**MEMORANDUM**

**TO:** Pediatric Medical Providers

**FROM:** Richard Weishaupt, Senior Attorney, Community Legal Services

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**DATE:** January 16, 2020

**RE:** **Proposed Social Security Regulations to Conduct Continuing Disability Reviews More Frequently – COMMENTS DUE JANUARY 31, 2020**

In November 2019, the Social Security Administration (SSA) proposed a new rule that would that would change how often most people receiving Social Security disability benefits, including SSI, would have their disabilities reviewed. Children would be particularly targeted by the new rule.

SSA is collecting comments on the rule until **January 31, 2020**. It will be required to read and consider every comment submitted before it can make the rule final. Comments can be submitted here: <https://www.federalregister.gov/documents/2019/11/18/2019-24700/rules-regarding-the-frequency-and-notice-of-continuing-disability-reviews>. (The comment page includes an old deadline of January 17, 2020 but SSA has extended that deadline to January 31.)

Pediatric medical providers have unique expertise and moral authority to speak out against this proposal. We hope you will make a comment and thank you in advance for your interest on this important subject. This comment guide provides some background on the proposed rule and some template comments that you can adapt and submit by the deadline.

Please note that federal commenting software will screen out comments that do not have original content, so including your own experiences and perspective is vitally important.

**BACKGROUND**

**What Does The Proposed Rule Do?**

It can take years for children to qualify for SSI based on disability. Once they qualify, they face continuing disability reviews (CDRs), or routine reviews to see if they still meet the disability standard. If medical improvement is expected (for example, for low birthweight infants), SSA will review the claim in six to 18 months. If medical improvement is possible, SSA will review the claim every three years. If medical improvement is not expected, SSA will review the claim every five to seven years.

Under the proposed rule, SSA would review most people every two years instead. SSA plans to conduct an additional 2.6 million reviews, and **627,000 of the reviews will be just for children with disabilities.**

SSA says it will “save” $2.6 billion from disability beneficiaries they project to be terminated under these accelerated and increased CDRs. They refuse to reveal how many will be cut off altogether.

**SSA projects that there will be $1.8 billion in increased administrative costs in conducting these additional reviews.**

**How Will Children Be Affected?**

The proposed rule would disproportionately harm children. It would mandate automatic reviews as children reach school age (age six) and adolescence (age twelve), even if there is no reason to believe that their conditions have improved. The proposed rule also targets impairments that particularly affect children and youth, like speech disorders, attention-deficit hyperactivity disorder, oppositional defiant disorder, eating disorders, and asthma. It also targets certain other childhood conditions, like congenital heart disease for children under age three.

The proposed rule further targets both children and adults with certain serious behavioral health conditions, like major depressive disorder, bipolar disorder, generalized anxiety disorder, and panic disorder. **It also targets children and adults who have disabilities due to certain cancers.**

SSA has provided little or no medical or scientific bases for these targets and reviews. It has also said that it will target further disabilities for more frequent reviews in the future.

**What’s Wrong with More Frequent CDRs?**

Qualifying for disability benefits is difficult and stressful. It is not uncommon for eligible children and their families to apply several times, and wait for years, to qualify. The test is so strict and onerous that more than 60% of applicants for disability benefits get denied at the initial application stage.

The CDR process can be equally hard to navigate, and very few families of children with disabilities have legal advocates to assist or represent them because of restrictions on attorney fees in CDR cases.

Families whose children are undergoing full medical reviews have to fill out extensive paperwork and provide medical evidence. In many cases, they also have to bring their children to SSA doctors. If they miss a step, their children’s benefits can be cut off for non-cooperation. Throughout the process, the threat of losing needed income hangs over their heads. For parents with inflexible work schedules, they are sometimes forced to choose between full cooperation and putting their jobs at risk. For parents with conditions like anxiety or depression, the process exacerbates their own disabilities. **More frequent disability reviews makes the process even worse for families.**

Even worse, SSA regularly does not follow the law for CDRs. In conducting CDRs, the Social Security Act requires SSA to look at whether children have “medically improved” – a very specific legal standard. Advocates, like those at Community Legal Services, have been showing SSA case evidence for years that demonstrates that SSA does not follow the law for CDRs. **Adding 2.6 million more CDRs means that SSA has that many more opportunities to disregard the law.**

**TEMPLATE COMMENTS**

January 15, 2020

**Via www.regulations.gov**

Andrew Saul

Commissioner

Social Security Administration

6401 Security Boulevard

Baltimore, MD 21207

# 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

I *[We]* write in opposition to the Social Security Administration’s (SSA’s) proposed rule to conduct many continuing disability reviews (CDRs) more frequently. I *[We]* are particularly concerned about the proposed rule’s impact on families of children with disabilities.

*[Please insert background information about who you are. Here, you might include information about your medical education, the nature of your pediatric practice, the patient population you serve, the community in which you work, and/or the institution at which you practice.]*

1. **More Frequent CDRs Will Be Burdensome for Families of Children with Disabilities.**

The families of children with disabilities often struggle to get by. Children with disabilities frequently have multiple daytime medical appointments in a single week and are often absent from school because of illness. Schools are resistant to providing appropriate accommodations, forcing parents to fight for their children’s rights, and often resulting in children being out of school inappropriately. Few dedicated child care options exist for children with disabilities. As a result, parents and caretakers with lower-wage and/or inflexible jobs struggle to remain connected to work, placing their families at risk of eviction, utility shut-off, and hunger.

SSI is a lifeline for families of children with disabilities, because it provides income that can supplement lost wages. It also helps pay for expenses like special diets, medical copayments, and transportation to medical appointments that are common among families of children with disabilities.

Unfortunately, for families of children with disabilities, applying for SSI is not easy. As parents and caretakers are juggling medical appointments, caretaking challenges, school accommodation disputes, and other challenges, they also must navigate a complex bureaucratic process that denies 60% of applicants at initial application.

*[Please insert discussion of the challenges that you see families experience in trying to access SSI for their children with disabilities. Specific, anonymized examples would be very compelling, if available.]*

Once children qualify for SSI, keeping the benefits is just as difficult. CDRs require families to

fill out extensive paperwork and provide medical evidence that may be difficult to track down. In many cases, they have to bring their children to SSA doctors on top of many other medical appointments. If they miss a step, their children’s benefits can be cut off for non-cooperation. Throughout the process, the threat of losing needed income hangs over their heads. For parents with inflexible work schedules, they are sometimes forced to choose between full cooperation and putting their jobs at risk. For parents with conditions like anxiety or depression, the process exacerbates their own disabilities.

I am *[we are]* very concerned that this proposed rule will cause significant benefit interruptions to otherwise eligible children, due to their families’ inability to cooperate with the complicated bureaucratic process every two years. *[Please insert a sentence or two about how losing SSI will affect the families you care for.]*

1. **More Frequent CDRs Will Force Families of Children with Disabilities to Wait Even Longer for Benefits.**

Families already wait too long for their children to qualify for SSI. A majority of children are denied SSI at application. Even if they are eventually found eligible for SSI, they often must wait up to two years – and in a few cases, even longer – to prove to an administrative law judge that they meet SSA’s disability rules.

*[Please insert discussion of the challenges that you see for families who are waiting to prove SSI eligibility. Specific, anonymized examples would be very compelling, if available.]*

More frequent CDRs will slow down the process for all families, by pushing more children into the pipeline for administrative hearings. Families cannot afford to wait any longer than they already do for SSI benefits for their children.

1. **SSA’s Decision to Target Children for More Frequent CDRs Is Arbitrary and Capricious.**

*[Note: “Arbitrary and capricious” is a legal term of art that creates a basis to sue to invalidate the proposed rule if it goes forward.]*

The proposed rule says that it will require all children nearing ages six and twelve to be subject to more frequent reviews, regardless of the nature and severity of their disability or their likelihood of medical improvement. Subjecting all children with severe disabilities to more frequent reviews *en masse*, merely based on their age, is a textbook example of arbitrary and capricious rulemaking and is without medical or scientific support. It threatens the stability of families of children with disabilities by forcing them through additional bureaucratic processes, regardless of their children’s medical prognoses.

SSA has not provided sufficient medical justification for this change, likely because none exists. To be sure, I am *[we are]* aware of no medical justification for assuming that all children reaching the age of six and again at twelve are likely to have improved. *[Please insert anything else you can add here. This specific provision is likely to be the subject of litigation, and your medical expertise will bolster an eventual lawsuit.]*

The proposed rule also assumes that children with serious behavioral health conditions like depressive disorder, bipolar disorder, generalized anxiety disorder, panic disorder, attention-deficit hyperactivity disorder, oppositional defiant disorder, or generalized anxiety disorder are likely to improve medically in two-year increments. SSA provides no rationale for this assumption, and it is unsupported by medical evidence. *[Please insert anything you can say here about the persistent nature of those conditions, based on medical studies and/or your own patient population. Also, please feel free to describe the challenges imposed by evaluating chronic behavioral conditions that can be episodic in nature at fixed points in time.]*

Finally, I am *[we are]* very concerned about SSA’s reliance in the proposed rule on a study that shows that terminating SSI benefits of children with disabilities deters other family members from applying for other Social Security benefits to which they are entitled. By explicitly citing this rationale, SSA goes against decades of Congressional intent to ensure that eligible family members with disabilities get income supports that they need. SSA suggests that this rule is motivated by deterrence rather than on any sort of program improvement. I *[we]* fail to see why denying children with disabilities of necessary income supports families is an outcome to champion.

In sum, I *[we]* strongly oppose SSA’s proposed rule to conduct CDRs more frequently, because it would be harmful to families of children with disabilities and it is unsupported by medical evidence. I *[We]* respectfully request that SSA rescind the proposed rule.

Thank you very much for your consideration of this comment.

Sincerely,