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January 27, 2020

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

**Submitted via [www.regulations.gov](http://www.regulations.gov)**

**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**

Dear Commissioner Saul:

These comments are submitted on behalf of the National Down Syndrome Congress (NDSC). NDSC supports the comments submitted by the Consortium for Citizens with Disabilities' Social Security Task Force on January 16, 2020. We are supplementing them with additional comments to provide the unique perspective from the Down syndrome community.

NDSC is the country's oldest national organization for people with Down syndrome, their families, and the professionals who work with them. We provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome, and work to create a national climate in which all people will recognize and embrace the value and dignity of people with Down syndrome.

Down syndrome is a genetic condition that is caused by the presence of an additional full or partial copy of the 21<sup>st</sup> chromosome. There is no known cause, and no "cure." Down syndrome is not related to race, nationality, religion or socio-economic status, and is occurs in approximately one in every 700 births in the United States. There is a wide range in the cognitive abilities and physical development of people with Down syndrome. Having Down syndrome increases the risk of other health conditions, including congenital heart problems, endocrine problems, intestinal problems, dental problems, seizures, ear infections, and hearing and vision problems. It also increases the risk of developing Alzheimer's disease and childhood leukemia. We are therefore concerned that the proposed rule does not explain how Continuing Disability Reviews (CDRs) will be scheduled when people have multiple impairments, especially when the individual impairments would dictate placement into different CDR categories.

Most people with Down syndrome will automatically qualify for Social Security benefits under the Category of Impairments, Section 10.0 Congenital Disorders that Affect Multiple Body Systems. Approximately 2% of people with Down syndrome have the mosaic form (in which some cells have an extra copy of the 21<sup>st</sup> chromosome and some cells do not). People with Mosaic Down syndrome

do not automatically qualify for benefits and need to prove the extent of their disability. As a result, we oppose SSA's plans to place those who are awarded benefits at Step 5 of the sequential evaluation process in the Medical Improvement Likely category, where they will be scheduled for a CDR every two years. There is no evidence that people with mosaic Down syndrome are likely to improve.

We also wish to point out that in millions of disability awards, SSA does not know whether the award was made because a person met or equaled a listing, or because medical and vocational factors were considered; SSA's annual statistical reports place these awards in an "other" category. More than 70% of disabled adult child awards over the past four years were classified as "other." Since many people with both types of Down syndrome receive disabled adult child benefits (for example, when their parent dies, retires, or becomes disabled) we are concerned that the proposed rule does not explain how SSA will handle these cases.

Regardless of the category and type of Down syndrome, we have heard from our members all over the country about how stressful, cumbersome and confusing the process of CDRs tends to be. It is very time-consuming to fill-out medical CDRs, even for those who do it every 7 years. Parents and individuals with Down syndrome often have to take off work to attend various doctors' appointments, and one slight mistake by either the beneficiary or the local SSA office has thrown people's benefits into jeopardy. We have heard many stories of people with Down syndrome and their families having to hire independent evaluators and ultimately lawyers to help restore their benefits.

While we recognize the need and mandate for CDRs in general, we do not believe that the proposed changes will benefit people with Down syndrome or their families. Quite the contrary, more frequent CDRs will further increase the burden on disability beneficiaries, their families, representative payees and others, and will increase the likelihood that their benefits will become jeopardized. We urge SSA to rescind this proposal.

NDSC appreciates the opportunity to provide this input. Please contact Heather Sachs, NDSC Policy & Advocacy Director, with any questions at [heather@ndscenter.org](mailto:heather@ndscenter.org).

Sincerely,



David Tolleson  
NDSC Executive Director



Heather Sachs  
NDSC Policy & Advocacy Director