



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 on Rules Regarding the Frequency and Notice of Continuing Disability Reviews, Docket No. SSA-2018-0026, RIN 0960-AI27

Dear Commissioner Saul:

Thank you for the opportunity to comment on the proposed regulation “Rules Regarding the Frequency and Notice of Continuing Disability Reviews.” People with epilepsy are frequent recipients of SSI and/or SSDI throughout their lifespans, receiving essential income support and access to health care through Medicaid and Medicare.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of the 3.4 million¹ Americans with active epilepsy. Together we foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime.

Epilepsy is a highly variable condition. People may have epilepsy alone, or it may co-occur or be caused by another condition. Epilepsy may be associated with stroke,² traumatic brain injury,³ brain tumors, Alzheimer’s, and other brain conditions.⁴ Epilepsy frequently co-occurs with autism⁵ and other intellectual/developmental disabilities (I/DD).⁶ One third of Americans with epilepsy do not have seizure control despite available treatments.⁷

People with epilepsy may access Social Security through a variety of means. A young person with epilepsy and I/DD may receive SSI as a child and young adult, then transition to be a Disabled Adult Child when his parent retires. A veteran may return from abroad with a TBI and seizures, then need SSDI because she cannot return to the workforce. A middle-aged worker may develop seizures suddenly from no apparent cause, and need SSDI for a few years while they get their seizures under control. Each of these people and their families rely on the Social Security system for income support and access to health care.

Provisions of the Proposed Rule Raise Concerns About the Impact on People with Epilepsy

The NPRM proposes three buckets of changes and offers different justifications for each. However, these justifications do not provide sufficient information for us to determine the impact on people with epilepsy.

Our mission is to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. **Please learn more about our advocacy work at epilepsy.com/advocacy.**

Despite the substantial burden the changes place on beneficiaries by the proposed rule, SSA has not provided evidence that the changes are necessary or are based on evidence.

The NPRM states that epilepsy is commonly categorized into the Medical Improvement Possible diary category. However, it is not clear how people with epilepsy will be treated under the proposed change. Epilepsy is not included in either of the documents that SSA cites: Cessation Rates by Diary Category or Cessation Rates by Impairment. We are also concerned and unclear about how SSA will treat people with multiple impairments. People with epilepsy frequently have multiple co-occurring conditions, including degenerative conditions like dementia. Given the lack of evidence proposed, we cannot meaningfully comment and urge SSA to withdraw the rule until SSA can present more evidence on the impact on people with epilepsy and other conditions.

SSA proposes to end their previous practice of categorizing an individual as Medical Improvement Not Expected (MINE) if they would be 54 ½ or older when a next CDR diary would be due. The NPRM does not provide any rationale for ending this evidence-based policy and instead placing the older individuals awarded at Step 5 of the sequential evaluation process into the MIL category. The NPRM also does not provide any data, evidence, or rationale for reviewing people awarded benefits at step 5 of the sequential disability evaluation process more frequently. There is no reason why SSA should treat people with epilepsy who are awarded benefits due in part to vocational factors differently than they treat people with epilepsy awarded benefits at step 3.

The NPRM states that the new two-year Medical Improvement Likely (MIL) category will allow SSA to assess beneficiaries after they have received the benefit of Medicare or Medicaid enrollment. Medicare and Medicaid typically have better access to medications than private insurance due to the Six Protected Classes policy and the Medicaid Drug Rebate Program. However, SSDI has a 24-month waiting period for Medicare enrollment. Many states that have not expanded Medicaid still have highly restrictive Medicaid enrollment criteria for adults who are not SSI eligible.

It can take years to determine a successful course of treatment for epilepsy, including multiple tried and failed medications, surgery, and devices implanted in the brain. Even an evaluation every three years is too soon to know if a person with epilepsy is benefiting from medical treatment, especially if they spent the first two years without access to health care.

Once they are enrolled in health care, people on SSI/SSDI may achieve seizure control because they have access to specialty and primary care, as well as appropriate medications and other treatments, through Medicaid and/or Medicare. However, if they are found to have improved during a CDR, they may lose access to the very health care services and medications that enabled them to obtain seizure control. Delaying access to the anti-seizure medication(s) that work(s) for a particular person puts him/her at risk for breakthrough seizures and related complications including injury, disability, loss of mobility or employment, and even death.

Finally, SSA proposes to increase CDRs across categories. In addition to creating the new MIL category with more frequent review, this also includes changing the MINE frequency from 5-7 years to 6 years.

This would include people with epilepsy stemming from conditions from which a person cannot currently recover, like dementia. We do not understand the need for increased reviews for people with degenerative, incurable diseases, and urge SSA to not use its limited resources in this way.

The Burden of CDRs on People with Epilepsy

We are concerned about the burden that additional CDRs will place on people with epilepsy, their caregivers, and their physicians. People frequently have epilepsy as a result of brain injuries, stroke, or other neurological conditions that affect memory, concentration, and executive functioning. Seizures themselves can also affect these skills. People with epilepsy may have difficulty completing the forms correctly, or need to seek assistance from family to complete the forms.

The full medical CDR 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, report all the medication(s) they take and all of the medical treatments they receive and providers they attend, and all of their daily activities. For adults and children with disabilities, this is usually a huge amount of information. It asks for detailed summaries of the medical treatment received over the past 12 months, information that the individual themselves is unlikely to know in the detail required and thus necessitating assistance from health care professionals or other service providers.

Healthcare providers treating people with epilepsy – including neurologists and epileptologists – are already overburdened with paperwork. This paperwork stems from insurance and other administrative requirements. Meanwhile, people with epilepsy have a hard time getting appointments with these specialists, in part because the valuable time of these highly trained clinicians is absorbed with paperwork. According to a study sponsored by the American Medical Association, for every hour a physician spends with a patient, they spend two hours doing paperwork.⁸ The Centers for Medicare and Medicaid Services (CMS) have already recognized this burden and the Foundation is grateful that CMS is interested in addressing it with their Patients over Paperwork initiative. We are concerned that increasing the frequency of CDRs will add to the paperwork burden faced by clinicians, increasing physician burnout and decreasing access to specialists.

Additionally, the rule fails to address the very real problem of discrimination in employment against people with disabilities. Fully 32.2 percent of the charges of employment discrimination filed with the Equal Employment Opportunity Commission in 2018 (the most recent year for which data is available) was for disability discrimination.⁹ Even the Supreme Court has recognized that an individual can be receiving SSDI benefits and still be able to sue his or her former employer for refusing to reasonably accommodate them in their job. In *Cleveland v. Policy Management System Corp.* 526 U.S. 795 (1999) 120 F.3d 513, vacated and remanded, the Supreme Court recognized that a recipient of SSDI benefits is not automatically estopped from pursuing an ADA claim that the recipient could have continued working if the employer had provided the legally required reasonable accommodation. This was so because the SSDI system simply does not account for employment discrimination in its determinations. Finally, the rule fails to recognize the impact of a significant gap in employment on an applicant's ability to secure a job.

Conclusion

We are concerned about the proposed increases in CDRs for people with epilepsy, as well as concerned about the unknown impact of many of the changes proposed in this rule. We found it difficult to comment effectively on the proposed rule because of the lack of evidence provided, but on the basis of the limited evidence we were provided, we oppose these changes and urge SSA to withdraw the rule. If you have any questions, please contact Senior Director of Government Relations & Advocacy Rachel Patterson at rpatterson@efa.org.

Sincerely,



Vice President, Government Relations & Advocacy
Epilepsy Foundation

¹ <https://www.cdc.gov/epilepsy/data/index.html>

² <https://www.cdc.gov/epilepsy/communications/features/stroke.htm>

³ <https://www.cdc.gov/epilepsy/communications/features/TBI.htm>

⁴ <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Epilepsies-and-Seizures-Hope-Through>

⁵ <https://www.epilepsy.com/article/2017/3/epilepsy-and-autism-their-relationship>

⁶ <https://www.epilepsy.com/living-epilepsy/parents-and-caregivers/about-kids/when-its-more-just-seizures>

⁷ <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Epilepsies-and-Seizures-Hope-Through>

⁸ <https://www.ama-assn.org/practice-management/digital/clicks-and-keyboards-stealing-face-time-patients>

⁹ <https://www.eeoc.gov/eeoc/newsroom/release/4-10-19.cfm>