakeshore Foundation
National Association of Disability Representatives (NADR)
National Committee to Preserve Social Security and Medicare
National Council on Independent Living
National Down Syndrome Congress
National Organization of Social Security Claimants' Representatives
The Arc of the United States
United Spinal

³ SSI Annual Statistical Report, 2018: Suspension, Terminations, and Duration of Eligibility. *Social Security Administration Research, Statistics, and Policy Analysis*, https://www.ssa.gov/policy/docs/statcomps/ssi_asr/2018/sect11.html#table77