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Chartered by the Congress of the United States

January 31, 2020

Commissioner Andrew Saul
Social Security Administration
6401 Security Boulevard
Baltimore, MD 21235-6401

Submitted via www.regulations.gov

Re: Notice of Proposed Rulemaking (NPRM) 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 by the Paralyzed Veterans of America (PVA). PVA is the nation's only Congressionally chartered veterans service organization solely dedicated to representing veterans with spinal cord injuries and/or disorders. If they are not in the workforce or retired, our members usually qualify for Social Security Disability Insurance (SSDI). Consequently, we are keenly interested in any proposed changes to the SSDI system and program.

Most PVA members have catastrophic spinal cord injuries which meet the listings level criteria to qualify for disability benefits. They are typically designated "Medical Improvement Not Expected" (MINE). However, we also have members with Amyotrophic Lateral Sclerosis (ALS), Multiple Sclerosis (MS) and other diseases of the spinal cord. According to the narrative in the NPRM, ALS and MS are identified as examples "of impairments in the MINE diary category that generally occur only in adults."

We understand that the Social Security Administration (SSA) is proposing several changes to its current rules governing when and how often the agency performs continuing disability reviews (CDRs). Our comments will focus on the changes to frequency of reviews for MINE diaried impairments and designation of certain impairments that receive a MINE diary based on the interaction of age and functional limitation. We also wish to align with the comments of the Consortium for Citizens with Disabilities.

Reducing the Time between CDRs for MINE

SSA is proposing to reduce the time between CDRs for those with a diary of MINE from 5 to 7 years to one every six years. This may appear to be a modest change in frequency of reviews but it can, in fact, have a significantly adverse impact on beneficiaries.

Because of the complexity of the process, if a veteran contacts PVA for assistance with a CDR, our service officers will assist that veteran as these reviews are similar to a Department of Veterans Affairs (VA) Compensation and Pension (C&P) exam that is scheduled for the purpose of a periodic review. However, for most veterans with a spinal cord injury or disorder like ALS, the VA determines the disability is permanent and total and does not schedule any subsequent exams or reviews.

The full medical CDR form is 15 pages long, costly to mail, and requires beneficiaries to provide short essays about their condition, report all of their medications, as well as all of the providers they see, and list all of their daily activities. The form asks for detailed summaries of medical treatments received over the past 12 months, information that an individual is unlikely to know in the detail required, thus necessitating assistance from health care professionals or other service providers. In the private sector, beneficiaries often need to pay for medical records or appointments with their doctors and other providers for assistance with completion of the CDR forms. Although some states require medical records to be provided for free to Social Security disability claimants, this does not extend to beneficiaries undergoing CDRs.

Failure to complete the CDR paperwork, or doing so incorrectly, can put at risk benefits that are a matter of life and death to people with disabilities—not only Social Security benefits, but also other critical benefits such as Medicare, Medicaid, housing assistance, and food assistance that are tied to SSA's finding of disability. Those who are found to have medically improved, and those who were deemed noncompliant with the CDR process, have only 10 days to request continuation of benefits while they appeal. If they don't appeal, they can be without income or health insurance for months or years. Retroactive benefits, once appeals are completed, will not ameliorate the problems faced by people with disabilities who will go without needed medication and health care, may lose their housing, go into debt, or be forced to declare bankruptcy. Those who do elect continuing benefits but are ultimately denied on appeal may be faced with overpayments withheld from future Social Security benefits, tax refunds, or other sources.

In many cases, people who lose their disability benefits they will become eligible for needs-based benefits or qualify for larger amounts of benefits. This proposal, therefore, should consider the offsetting programmatic and administrative costs to federally-funded programs such as SNAP, housing and homelessness assistance, TANF, WIC, LIHEAP, and VA Pension benefits, as well as to state and local programs that serve low-income individuals and households.

SSA's decision to modify the MINE category for permanent impairments from the current 5 to 7 year window does not seem to be grounded in any evidentiary basis. The agency does not say that a six year review period is medically appropriate. It identifies a five year review period as not medically appropriate, but says nothing about the appropriateness of the current seven year review period. While such a change does not seem excessive, for those with a lifelong disability who might rely on benefits for decades, it means more CDRs over the course of their lifetime, without any justification.

<u>Proposed Subregulatory Guidance for 17 Impairments</u>

The NPRM also contains confusing information about how the agency intends to treat certain conditions like ALS, MS. and other diseases of the spinal cord. The NPRM

narrative states that “We provide examples of impairments that we consider permanent in the current rule, including amyotrophic lateral sclerosis (ALS), Parkinsonian Syndrome (Parkinson's disease), diffuse pulmonary fibrosis in a person age 55 or over, and amputation of the leg at the hip. We provide additional guidance about permanent impairments in our current operating instructions……We may also revise the frequency of review for certain impairments because of improved tests, treatment, or other medical advances concerning the impairments. When we change the diary category for specific impairments, we incorporate the changes into our employee operating instructions, which are publically accessible.”

SSA proposes to retain the MINE category criteria for cases with a chronic or progressive impairment, or combination of impairments, with permanent, irreversible structural damage or functional loss and for which there is no known effective therapy, treatment, or surgical intervention. Most of the impairments SSA says it will consider permanent will meet or equal a listing in the Listing of Impairments. For impairments that do not meet or equal a listing, SSA proposes to retain consideration of the interaction of a person's age, functional limitations resulting from the impairment(s), and the time since the person last engaged in Substantial Gainful Activity (SGA) when we decide if the person's impairment(s) is permanent and, thus, subject to a MINE diary.

SSA goes on to say that it currently identifies 10 impairments that would receive a MINE diary based on the interaction of age and functional limitations and an additional seven based on the interaction of age, functional limitations, and time out of the workforce. Step 5 allowances based on these 17 impairments would continue to receive a MINE diary. Then, SSA states, “The table below describes SSA’s proposed sub-regulatory guidance for the 17 impairments that will be assigned a MINE diary based on vocational factors in combination with specific impairments.” According to SSA, these impairments are “subject to change with advancements in medical treatments and findings from our predictive model.”

Age and functional limitations	**Age, functional limitations, and time out of the workforce**
Amyotrophic lateral sclerosis, Angina, Late effects of injuries to the nervous system, Multiple sclerosis, Other diseases of the spinal cord, Parkinsonian syndrome, Peripheral arterial disease, Phlebitis, Rheumatoid arthritis, Spondylitis	Depressive, bipolar and related disorders. Huntington's disease. Intellectual disorder. Late effects of cerebrovascular disease. Neurocognitive disorders. Other cerebral degenerations. Schizophrenia spectrum and other psychotic disorders.

This table offers no more guidance than the identification of conditions to be evaluated in the context of age, functional limitations, and time out of the work force. There is no explanation as to how the interactions will be evaluated. There is no description of the process SSA will follow in making subsequent changes. The proposed rule does not provide any detail of how a beneficiary’s age, functional limitations, and time outside of the workforce will be considered for placement in the MINE category. For example, what is the age that qualifies a beneficiary for such placement? Will it be the same age for each of the 17 listed disorders? What functional limitations are considered in the decision? How much time outside of the workforce is qualifying and how will the three criteria be considered together?

PVA is uncertain as to why ALS has been placed on this list of impairments since the severity of that disease is irreversible and results in death in just a few years. As noted earlier, the VA determines that a condition like ALS is permanent and total and dispenses with any subsequent exams or reviews. Not only does this seem like a more merciful treatment of those with this illness it no doubt reduces administrative costs. SSA offers no details from its "predictive model" to explain why those with ALS should be subject to CDRs.

PVA also objects to SSA's repeated assertion that any changes it may make to the frequency of review for certain impairments, guidance on specific impairments to be assigned to particular categories, or other revisions to its regulations will be placed in its "publicly accessible employee operating instructions." Most members of the public would find it very difficult to locate that information, assuming they were even aware of any changes being proposed. Using the Program Operations Manual (POMS) or other subregulatory guidance documents to clarify these issues is a complete subversion of the Administrative Procedure Act's notice and comment policies.

Potential Employment Effects

PVA appreciates SSA's specific clarification that the NPRM will not change regulations that protect those using a Ticket to Work from medical CDRs or those that exempt work activity as the sole basis for initiating a medical CDR for people who work and receive disability benefits under Title II. However, we nevertheless have several concerns about the impact of this rule on work incentives and employment of beneficiaries.

We know that SSA informs beneficiaries about the Ticket to Work program at the beginning of their receipt of benefits but only then and at no other time thereafter. For a beneficiary who has gone through the arduous claims process and likely multiple appeals to obtain disability benefits, this is not the most feasible time to invite them to return to work. Providing information about Ticket to Work and its protections against CDRs at some point prior to initiation of a review might encourage some beneficiaries to explore returning to work. Unfortunately, it is our understanding that CDRs are scheduled before a beneficiary receives notice of their review. So it is possible a beneficiary could engage with an employment network even as he or she is about to become subject to a CDR. More frequent CDRs could discourage many beneficiaries from attempting to seek employment.

SSA offers no evidence that terminating benefits faster encourages people to return to work. The NPRM's data cited is about people who left the workforce for any reason, not those whose chronic or terminal disabilities made them unable to perform SGA. Supplemental material cited at Footnote 43 of the NPRM equates time out of the labor force to years without earnings above $1000, well below SGA. If SSA intends to use that level of income as a benchmark for CDRs, that will be a significant work disincentive.

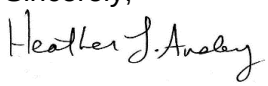
To the extent that CDRs remove people from the disability rolls, this is often because their impairments make it difficult for them to understand and comply with the CDR process, not because their impairments have improved in a way that dictates cessation of benefits. If anything, termination of financial and health-care benefits may lead to crises such as eviction, homelessness, hospitalization, bankruptcy, incarceration,

declining health, and extreme poverty—all of which make locating and maintaining employment more challenging than it otherwise might be.

This is a deeply flawed proposed rule that lacks evidentiary bases for many of its provisions. We urge SSA to withdraw it.

Thank you for your attention to PVA's comments.

Sincerely,



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