

January 31, 2020

The Honorable Andrew Saul
Commissioner, Social Security Administration
6401 Security Boulevard
Baltimore, MD 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:

The following comments are submitted on behalf of the United Spinal Association in response to the recent Notice of Proposed Rulemaking on Rules Regarding the Frequency and Notice of Continuing Disability Reviews.

United Spinal Association is the largest non-profit organization, founded by paralyzed veterans, dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D), including veterans, and providing support and information to loved ones, care providers and professionals. United Spinal has over 70 years of experience educating and empowering approximately 2.5 million individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. United Spinal has over 50,000 members, 54 chapters, close to 200 support groups and more than 100 rehabilitation facilities and hospital partners nationwide including 10 distinguished Spinal Cord Injury Model System Centers that support innovative projects and research in the field of SCI. United Spinal Association is also a VA-accredited veterans service organization (VSO) serving veterans with disabilities of all kinds.

United Spinal supports comments submitted on January, 16, 2020, by the co-chairs of the Social Security Task Force of the Consortium for Citizens with Disabilities (CCD).

United Spinal wants to emphasize that the Social Security Administration (SSA) is already mandated by Federal law to perform periodic Continuing Disability Reviews (CDR) for recipients of Supplemental Security Income (SSI) or Title II Social Security benefits awarded on the basis of disability. United Spinal strongly believes current law and applicable regulations are sufficient to maintain the integrity of these two programs that are essential lifelines for our members and for millions of Americans with disabilities.

SSA should be aware of the tremendous burden CDRs already place upon disability beneficiaries and their families. Increased frequency of CDRs will only increase the burden on people who already must live daily with multiple physical, mental, economic, transportation and personal care assistance challenges. Our members face these challenges and more on a minute by minute basis as they work to meet the challenges of living with neurological disorders and diseases to perform life's most basic tasks.

United Spinal is aware of the torturous physical, mental and emotion strain the SSA Disability Insurance program application process and the claims backlog can place on a claimant, their family and support ecosystem. Needless to say, when people's benefits are ceased after medical CDRs (either because SSA thinks they have 'medically improved' or because the person unintentionally did not comply with the CDR), these strains recur and often with increased severity

because people almost assuredly have not recovered economically from the gross delays in the initial claim application. Even electing the statutory continuation of benefits (especially given the 10-day deadline) is fraught with understandable pitfalls for those in our community whose time and attention are predisposed to getting through the day with a minimum of interruptions to a routine for daily living that is exceedingly time consuming in and of itself.

Add the additional time required to find representation, gather the requisite necessary information and/or medical evidence, scheduling appointments, identifying and scheduling transportation, completing forms, often by finding individuals who can assist with this burdensome task, for appealing a termination of benefits, and you have a recipe for stress laden with physical, mental and emotional strain and the incumbent medical reactions to that stress. SSA's calculation that completing CDR paperwork only takes an hour certainly does not take into consideration any of the burdensome challenges such paperwork already places on people living with neurological disorders and diseases.

General vagueness of Medical Improvement Not Expected (MINE) proposal: The NPRM states "We propose to retain the 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 we consider permanent will meet or equal a listing in the Listing of Impairments. For impairments that do not meet or equal a listing, we propose 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 SGA when we decide if the person's impairment(s) is permanent and, thus, subject to a MINE diary."

Certainly, many United Spinal members' conditions would fall into the above description, but many neurological impairments (arthritis, spinal stenosis, etc.) are not specifically mentioned and so it is unclear what CDR category people would be placed in. It is also not clear how SSA will use the "interaction of a person's age, functional limitations resulting from the impairment(s), and the time since the person last engaged in SGA" to place people in CDR categories, and no evidence is provided for SSA's plans in this regard. This uncertainty is stressful to United Spinal members who could face CDRs as often as every 6 months or as rarely as every 6 years under the proposed rule, and it prevents meaningful comment about how the proposal would affect people United Spinal serves.

Listings where age is considered for MINE status: The proposed rule lists "diseases of the spinal cord," ALS, and MS among the ten impairments where age and functional limitations could put people in the Medical Improvement Not Expected category and review them every 6 years. But SSA does not explain what age would qualify someone for this MINE status, how age and functional limitations would work together to classify someone as MINE or not, or whether a traumatic injury to the spinal cord would be considered a "disease" of the spinal cord. As a result, the proposal is too vague to provide meaningful comments but it seems likely to subject younger people with spinal cord injuries to more frequent reviews. For instance, unfortunately, even though the average age of injury has increased since the 1970's, a predominant number of spinal cord injuries occur in young people who still must start receiving disability benefits in order to survive. However, we are not aware of any data suggesting younger people with spinal cord injuries who receive disability benefits are any more likely to medically improve than older people. Certainly, qualifying for disability benefits at a younger age should be considered a neutral factor in CDRs.

Step 5: SSA's proposed rule would place most people who were awarded benefits at Step 5 of the sequential evaluation process into a new CDR category called, Medical Improvement Likely, in which they would be reviewed every 2 years. SSA doesn't provide any data for why people awarded at Step 5 should be reviewed more often. Such data would form a basis for comment and of course possible justification for regulatory consideration. United Spinal believes it is worth noting that since the 1990s, SSA's data classifies about a third of disability awards as "other"—not awarded for meeting a listing, or at Step 5. The proposed rule does not explain how SSA will schedule CDRs for these "other" cases. Could SSA please provide an explanation for this?

Multiple health impairments: The current proposal does not address people who have multiple health impairments. Many neurological disorders and diseases are closely associated with chronic secondary medical conditions such as diabetes, hypertension, deep vein thrombosis, urinary tract infections, muscle spasms, osteoporosis, pressure ulcers, chronic pain, and respiratory complications, to name several. Our members often experience more than one impairment. And at times, there are multiple impairments to be recognized as just which impairment at the moment is most severe medically. Reason dictates that the combined effects of multiple impairments reduce the likelihood that a beneficiary will medically improve.

Children: The proposed rule suggests reviewing children at approximately ages 6 and 12. However, what evidence exists to determine that children with spinal cord injuries and other neurological disorders and diseases are likely to improve at these ages? Nor does the proposed rule address timelines for CDRs for beneficiaries aged 6 or 12: would a CDR be conducted within weeks or months? Adding reviews at arbitrary intervals burdens families, educators, and medical providers for no obvious reason.

In short, the issues explained above would be unnecessarily exacerbated by increased CDRs. And any reasonable taxpayer should ask at what cost? Given the current extraordinary claims backlog and the extreme harm those backlogs have on families and the national economy, SSA's estimation of \$1.8 billion in administrative costs to conduct additional CDRs should be more effectively spent reducing existing backlogs before speculative and additional burdensome (on claimants and beneficiaries) administrative procedures are even considered.

United Spinal urges SSA to rescind this proposal. The proposal is not supported by data nor does it fully explain how it would work if enacted so it is not possible to provide full comments on it. And it would greatly increase the burden on people with disabilities and their families and providers. SSA should not go forward with this proposed rule. United Spinal welcomes additional dialogue with SSA on the current proposal and other issues. Please do not hesitate to contact Kent Keyser, Public Policy Fellow, with any questions at kkeyser@unitedspinal.org.

Sincerely,

A handwritten signature in black ink, appearing to read "Alexandra Bennewith".

Alexandra Bennewith, MPA
Vice President, Government Relations
United Spinal Association