



January 31, 2020

Submitted at www.regulations.gov

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

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, RIN 0960-AI27

Dear Commissioner Saul:

These comments are submitted on behalf of Community Legal Services, Inc. of Philadelphia (“CLS”). For more than 50 years, CLS has provided free legal services to address the legal needs of low-income Philadelphia residents in civil matters affecting their families, health, their jobs, homes, and incomes. The Supplemental Security Income (“SSI”) Unit is a unit within CLS that provides representation to individuals primarily seeking Title XVI benefits. We advise clients and provide representation in appeals relating to disability before the Pennsylvania Bureau of Disability Determination, and the Office of Hearing Operations, and in federal court. Additionally, CLS attorneys engage in advocacy efforts concerning questions of Social Security and SSI policy, including co-chairing a National Advocates for SSI Coalition. We appreciate your recent meeting with us to discuss critical issues facing our clients and disability claimants, and we look forward to an ongoing dialogue during your tenure.

We are one of the few organizations in Pennsylvania that provide free legal representation to Title II and Title XVI beneficiaries undergoing Continuing Disability Reviews (“CDRs”). Indeed, because the private bar does not take these cases, particularly when beneficiaries have elected statutory beneficiary continuation, we prioritize these cases and have significant on-the-ground experience in direct client representation at every level. CLS appreciates the opportunity to comment on the Notice of Proposed Rulemaking (“NPRM”) that SSA issued on November 18, 2019.

We agree that the Social Security Administration (“SSA”) is required by Congress to perform periodic CDRs on recipients of SSI and Title II Social Security benefits awarded on the basis of disability. We also are not advocating for changes to the current Medical Improvement Review Standard.



We have significant concerns, however, with other aspects of this proposal. SSA in its NPRM seeks to increase the frequency of CDRs for many beneficiaries by shortening the time period between CDRs and by creating a new diary classification, medical improvement likely (“MIL”).

By SSA’s own estimate, these changes will add 2.6 million CDRs in the next ten years, thereby increasing the already heavy burden placed on beneficiaries undergoing full medical review (“FMR”) CDRs who have continuing disabilities with no medical improvement. Despite the magnitude of the proposed burden, the proposal relies on very little, and often questionable, evidence to justify or explain these drastic changes. Indeed, there is no medical evidence or data to explain the decision to arbitrarily target all children’s SSI cases for review, *en masse*, regardless of the underlying disability at six and twelve, or to explain placing most older beneficiaries adjudicated disabled at Step 5 for more frequent reviews. The proposal also does not provide sufficient medical evidence to explain its focus on other populations, like cancer survivors, for more frequent review. The proposal also lacks a thorough analysis of its costs to the agency or the public. The proposal fails to address the current system’s low overall cessation rate and poor appeal record on initial cessations. Finally, we are very concerned that SSA seems to justify this proposal, in part, on evidence that more frequent reviews of children will discourage other eligible individuals from seeking benefits, counter to the SSA’s core mission.

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

Below, we discuss our objections to the NPRM in greater detail.

I. CDRs Are Inherently Burdensome on Disability Beneficiaries, who Largely Lack Legal Representation, Placing Them at Heightened Risk of Bureaucratic Disentitlement.

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 three years.¹ The NPRM gives no consideration to the increased burden placed on the vast majority of beneficiaries who have disabilities with no medical improvement, and who would be required to undergo time-consuming, invasive FMR CDRs, which have a low initial cessation rate and are frequently reversed on appeal.

Every person who is subject to a CDR is vulnerable. Beneficiaries subject to CDRs have already been found to have at least one very severe medically determinable impairment that has

¹ 42 USC § 421(i)(1).



prevented them from working for 12 months, or is fatal. While a requirement to complete paperwork and submit documentation at the risk of losing monetary benefits and health care would be stressful for anyone, it is likely more difficult, stressful, and time-consuming for disability beneficiaries, who as a group are older,² poorer,³ and sicker than the general population.

SSA subjects beneficiaries to CDRs even when SSA is aware that particular beneficiaries face obstacles that are likely to prevent them from participating in the reviews. If they do not complete the process, they will become part of an increasing number and percentage of CDR recipients⁴ whose disability benefits are terminated for “failure to cooperate” with the CDR process. CLS is very concerned that this NPRM will cause significant benefit interruptions to otherwise eligible beneficiaries, due to their inability to cooperate with this complicated bureaucratic process.

For example, our office recently represented a claimant before an Administrative Law Judge (“ALJ”) on an appeal of a cessation. The client, Ted Wilson,⁵ had been receiving SSI benefits as an adult for a decade, based on a combination of behavioral health conditions and a well-documented intellectual disability. Evidence in SSA’s possession, and indeed considered by a claims adjudicator that evaluated Mr. Wilson’s continued eligibility, showed that SSA knew that one of Mr. Wilson’s documented limitations related to his intellectual disability is that he has trouble decoding, which prevents him from reading.

Despite this knowledge, SSA sent Mr. Wilson a series of letters informing him that his disability case was up for review. In addition SSA instructed that, if he wanted his benefits to continue, he needed to complete a 15-page form (SSA-454) (which includes essay questions) and then sent another letter instructing him to call IMA, the agency contracted by Pennsylvania’s Disability Determination Services (“DDS”) to provide Consultative Exams (“CEs”) in Pennsylvania, to schedule an exam. Unsurprisingly, Mr. Wilson was unable to read or understand any of the more than twenty pages of instructions sent to him, and he did not respond. He also did not read or understand his notice for a hearing before the DDS hearing unit. Yet, SSA decided to terminate

² More than 75% of SSDI beneficiaries are age 50 or older, over 35% are age 60 or older, and nearly 6% are age 65. https://www.ssa.gov/OACT/ProgData/benefits/da_age201612.html

³ 71% of Title II disability beneficiaries have a household income below 300% of the poverty level; 20% were in poverty. Among SSI recipients, the poverty rate was 34% for children and 43% for adults aged 18-64. <https://www.ssa.gov/policy/docs/rsnotes/rsn2015-02.html>

⁴ According to SSA’s annual CDR reports to Congress, in 2013 there were 2,256 failure to cooperate (FTC) terminations, reflecting less than 2% of all terminations after CDRs. By 2016, these had increased to 9,956 FTC terminations, 5.1% of all CDR terminations.

⁵ Name changed to protect confidentiality.



his benefits for insufficient evidence, precisely because he could not decode SSA's complicated correspondence, which SSA had knowledge was a documented symptom of his disability.

It was only after SSA cut off Mr. Wilson's SSI benefits, leaving him completely without life-sustaining resources, as well as health insurance and access to prescribed medications, that he, by himself, and without the assistance of a lawyer or any sort of representative, took those letters to a Social Security Field Office to learn what happened. The SSA claims representative explained that his case had been reviewed. Because he failed to return the paperwork, SSA had stopped his benefits due to insufficient evidence. Moreover, because he did not realize any of this was happening until his benefits stopped, he had already missed both his appeal deadline and the deadline to elect benefit continuation. He told the representative that he was not aware this was happening because he could not read SSA's notices. The representative recorded his statement and noted his request for good cause for late appeal and for benefit continuation. Although SSA agreed to reinstate the appeal for good cause, despite this same good cause, they refused his request for benefit continuation pending appeal. This decision left a clearly vulnerable man, who lost his benefits due to symptoms of a disability SSA was aware of, without any resources during an appeal to allow him to prove he still had those same symptoms. The loss of SSI also caused him to lose his Medicaid benefits, and his access to behavioral health medication. He became homeless and was forced to rifle garbage bags for food to sustain himself.

Shortly after these events occurred, Mr. Wilson came to CLS. We have worked with SSA to restore Mr. Wilson's medical insurance and SSI. Indeed, he received a fully-favorable decision on the record from the ALJ, granting him benefit continuation. The fact that his case was continued on the record, without even the need for a hearing, speaks to how clear it is that he continued to be eligible for disability benefits; yet he needlessly suffered for seven months without income support.

Mr. Wilson's story is not unique. He is just one example of the many clients we see who, despite having severe disabilities that clearly continue to make them eligible for Social Security Disability and SSI benefits, are unable to keep those benefits because symptoms of their disability prevent them from complying with the complicated requirements of the CDR review process. In fact, the experience of the 1980's that led to the Social Security Disability Benefits Reform Act should have put SSA on notice as to the suffering that could be created by excessive CDR processes.

Sandra's⁶ case illustrates a different sort of obstacle to complying with CDR reviews. Sandra is a seven-year-old child who had been receiving SSI benefits for years due to severe disabilities, including sleep apnea that requires her to use a continuous positive airway pressure machine

⁶ Name changed to protect confidentiality.



(CPAP) at night. Her SSI benefits were terminated as a result of a CDR for insufficient evidence. Like Mr. Wilson, Sandra's mom failed to complete the 15-page CDR and attend a CE appointment and hearing, because notice of the CDR and the subsequent correspondence came to their address right after she and her mother fled to new housing due to domestic violence. Like Mr. Wilson, Sandra's mother only learned of the review after Sandra's benefits were terminated. She appealed. Despite her domestic violence, SSA did not grant her request for good cause for late filing. Sandra's mother came to CLS for help.

Sandra's circumstances were dire. Mom had to leave her job in order to escape her abuser; thus, she and Sandra were relying on the SSI money to help pay for rent and utilities. Without the SSI money, the family was facing eviction in their new home and a utility shut-off, which was particularly concerning in light of Sandra's dependence on a CPAP machine. In this case, despite attorney intervention, we could not convince SSA to allow Sandra good cause for late filing for her appeal. Instead, she had to reapply for SSI benefits and it took several months for SSA to find her disabled, once again.

To be clear, CLS does not advocate for an end to CDRs altogether. We recognize that they are mandated by the Social Security Act, and that some claimants may show medical improvement that will render benefit continuation inappropriate. But the examples above show that SSA's processes surrounding CDRs are inflexible and even inhumane at times. If SSA goes forward with its CDR proposal and substantially increases the number of CDRs every year, more people, like Mr. Wilson and Sandra, who are clearly eligible and in need of Social Security disability benefits, will lose their benefits merely due to bureaucratic disenfranchisement. The NPRM will exacerbate and amplify the errors that are already endemic in SSA's CDR system.

To wit, even though SSA knew Mr. Wilson had failed to participate in this CDR only because he could not understand the notices, and SSA knew that Sandra missed her appeal because her family had fled domestic violence, neither client was able to convince SSA to restore their benefits on their own. Both their cases required legal intervention. This fact is alarming because 95% of people facing CDRs must navigate the review process alone, without representation.

SSA data show that only 5% of individuals have representation when facing CDR actions at DDSs and only 17% are represented when facing hearings before ALJs. That means at least 83% of all claimants, whom SSA has already determined have a severe disability, are asked to engage in a complicated review process by themselves. Limited access to representation for people facing CDRs is not surprising. We have seen limited capacity to take on CDRs from our local private bar, especially when the beneficiary opts for statutory benefit continuation, because without retroactive benefits, claimants often have no resources to pay a fee for legal services. Limited access to representation is of great concern: 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.⁷

Non-profits law firms like CLS often prioritize helping people facing CDRs because we know legal representation is limited. But, due to limited resources, at CLS we turn away 50% of all individuals who seek our help on Social Security claims. 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 and to support non-profit representation, to help ensure an accurate and fair process.

II. The CDR NPRM Will Increase SSA's Longstanding Hearing Backlog.

SSA only recently began making any progress at working down its long-standing hearing backlog. This is of particular concern to CLS because we practice in Philadelphia. Two years ago, the Philadelphia hearing offices had some of the longest waits for hearings in the country.⁸ People literally died waiting for hearings and SSA should not adopt policies that risk an increase to the backlog again.

By committing to 2.6 million new CDRs over the next decade, SSA will cause hundreds of thousands of current beneficiaries to lose their benefits, and many will appeal those terminations or file new disability claims. We are very concerned that these appeals will add to the current pending hearing backlog, and drive up hearing wait times once again.

This NPRM does not, but must, provide an estimate of how many increased appeals it anticipates from this policy at the Office of Hearing Operations, the Appeals Council and in federal courts, to allow for a more thorough evaluation of the impact of this policy. Also, the added administrative costs of \$1.8 billion in the NPRM does not appear to take into account the numbers and costs from new claims made by those people ceased through the CDR process.

III. This Proposal Arbitrarily and Capriciously Targets Children's Cases for Needless Reviews.

⁷ 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).

⁸ Claudia Vargas, *SSI Backlog: Thousands around Philly waiting more than two years for disability hearing*, PHILADELPHIA INQUIRER, Jan. 7, 2018, available at <https://www.inquirer.com/philly/news/politics/ssi-delays-disability-hearing-20180107.html>



We are very concerned that SSA's proposal arbitrarily targets children's cases for *en masse* review. The proposal provides that all children nearing ages six and twelve will be reclassified and subject to more frequent reviews regardless of the nature of their underlying disability.⁹ Furthermore, the proposal targets impairments that particularly affect children and youth for inclusion in the MIL two-year review category, like speech disorders, attention-deficit hyperactivity disorder, eating disorders, and asthma. As a result, SSA estimates this proposal would lead to an additional 627,000 CDRs just for children with disabilities.

The proposed rule does not provide any explanation, nor does it provide medical evidence to support or explain why the agency proposes that all children nearing ages six and twelve, should be reclassified and subject to more frequent reviews as part of the MIL category. SSA provides no data suggesting children's cases experience exceptionally high rates of cessations. Because this proposal does not distinguish between children based on impairment, but instead seems to target *all children* receiving benefits, it is not surprising that SSA does not include any medical evidence that suggest impairments suffered by children are more likely to show improvement around ages six or twelve. Subjecting all children with severe disabilities to more frequent reviews *en masse*, merely based on their age, is the definition of arbitrary and capricious. It threatens the stability of a very vulnerable population – that is, low-income families raising children with severe disabilities – by forcing them through additional bureaucratic processes, regardless of their children's medical prognoses.

The futility of his policy is demonstrated by the medical circumstances of Nadeem Cozen.¹⁰ CLS represented Nadeem Cozen in a hearing before an ALJ when he was four years old. Nadeem suffers from multiple impairments including a large plexiform neurofibroma (essentially a benign tumor) in his tongue. Medical professionals agreed that even though this tumor prevented Nadeem from most communications and rendered him unable to eat solid foods, it could not be operated on safely. As a result, Nadeem has complex feeding and swallowing problems and speech problems that clearly limit his development, as well as global developmental delays, asthma, and scoliosis. The ALJ found him clearly eligible for benefits. His impairments were not expected to improve and did not. His mother informed CLS in January 2020 that Nadeem continues to have the same problems with feeding and communication due to his tumor. He can only attend school with an Individualized Education Plan and with the assistance of a home health aide to help him eat and go to the bathroom. Yet, because he just turned six, under this proposal, he would be targeted for a CDR. Undergoing such a review right now would be burdensome for the family, and a total waste of money and resources for SSA.

⁹ 84 F.R. 635593.

¹⁰ Name changed to protect confidentiality.



We are further concerned that SSA is proposing to accelerate the review of children's SSI cases in order to discourage otherwise eligible individuals from seeking disability benefits. Such a goal would be plainly contrary to SSA's mission to provide all those eligible life-sustaining benefits. In the NPRM, SSA relies on findings from Manasi Deshpande's study, "The Effect of Disability Payments on Household Earnings and Income: Evidence from the SSI Children's Program,"¹¹ and states:

The evidence also showed that the loss of the child's SSI payments decreased the number of SSDI and SSI applications from other members of the household. These responses to the loss of SSI payments suggest that there may be a shift in the reliance on SSDI and SSI as a permanent, reliable income source for the household.¹²

In other words, this proposal cites evidence that CDR benefit terminations *discourages otherwise eligible individuals from seeking Social Security benefits*. SSA's reliance on this study to support this point is alarming at worst and misguided at best. SSA's own statement seems to suggest that it is justifying its mass child reviews proposal to increase CDRs, *in order* to reduce overall benefits paid because evidence allegedly shows benefit terminations of children *discourage otherwise eligible family members from seeking benefits*. This justification is plainly contrary to the clearly articulated purpose of Title XVI of the Social Security Act, which is "to provide supplemental security income to individuals . . . who are blind or disabled."¹³ As a factor to be considered in increasing the frequency of CDRs, it is plainly contrary to federal law.

IV. The CDR NPRM Arbitrarily and Capriciously Targets Beneficiaries Adjudicated Disabled at Step 5 of the Sequential Analysis Process.

The NPRM proposes to assign most cases awarded at Step 5 of the sequential evaluation process to the new MIL diary with reviews every two years. This proposal is not supported by evidence or even much explanation. The NPRM does not provide any data, evidence, or rationale to support this decision to move most Step 5 cases to MIL or to explain why SSA finds that the current method of dairying Step 5 allowances as MIP cases is inadequate. Absent from the proposal is any explanation as to why SSA is making an arbitrary administrative distinction among beneficiaries without consideration to the beneficiaries' specific, individualized medical circumstances. None of the supplementary documents provided by SSA in support of the

¹¹ 84 F.R. 63591, n. 50 (citing Manasi Deshpande, "The Effect of Disability Payments Household Earnings and Income: Evidence from the SSI Children's Program," *Review of Economics and Statistics*, October 2016, 98(4) 638-654).

¹² *Id.*

¹³ 42 U.S.C. § 1381.



NPRM demonstrates whether the potentially affected adult beneficiaries were awarded benefits at Step 3 or Step 5: thus, SSA has not provided any evidence to support this change. And in general, SSA reports no publicly available information as to how many beneficiaries are categorized as Step 5 allowances, making it impossible for the public to evaluate this change through its own investigation.

Informed by nearly a half-century of direct representation in SSI cases, CLS understands that most individuals who benefit from Step 5 allowances are older – typically 50 or older – and are often people with multiple impairments. Many of these claimants have at least one impairment that worsens, rather than improves, with age. SSA has not included any data that explains why this group is more demonstrative of improvement in two years, and fails to cite, explain, consider, or acknowledge significant data, which concludes the opposite. Indeed, data shows that older people have shorter lifespans after they begin receiving disability benefits.¹⁴ In all age groups, SSDI and SSI program beneficiaries have higher death rates than their same-aged peers.¹⁵ SSA does not cite or discuss this evidence, or the vast evidence, showing that disabilities tend to progress rather than improve with age.

V. The CDR NPRM Would Layer New Reviews upon a Review Process that SSA Knows to Be Seriously Flawed, which It Has Failed to Remedy.

CLS acknowledges and agrees that SSA needs to perform CDR reviews. However, SSA is already failing to implement these reviews consistent with Congressional mandate. CLS and partner organizations have been witnesses to both DDS's and ALJ's routine failures to properly apply the mandated medical improvement standard. One systemic failure we see is that the agency frequently fails to follow the Social Security Act and include the Comparison Point Decision ("CPD"), or the underlying evidence upon which eligibility was initially based, precluding the ability to measure medical improvement.

In addition, after claimants face cessation at an early state in the CDR process, we see many claimants receiving overpayment notices for their receipt of continuing benefits, even though they are still appealing their cessation. This practice often discourages claimants from pursuing CDR appeals. Worse, it implicates their rights to due process under the U.S. Supreme Court's landmark *Goldberg v. Kelly* case.¹⁶

¹⁴ Kathy Ruffing, *No Surprise: Disability Beneficiaries Experience High Death Rates*, CTR. ON BUDGET & POLICY PRIORITIES (April 4, 2013), <http://www.cbpp.org/blog/no-surprise-disability-beneficiaries-experience-high-death-rates>

¹⁵ *Id.*

¹⁶ 397 U.S. 254 (1970).



CLS and partner organizations have been raising the issue of non-compliance with the Social Security Act and its implementing regulations to SSA's executive leadership for years. Please see attached Exhibits A and B. We have cited research and attached exhibits demonstrating the harms of these proposals and we respectfully request that SSA review each of the attached exhibits and each of the sources cited and made available to the agency through active hyperlinks. We further request that the full text of each of the exhibits and sources cited, along with the full text of our comments, be considered part of the administrative record in this matter for purposes of the Administrative Procedure Act. We are concerned that increasing the number of CDRs will only expand the problems of non-compliance with the law. Instead of expanding the number of CDRs, CLS recommends withdrawing this proposal and instead putting money into fixing systems issues with the implementation of CDR reviews.

VI. The CDR NPRM Is So Vague and Poorly Supported that It Is Arbitrary and Capricious.

A. The NPRM Fails To Properly Estimate the Burden and Expenses of CDRs.

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, like that of Ted Wilson described above, the impairments that prevent beneficiaries from working also prevent them from accurately completing CDR forms and complying with the CDR process. Due to our clients' significant impairments, we receive frequent requests to help them complete the fifteen-page Continuing Disability Report (SSA-454-BK). We frequently see clients struggle to complete these forms on their own 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. When we step in to assist clients, the continuation of the underlying disability is almost never the issue – the issue is helping them convey all that information on that lengthy form.

The proposal estimates that the public will bear a very small cost as a result of this rule: that it will only take fifteen minutes to complete the short CDR mailer and sixty minutes to complete a FMR form. Our experience is not consistent with SSA's estimates. SSA does not provide any data to support this estimate.

In our experience, even with the help of an attorney or paralegal, completing the fifteen-page form will take about 1.5 hours of both the attorney's and client's time. This three-hour estimate does not include the additional time the client already spent compiling information and



reviewing the form beforehand. Many clients would spend far more time than the three to six hours spent with an attorney if they are trying to complete this paperwork themselves.

SSA's proposal also omits considerations of many costs associated with this process. SSA's proposal does not factor in any of the time spent by case managers or friends helping beneficiaries read these forms and complete them. It also does not seem to factor in time gathering medical evidence, talking to the DDS, attending CEs, or appealing decisions. In cases where CDRs require an appeal before an ALJ, our office will spend an average of twenty-five to thirty hours on that case, which far exceeds the sixty minutes estimated. As a result, we believe the costs to the public is grossly underestimated.

The proposal further estimates that the increased administrative costs to SSA will be \$1.8 billion to do 2.6 million reviews over the next ten years. The proposed rule indicates that this assumes "fully-loaded costs of performing full medical CDRs, work CDRs and mailers."¹⁷ Like costs to the public, we are concerned that this proposal greatly underestimates the cost to SSA. Does this estimate account for the additional costs for appeals of CDR terminations at the DDS hearing office, the Office of Hearing Operations and the federal court level? If not, can SSA provide that estimate? We also ask if the proposal specifically consider the costs SSA will incur adjudicating new claims from terminated individuals. (See, e.g., the example of Sandra's cessation and reapplication above, a very common occurrence.) If so, SSA should release that estimate to the public to support its rulemaking.

Under the terms of the NPRM, it does not appear that the very likely administrative costs described above have been considered, undermining the financial savings this rule predicts. If these actual costs are not included, the NPRM cost estimate is inadequate, and, as such, arbitrary and capricious. The public and the Congress need a full estimate of this rule to evaluate and comment on its value and utility.

This proposal also acknowledges that the increase in medical reviews will also create a medical cost on medical offices, due to increased requests for medical records. The NPRM claims it is "not currently possible for us to estimate lost opportunity costs in this area."¹⁸ What studies, research, or other information were reviewed in order to come to this conclusion? Many beneficiaries have multiple impairments requiring the acquisition and review of records from many providers, often including specialists, to assess determined eligibility. The administrative and financial costs of getting these records are likely substantial and need to be assessed before any final action is taken. .

¹⁷ 84 F.R. 63596.

¹⁸ *Id.*



B. The Arbitrary Expansion Of The Medical Diary Categories from Three to Four Raises Multiple Concerns.

1. SSA's Mysterious "Predictive Model."

In the proposal, SSA explains that it currently schedules cases for CDR's based on the agency's "predictive model that identifies the cases most likely to exhibit MI [medical improvement]." ¹⁹ SSA uses this same "predictive model" to propose revisions to and an expansion to the diary categories. ²⁰ Moreover, this model, coupled with SSA's "experience," appears to be SSA's principle source that is identifying who, what, and which impairments should be revised based on different projections of medical improvement.

After reviewing this proposal repeatedly, we are left with a large unanswered question: what predictive model is SSA relying upon? At no point in the proposal does SSA define, describe, or explain what this predictive model is or how it works. The proposal also does not document any costs associated with creating, maintaining, or using this model, or whether changes made by this proposal will require changes be made to the predictive model (and any costs associated with that) or changes in how outputs from that model are interpreted. Such information is necessary for the public to comment on this effect and cost of this proposed rule.

The omission of details regarding this predictive model is glaring. This predictive model appears to be making extraordinary or even impossible predictions. For example, this proposal predicts that all individuals determined eligible for disability at Step 5 have quicker *medical* improvement justifying being scheduled for review every two years. But Step 5 does not relate to medical issues at all; it is an adjudicative classification that refers to individuals who have any number of different types of impairments and also can include consideration of a wide-range of vocational criteria. It is puzzling that a "model" could predict that a class of individuals who do not necessarily have any medical similarities at all could somehow have similar "medical improvement" based on the way their cases were adjudicated.

Without any information regarding this model, it is impossible to comment on its accuracy or effectiveness or ascertain its continued accuracy or effectiveness of the model if subjected to changes required by this proposal. Such information is critical, as this model appears to be one of the main tools SSA is relying on to propose changing diary designations for millions of Social Security Disability Beneficiaries.

¹⁹ 84 F.R. 63590.

²⁰ 84 F.R. 63592.



2. SSA's Reliance on Medical Coverage to Justify Adding an Additional Diary Category.

We find SSA's comment that the new two-year Medical Improvement Likely ("MIL") diary category "will allow [SSA] to assess MI after some beneficiaries benefit from access to health care through Medicare or Medicaid" to be nonsensical.

First, the agency undoubtedly knows that most new SSDI beneficiaries in the MIL diary category will be *unable* to benefit from new access to health insurance coverage, as they face a 24-month statutory wait for Medicare benefits (in addition to a five-month wait for SSDI itself). Unless their payment amounts are so low that they are dually eligible for Medicaid, most beneficiaries will be without health insurance coverage for the entire period preceding their first CDR if they are included in the new MIL category. A longer review period will thus more credibly capture beneficiaries' capacity for medical improvement.

Second, while SSI beneficiaries will benefit from two years of continuous Medicaid coverage, SSA's comment ignores persistent inequities in health care access for Medicaid recipients, particularly in rural areas, and particularly in the behavioral health context. In Philadelphia, where we practice, we regularly see beneficiaries struggle to access appropriate Medicaid-covered behavioral health treatment, particularly if they need treatment that is trauma informed. Yet access to behavioral health treatment in Philadelphia is light years better than access to treatment in rural portions of Pennsylvania, where quality treatment is hard to find, difficult to travel to, and subject to long waiting lists. As the proposed rule explicitly targets beneficiaries with serious behavioral health diagnoses, its assumption that two years is an adequate review period because of improved access to health care ignores the realities that those beneficiaries face.

3. SSA's Insufficient Analysis or Evidence to Justify Its Diary Changes.

Why is it necessary for SSA to change many of the diary categories and add a new 2-year review cycle? The proposal never sufficiently answers that question.

SSA bases many changes of diary categories on SSA's "experience" and its analysis for CDR case outcomes of MIE diaries. The proposal states that SSA "noticed that there were some types of cases where the MIE category resulted in a continuance for the first CDR but resulted in a cessation for the subsequent CDR. This was often an indication that the first CDR was conducted too early to identify MI." SSA fails to provide or describe any of its analysis to justify its conclusion. It also does not describe any guidelines for how it determined that cessations are occurring too early.



SSA provides a supplementary document, “Cessation Rate by Impairment.” The document states that it presents data on “Centrally-initiated Periodic CDRs and CDR Mailer Deferrals with Initial Determination or Deferral Decision in FYs 2014-2016 Top Fifteen Impairments Based on Highest Ultimate Cessation Rate.” This document does not reflect the breadth of SSA’s experience, as it only includes three years of data, and lists only fifteen impairments. There is no explanation for why SSA opted to focus on only fifteen impairments and only during a two-year period. Data showing more longitudinal improvement would be more persuasive at showing clear changes.

The data provided in the “Cessation Rate by Impairment” document is so devoid of any context that it is impossible to evaluate its import. Even if there are more benefit cessations for individuals with these fifteen impairments, without more, it is unclear why this matters. Even if it does, it is unclear if this document covers them. Who is covered by this data? The document does not specify whether this data represent all individuals whose cases were ceased from 2014 to 2016, or only those ceased pursuant to full medical reviews. Such a distinction makes a difference. If it includes all cessations, it would include many cases where people lost benefits for reasons unrelated to medical improvement, for example, when they die or reach full retirement age. If cases are being ceased due to impairment related death, that would emphasize the gravity of symptoms related to that impairment, and undercut any arguments for more frequent reviews. Also, how many individuals are represented by each cessation rate in this document? Are some of the cessation rates high because they only represent fifteen people, rather than several thousand? Without more information it is impossible to evaluate the import of this data.

SSA also cites supporting document “Cessation Rate by Diary Category” to support its proposal to change CDR categories when it states:

Based on the number of cases that seemed to fall between the MIE and MIP diary periods, we analyzed CDR outcomes for certain conditions, their assigned diary categories, and their associated MI rates. We identified several conditions that could have diaries in either the MIE or MIP categories. The MI rates were similar between both diary categories, suggesting that the MIP diary may not have captured MI at the optimum time.²¹

SSA does not present, describe, or explain how this supporting data supports its assertions that the CDR diaries need to be changed. This document only provides one year of data, from three years ago, about the cessation rates of seventeen impairments. Notably absent from this list are many impairments proposed for the MIE and MIL categories. SSA also does not explain how

²¹ 84 F.R. 63591.



these cessation rates are similar (many of them are more than five percentage points different) or why, if a condition has a similar cessation rate when evaluated in both MIE and MIP, it somehow indicates that medical improvement is being determined too late. It is also unclear what data this document represents. How did SSA select which impairments to list in this document? Are these cessation rates for all CDRs, or just full medical CDRs? Why did SSA only present data from one year? Without more information and discussion, it is unclear how this document supports the contention that SSA needs a new medical diary category.

We are very concerned that SSA has proposed changes to CDR categories that will greatly burden claimants, without providing evidence that supports the need for these changes. Absent that, these changes are arbitrary.

4. SSA’s Flawed Reliance on “Evidence” Connecting Time Out of the Work Force and Return to Substantial Gainful Activity.

One of the NPRM’s stated goal is to identify medical improvement at the earliest point and interrupt the receipt of disability benefits, so that it will increase workforce participation and have a positive effect on employment. There is no satisfactory evidentiary basis for this assumption.

SSA itself states in the NPRM that the agency cannot quantify the effects that more frequent CDRs will have on workplace participations: SSA states that while [SSA] believes “that there may be positive employment effects as a result of these proposed rules, [but SSA] cannot currently quantify them.”²² In other words, the proposed rule relies on mere guesses to justify a change that evidence shows to be harmful, again a reflection of how arbitrary and capricious this proposal is.

The data provided to support this point is not only unpersuasive, but also misleading. This NPRM posits that “shortening the time a person spends out of the labor force may improve work outcomes.”²³ The proposed rule notes that SSA’s “analysis of administrative data confirms that the majority of all working-age people in the general population who spend one year or more out of the work force do not return to work at the SGA.”²⁴ The data SSA cites is about people who left the work force for any reason (e.g., having a baby, going back to school) – not those who are rendered unable to perform substantial gainful activity due to a long-term disability. Even the NPRM acknowledged the correlation between time out of the workforce and return to SGA-work is “modest” and there is no evidence of causation.

²² *Id.*

²³ *Id.*

²⁴ *Id.*



Other evidence cited is equally problematic. For example, SSA cites the study “The Employment Effects of Terminating Disability Benefits” by T.J. Moore published in the *Journal of Public Economics* in 2015 and states:

For example, using our administrative data on entitlement periods and earnings for a group of beneficiaries and recipients whose benefits terminated due to a 1997 statutory change, a researcher at the National Bureau of Economic Research looked at the effect of the loss of benefit eligibility on work activity during the year of benefit termination and the next 11 years (1997 through 2008). Overall, about 22 percent returned to work at an SGA level during the first three years following benefit termination.²⁵

This article cited by SSA is 25 years old and applies to a group of people who are distinct from the current SSA disability population (only those terminated from SSA benefits when SSA removed alcohol and drug dependence as qualifying conditions in 1997). SSA does not explain why findings related to this population are relevant to the current SSA disability population subject to the proposed rule. Indeed, SSA probably cannot because they are not relevant. SSA also does not acknowledge T.J. Moore’s own warning that “[g]iven that DI beneficiaries with drug or alcohol addictions were the only ones removed, *it is difficult to know how these findings would generalize to other beneficiaries*” or how or why its inapplicable. (emphasis added) In short, SSA does not explain how this study is useful since, on its face, it does not support SSA’s assertion that more frequent reviews on people who are currently eligible for SSA disability benefits will have positive employment outcomes. The other supplemental material SSA cites (footnote 44) does not address work at the SGA level, randomly defining employment as annual earnings above \$1,000.00.

As noted above, SSA also relies on findings from the study of Manasi Deshpande, “The Effect Of Disability Payments On Household Earnings And Income: Evidence From The SSI Children’s Program.”²⁶ This study found that parents of children with disabilities often replace lost SSI income when those benefits are disrupted through a CDR, and that their family members are discouraged from seeking SSI benefits after the disruption occurs.²⁷

²⁵ *Id.*

²⁶ 84 F.R. 63591, n. 50 (citing Manasi Deshpande, “The Effect of Disability Payments Household Earnings and Income: Evidence from the SSI Children’s Program,” *Review of Economics and Statistics*, October 2016, 98(4) 638-654).

²⁷ 84 F.R. 63591, n. 50.



As discussed above, SSA's reliance on this study to support increasing reviews is alarming because it suggests that SSA is purposely and knowingly trying to discourage otherwise eligible family members from seeking benefits, contrary to the clearly articulated purpose of Title XVI of the Social Security Act and counter to SSA's core mission. SSA's reliance on this study is also problematic because SSA fails to acknowledge Dr. Deshpande's warning that her study's results "do not have clear normative implications" and should be approached with "caution":

As a final note of caution, the findings on household earnings and income *do not have clear normative implications*. Parental substitution toward work may be costly in the sense that it reduces the amount of time available for parents to care for their disabled children. Household earnings and income responses are an important but incomplete channel in understanding the effect of the SSI children's program on the long-term outcomes of enrolled children, which are of interest in the policy debate surrounding the expansion of the SSI children's program. In future work, it will be important to assess the normative effects of the SSI children's program by evaluating the health, education, and employment outcomes of enrolled children.

SSA does not note, as Deshpande did, that the true value of SSI benefits is not just its cash value. Often, for children, the value of SSI is that it can serve as an income replacement to allow parents to provide them necessary care. Thus, any "positive effects on employment activity" in the child disability context, for non-disabled parents or guardians, may undermine the health and long-term benefits of the disabled child, an underlying aim of the SSI children's program that the NPRM does not acknowledge

5. SSA's Failure to Adequately Address Critical, Outstanding Questions.

A great deal of critical data is missing from this proposal, making it impossible to assess the true costs and impact of the NPRM. We recommend that SSA withdraw this proposal and consider reissuing it only after much more research has been completed. Some critical questions that must be answered include, but are not limited to:

- How many total beneficiaries are expected to lose their benefits as a result of this new proposal, justifying the expected costs savings of 2.6 billion? Specifically:
 - How many child beneficiaries does SSA anticipate will have their benefits terminated as a result of this proposal? What categories of disabling conditions are most likely to be terminated?
 - How many Title II recipients does SSA anticipate will have their benefits terminated as a result of this proposal? What categories of disabling conditions are most likely to be terminated?



- How many Title XIV adults does SSA anticipate will have their benefits terminated as a result of this proposal? What categories of disabling conditions are most likely to be terminated?
- How many adults who currently receive Title II or Title XVI benefits were awarded their benefits at Step 5 within the past 7 years?
- What basis does the proposal rely on to support the assumption that all children may experience medical improvement due solely to them reaching the age of six?
- What basis does the proposal rely on to support the assumption that all children may experience medical improvement due solely to them reaching the age of twelve?
- Have any pediatric specialists, with expertise in childhood disabilities, provided expertise to support the conclusion that children with disabilities will experience improvement due to reaching the ages six and/or twelve?
- What data, studies, or reports support SSA’s assumption that many cancer survivors experience medical improvement in two years?
- What research informs the assumption that individuals found to meet the disability standard at Step 5 will find improvement with age, especially as they near retirement age?
- Is there outstanding research, data, reports, studies, or other investigations that SSA has requested, commissioned, or is aware of that will help determine which impairments have a likelihood to improve earlier than three years?
- Does SSA plan to factor in any comments or opinions from the recent National Disability Forum on What Impairments Have Likelihood to Improve, held on December 3, 2019 in Washington, D.C., on the implementation of this policy?
- The proposal indicates that “specific claim characteristics” are used to determine cases in the MIE, MIL and MINE diary categories, and the MIP would continue to be the category of “last resort” for impairments that do not meet the other criteria.²⁸ What “specific claim characteristics” are relied on to determine that an eligibility

²⁸ 84 F.R. 63595.



determinations based on the inability to adjust to other work (Step 5 cases) should be reviewed every two years, instead of three years, like other cases of last resort?

- How many cessation appeals does SSA anticipate will be appealed to the DDS level, to ALJs, and to the Appeals Council as a result of this proposal?
- What data and studies have been reviewed, if any, to assess how increased appeals from cessations will affect the hearing office and Appeals Council average processing time, and hearing and appeals backlog?
- How many new initial claims does SSA anticipate from prior recipients whose benefits were ceased as a result of this proposal? What will the costs of the new initial claims, and have these costs been factored into the anticipated administrative costs outlined in this proposal?
- Does SSA have medical evidence establishing that each impairment identified for inclusion in the MIL, is expected to improve in two years?

VII. 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. SSA should also rescind the current rule because it is arbitrary and capricious, as it is not backed by a coherent legally acceptable rationale and evidence.

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

Respectfully submitted,

Jennifer Burdick, Supervising Attorney
Kristen Dama, Managing Attorney
Jonathan Stein, Of Counsel
Richard Weishaupt,
Community Legal Services of Philadelphia



Exhibit A

October 11, 2017

Theresa L. Gruber
Deputy Commissioner, Disability Adjudication and Review

John E. Owen
Associate Commissioner, Disability Determinations

VIA EMAIL

Re: Failings in ODAR and DDS Medical Improvement and CDR Adjudications

Dear Ms. Gruber and Mr. Owen,

As you will recall, on August 16, 2017, we sent you a number of Continuing Disability Review (CDR) cases where the agency failed to comply with the Social Security Act and SSA policy regarding the need to have a full record that contained the Comparison Point Decision (CPD) in order to make a proper determination of whether there was medical improvement that justified a finding of cessation. We also offered to provide you with identifying information for these cases should you wish to investigate further.

According to the response Kate Lang received from the Office of External Affairs on August 29th, you are unable to respond to our concerns because the cases we have cited are still pending at one level or another at the appeals process. Instead, you asked us to submit only closed cases that illustrate the problem.

We take issue with this approach. We know of no legal barrier to discussing the current cases we have identified as typical and, indeed, we have discussed problems with open cases in the past with the Social Security Administration (SSA). Given the delay currently inherent in the appeal system, discussing only closed cases will confine us to cases that are at least three years old (assuming it takes two years to get a decision from an ALJ and at least another year to get a decision from the Appeals Council) and even longer, if by “closed cases” you also mean to preclude cases that are currently pending in the federal courts.

Moreover, since the problems that we have seen have mostly arisen more recently than 3 or 4 years ago we are concerned that we will be unable to find a representative number of closed cases that will satisfy your request. Of course, the problem is even more concerning since cases pending in the Appeals Council or beyond do not receive aid paid pending a decision, causing



irreparable damage to the former beneficiary. Our concern is to prevent that injury and prevent further violations of the Act and implementing policy.

We point out that if you wish to examine closed cases you could look at reported cases where not only was the CPD lacking but the Appeals Council failed to address the problem and the SSA defended the illegal action in federal court. A sample of such cases would include: *Hallaron v. Colvin*, 578 F. App'x 350 (5th Cir. 2014); *Walker v. Sec'y of Health & Human Servs.*, 817 F.2d 26, 28–29 (6th Cir. 1987); *Smith v. Comm'r of Soc. Sec.*, No. 3:16CV212-RP, 2017 WL 2292795 (N.D. Miss. 2017); *Granillo v. Colvin*, No. 14-CV-04658-JCS, 2016 WL 4411811 (N.D. Cal. 2016); *Carbonell v. Comm'r of Soc. Sec.*, No. 6:11-CV-400-ORL-22, 2012 WL 1946070 (M.D. Fla. May 11, 2012); *Holland v. Astrue*, No. 109 CV 849-SRW, 2010 WL 2041336 (M.D. Ala. 2010) and *Nunez v. Barnhart*, 87 Soc. Sec. Rep. Serv. 616, 2003 WL 21254639 (S.D.N.Y. 2003)(awarding benefits for failure to include the CPD).

Please be informed that unless we can meet with you to address this problem promptly, within the next two weeks, we will consider this the Acting Commissioner's final decision on the matter and proceed accordingly to seek redress of this irreparable injury.

Please contact Richard Weishaupt at rweishaupt@clsphila.org or Kate Lang at klang@justiceinaging.org to schedule a meeting.

Sincerely,

Catherine M. Callery
Louise Tarantino
Empire Justice Center

Carrie Chapman
Tom Yates
Legal Council for Health Justice

Racheal G. Henderson
Georgia Legal Services

Linda Landry
Disability Law Center

Kate Lang
Justice in Aging



Yvonne Perret
Advocacy and Training Center

Emilia Sicilia
Mental Health Project
Urban Justice Center

Richard Weishaupt
Community Legal Services of Philadelphia

CC: Nancy Berryhill, Acting Commissioner
Asheesh Agarwal, General Counsel
Gina Clemons, Associate Commissioner for the Office of Disability Policy



Exhibit B

April 2, 2018

Patricia Jonas, Esq.
Social Security Administration
Deputy Commissioner for Analytics, Review and Oversight

Re: Continuing Disability Reviews

Dear Ms. Jonas:

As you know, we are concerned about the proper handling of Continuing Disability Reviews (CDR), and particularly about the failure of many case files to include the Comparison Point Decision (CPD), which is crucial for the correct determination of whether there has been medical improvement. All too often, Administrative Law Judges (ALJ) and the hearing offices in which they work do not include the entire CPD in the file. As a result, it is difficult, if not impossible, to conduct a proper CDR at the ALJ hearing level.

The Social Security Administration's regulations clearly state that if the CPD is not in evidence, a finding of medical improvement cannot be made. 20 C.F.R. §§ 404.1594(b)(1), 404.1594(c)(3)(v), 416.994(b)(1)(i), 416.994(b)(2)(iv)(E). Many ALJs ignore this regulation and although they occasionally look at the CPD, they do not make it part of the record. Without including that CPD in the record, it is impossible to comply with the Social Security and Disability Reform Act of 1984. Moreover, the regulations make it clear that a finding of medical improvement cannot be made if the CPD is not available. More than one ALJ has told us that they don't need the CPD because if they find the beneficiary to no longer be disabled then the individual has improved. As you know this is contrary to the Act and regulations.

Unfortunately, the Appeals Council has not been consistent in enforcing this regulation in reviewing cases where improvement was found. The federal reporters are full of cases where the Appeals Council denied review even though the CPD was not in the record, as the citations in our prior letter of August 16, 2017 demonstrate.

Unfortunately, the HALLEX itself implies that the obligation to comply with the Act and regulations regarding the inclusion of the CPD is less than obligatory. HALLEX I-3-2-22 Note 2, allows the absence of CPDs to be excused on a "case-by-case" basis despite the lack of any statutory authority to allow such leeway. Similarly, the same HALLEX section allows for



violations of the statutory requirement to be overlooked “if the ALJ made all reasonable efforts” to include the CPD. Nothing in the Act or regulations allows CPDs to be omitted based merely upon a showing of a “reasonable effort.” In fact, the legislative history of the Act makes it clear that in the absence of the CPD or a full reconstruction a finding of medical improvement cannot be made. 42 U.S.C. (Supp. II) 423(f)(1), 1382(a)(5)(A); H.R. Rep. 98-618, 98th Cong., 2d Sess. 11-13 (1984); S. Rep. 98-466, *supra*, at 8-10.

It is our firm belief that all unfavorable ALJ decisions based on an incomplete CPD must be remanded by the Appeals Council for compliance with the law. There simply is no justification for case-by-case or reasonable effort permission to violate the plain meaning of the Act.

Our own experience has shown in a number of cases, that ALJs have refused to obtain the CPD, yet when we appeal to the Appeals Council, the cases are placed in the normal queue, which often takes a year or more to get a decision (during which time the claimant is without benefits). In one recent New York case, the Appeals Council denied review where there was no CPD; when the case was appealed to federal court, immediately the agency agreed to a request for voluntary remand and sent the case back to the hearing office. We can only surmise that the Appeals Council relied on the HALLEX to ignore this blatant violation of the Act. We therefore suggest that HALLEX I-3-2-22 be rewritten to eliminate all case-by-case and reasonable effort language.

We also suggest that in all CDR cases at the Appeals Council where there is either an allegation that the CPD is missing or where a brief examination of the case shows that the CPD is not in the file, the case should be immediately granted review, and if a fully favorable decision cannot be made, the case should be remanded to the hearing office with explicit instruction to include and develop the CPD and follow the regulations concerning the law.

This will save a great deal of time at the Appeals Council level and further effort in taking cases to federal court. Aside from cutting down on backlog at both the Appeals Council level and at the hearing office, getting this right the first time will ensure that the law is complied with as well as avoiding a great deal of human suffering. Many claimants find that they are without benefits for almost two years before their case gets back to the hearing office for the correct procedure.

We realize that not every CDR case can be readily identified, but many can be, either by the representative or by a cursory glance at the case. We believe that the vast majority of such cases can be intercepted and corrected. Hopefully, ALJs and OHO offices will soon learn of their responsibilities and the system will be improved and fewer cases will have to be appealed and/or remanded, adding to the workload.



We would be happy to discuss this with you further, and can fax you a list of cases where the problems that we talked about above are illustrated.

Thank you very much for your consideration. We look forward to talking with you further.

Very truly yours,

RICHARD WEISHAUP
Senior Attorney

KATE LANG
Senior Staff Attorney