January 28, 2020

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


Dear Commissioner Saul:

On behalf of the Autism Society of America, we urge the Social Security Administration to withdraw this proposed rule regarding the frequency and notice of continuing disability reviews. After reviewing the proposed rule, we believe there is not enough evidence indicating the changes are necessary. In addition, we believe the proposed rule will cause significant burdens on people with autism and their families and may result in many individuals losing benefits, not because their condition has changed, but because of the complex paperwork and confusion, it will create.

The Autism Society is the nation’s largest and oldest national organization representing individuals on the autism spectrum and their families. The Autism Society and its affiliates share a common mission of providing information and education, supporting research, and advocating for programs and services for the autism community. We have a very strong sense from our affiliates and from many parents and caregivers that these changes will create hardship for many families.

The proposed rule does not explain what CDR category many people with autism or other developmental disabilities will be placed in (the NPRM and supporting materials do not refer to autism at all). It could be as often as every 6-18 months, or as infrequently as every 6 years. Without knowing how SSA will handle many cases, it is difficult to provide meaningful comments on this proposed rule. The uncertainty itself is stressful for people with autism and their families.

Autism is considered a developmental disability. The current definition under the Developmental Disabilities Act defines “developmental disability” as a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; results in substantial functional limitations in 3 or more areas of major life activity; and is likely to
continue indefinitely. Autism also co-occurs with many other disabilities, including depression, anxiety, Down Syndrome, Rett Syndrome, epilepsy, and gastrointestinal ailments.

Since autism is likely to continue indefinitely, people with autism and other developmental disabilities should not be subjected to the burdensome experience of CDRs more frequently. Not completing CDR paperwork or doing so incorrectly can jeopardize benefits that are a matter of life and death to people with autism—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.

Furthermore, it is a waste of SSA’s budget to do so. CDRs can take a great deal of time, causing stress for families and administrative costs for SSA. Instead of SSA spending $1.8 billion in administrative costs to do more CDRs (SSA estimate for the next 10 years) the agency should spend that money on things that would help beneficiaries. Nearly all of the savings gained from dropping beneficiaries will go toward the administrative costs of conducting more CDRs. During a time in which everyone in our country should be looking to make government more efficient, these proposed changes do exactly the opposite.

We urge SSA to rescind this proposal. The proposal is not supported by data. It does not fully explain how it would work if enacted so it is not possible to give full comments on it. And it would greatly increase the burden on people with autism and their families and providers. SSA should not go forward with this proposed rule.

Thank you for allowing the Autism Society to comment.

Sincerely,

Christopher Banks
President/CEO