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January 31, 2020

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

Submitted via regulations.gov

Re: Notice of Proposed Rulemaking on Rules Regarding the Frequency and Notice of Continuing Disability Reviews, Docket No. SSA-2018-0026, RIN 0926-AI27

Dear Commissioner Saul:

These comments are written on behalf of First Focus on Children to show our strong opposition to the proposal to change the rules regarding the frequency and notice of Continuing Disability Reviews (CDR), published in the Federal Register on November 18th, 2019. We are particularly concerned as to how these proposed rules would disadvantage children.

First Focus on Children is a national bipartisan children's advocacy organization dedicated to making children and families a priority in federal budget and policy decisions. As an organization committed to improving the well-being of our nation's children, we are opposed to this rule because children will be unduly harmed. Thank you for reviewing our comments.

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

The families of children with disabilities face many difficulties throughout their days. Managing medical appointments, recurring illness, filling, and managing prescriptions, getting to and from work, school, and/or childcare all take on a different meaning when it involves a child with disabilities. Parents may be in constant contact with a school or child care center related to their child's condition and needed care or treatment. Access to prescribed medicine may be a struggle. Transportation to and from medical appointments, school, and/or childcare can may require much planning and asking others for help. If these families are also receiving lower wages and/or working at inflexible jobs with shifts, they have a harder time staying connected to work and thus their families are at higher risk of eviction, losing their utilities, and may become food insecure.

Families of kids with disabilities will have to schedule and attend more frequent doctor appointments in order to complete the CDR, creating a burden for them. Paying for copies of medical records is financially burdensome. Asking employers to complete comprehensive employment data in the Mailer could be an annoyance and create a rift between the employee and the employer. Some of the forms

may be too complex for some individuals with disabilities and/or their families to fill out, prompting them to miss answers or seek out help that will cost money. Families struggling to make ends meet, care for their children with disabilities and perhaps their own health needs do not have extra time to spend on arduous administrative red tape and paperwork.

In 2015 alone, 34% of initial cessations were reversed on appeal - revealing that this system does not work as it is now and should not be made more frequent. This is not the right step to improve the system.

CDRs are a burden on beneficiaries.

Everyone who receives a CDR has been found disabled by the Social Security Administration (SSA), meaning they have one or more severe and medically determinable impairment that will last at least one year or be fatal. Some of these disabilities, including intellectual disabilities and mental health disabilities, directly impact an individual's ability to respond to forms and will require additional assistance from service providers or family members to complete. In addition, disability beneficiaries are often older and have lower income, less stable housing situations, and less education than the general population, providing additional challenges when they need to fill out CDR paperwork and submit supporting documents like medical records. For children undergoing CDRs, the burden on families and service providers is substantial — adults must take time off of work and children from school for medical appointments in response to the form, as opposed to seeing doctors when it's medically necessary.

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 they take and all of the medical treatments 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. While it would be challenging and time-consuming for anyone to fill out, many of those who will need to fill it out have disabilities that will add additional complexity.

CDRs are also costly to beneficiaries, who often need to pay for medical records or appointments with their doctors and other providers to fill out forms. Although some states require medical records be provided free to Social Security disability claimants, this does not extend to beneficiaries undergoing CDRs. Beneficiaries or their parents may need to hire representatives to assist them in completing CDR paperwork or proceeding through multiple levels of appeals. This only adds costs to families who may already be struggling.

Not completing CDR paperwork or doing so incorrectly can jeopardize benefits that are a matter of life and death to people with disabilities—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. Those who are found to have medically improved, and those who were deemed noncompliant with the CDR process, have only 10 days to elect continuation of benefits while they appeal. If they don't, they can be without income or health insurance for months or years. Receiving retroactive benefits once appeals are completed does not fix the problems of people with disabilities who will go without needed medication and health care, lose their housing, go into debt, or declare bankruptcy. Paying back rent when one is homeless doesn't get the apartment back. Those who do elect continuing

benefits may be faced with overpayments withheld from future Social Security benefits, tax refunds, or other sources.

SSA should not force beneficiaries to experience the burden of a CDR more frequently or place beneficiaries more at risk of incorrectly losing their benefits without evidence that doing so will improve program integrity and outcomes for beneficiaries and conform to the Social Security Act. Unfortunately, the proposed rule offers no such evidence. Even more concerning, the proposed rule almost entirely fails to consider the impact that the NPRM would have on beneficiaries. It does not even provide an estimate for how many individuals will lose benefits, how many of those individuals are children, and how many individuals will have benefits reinstated at reconsideration or on appeal. SSA is completely ignoring a crucial impact that the rule will have on adults and children with disabilities.

The proposed rule lacks evidence to establish that the proposed change is necessary.

The NPRM proposes three buckets of changes and offers different justifications for each. Unfortunately, these justifications fail to provide sufficient data to allow us to effectively comment. Despite the substantial burden the changes place on beneficiaries by the proposed rule, SSA has failed to provide evidence that the changes are necessary or are based on evidence.

Expanding the Medical Diary Categories From Three to Four

SSA bases the change to the number of diary categories on the agency's "experience over time administrating CDRs in the existing three categories" and their own analysis of "CDR case outcomes for MIE diaries." The supplementary documentary evidence provided, entitled "Cessation Rates by Impairment" (cited at fn 36 of the NPRM) includes only the average of 3 years of data, from 2014 to 2016, and lists only 15 impairments. Since the current CDR rule has been in place since 1986, it is unclear why SSA is not providing more historical data and demonstrating trends that might show clear treatment improvement. In addition, the failure to detail how many individuals make up the percentage figures listed, render it impossible to comment on the accuracy of the data. A cessation rate of 52.3 percent might be high, but is less significant when it represents 20 people rather than thousands. We do not even know how many cessations were based on a Full Medical Review (FMR) or if the cessations all came from medical improvement versus other reasons for terminating disability benefits (like the beneficiary dying or reaching full retirement age). Without these numbers, these statistics are unhelpful.

The supplementary document entitled "Cessation Rates by Diary Category" (cited at fn 38 of the NPRM) only provides one year of data, which is now over three years old. It also fails to show the number of CDRs performed in each category, whether it includes all CDRs or just FMRs, or if the cessations all came from medical improvement versus other reasons for terminating disability benefits. It only lists 17 impairments and leaves out many impairments proposed for the MIE and MIL categories, including hearing loss treated with cochlear implantation, skeletal cancers treated with multimodal therapy, heart transplant, gastrointestinal hemorrhaging, chronic liver disease, liver transplantation, chronic kidney disease with transplant, low birth weight, pediatric genitourinary disorders, bone marrow or stem cell transplants, cancer of the testes, eating disorders, and HIV.

For every disabled worker whose disability benefits were terminated for medical improvement in Fiscal Year 2018, more than five disabled workers died and more than ten reached full retirement age. SSA has not provided data on what CDR category the relatively small number of disabled workers found to have medically improved were placed in, what their impairments were, how CDR outcomes differ for people

who receive Supplemental Security Income (SSI) instead of or concurrently with Social Security Disability Insurance (SSDI), or whether CDRs occurred as scheduled.

The New Category Allowing for Post-Health Care Assessment

The NPRM does not explain why most children should have CDRs when they turn 6 or 12 years old, or how SSA will handle situations where the disability determination occurred close to the child's 6th or 12th birthday. If an ALJ hearing occurs when a child is 11 years and 8 months old, and the fully favorable decision is sent when the child is 11 years and 10 months old, and the child first receives benefits the day before his 12th birthday, is a CDR appropriate the following day? SSA provides no evidence to demonstrate that it is, and provides no indication that it would not perform such a review. The NPRM seems to base this proposal on the idea (unsupported by evidence) that at these points in time, children are "approaching a chronological age with key developmental activities." This idea would, in fact, argue the opposite since children undergoing transitions into new settings or other major life changes would likely be at non-stable points. For instance, a child with asthma who begins school may in fact see a worsening of the condition while the new situation settles. Adding the burden of a CDR to a child and family during a key developmental period might in fact worsen the child's situation by requiring time and effort from caretakers that could otherwise be focused on the child. There appears to be no solid reasoning behind the addition of these two reviews.

The Proposed Rule Will Disproportionately Impact Children in the Child Welfare System, Compromise their Health and Well-Being, and Reduce the Capacity of the System to Adequately Serve Them.

SSI benefits are a vitally important resource for children and youth with disabilities in the child welfare system. For those who are in the system, SSI benefits can be a vital resource to help county and state child welfare agencies adequately meet their needs. These benefits can also help ensure that they remain in the least restrictive, most family like setting.

SSI receipt is important to the capacity of the child welfare system to meet the needs of children and youth in its care because a disproportionate number of children in the child welfare system struggle with physical, mental, or developmental disabilities. Up to 80% of children and adolescents enter foster care with a significant mental health need, and one third have a chronic medical condition.¹ Older youth in the child welfare system have especially high rates of mental and behavioral health needs; 25% of adolescents in foster care are diagnosed with Post Traumatic Stress Disorder (PTSD) – more than twice the rate of returning veterans and six times the rate of the general public.² While not all of these youth are eligible for or receive SSI, many are. One research study showed, for example, that nearly 15% of

¹ Szilagyi, Moira A., et al., "Health Care Issues for Children and Adolescents in Foster Care and Kinship Care," *American Academy of Pediatrics*, October 2015. <http://pediatrics.aappublications.org/content/pediatrics/136/4/e1131.full.pdf>. Accessed 31 January 2020.

² Deutsch, Stephanie A., et al., "Mental Health, Behavioral and Developmental Issues for Youth in Foster Care," *Current Problems in Pediatric and Adolescent Health Care*, Vol.45, Issue 10, pp. 292-297. October 2015. <https://www.sciencedirect.com/science/article/abs/pii/S1538544215001017>. Accessed 31 January 2020.

youth reported receiving either Supplemental Security Income or Social Security disability income during the reporting period.³

In addition to making reviews more frequent, the proposed rule impacts children by mandating automatic reviews as children reach school age (age 6) and adolescence (age 12), and it targets impairments that particularly affect children and youth in the child welfare system, including attention-deficit hyperactivity disorder, asthma, and certain serious behavioral health conditions, like major depressive disorder, and generalized anxiety disorder. These are impairments that youth in foster care experience at higher rates than their non-system peers. For example, researchers found that children who had been in foster care were twice as likely to have asthma, seven times greater risk of depression, and five times greater risk of anxiety, three times greater risk of attention deficit hyperactivity disorder, and twice as likely to have learning disabilities and developmental delays than their peers who were not in the system.⁴

By requiring more frequent SSI eligibility redeterminations, the proposed rule will create an insurmountable barrier to many eligible children and youth with disabilities in the child welfare system accessing benefits. Applying for and securing SSI benefits is an incredibly burdensome process for an already overstressed child welfare system. Staff currently struggle to submit applications and all the required documentation. Because many youth in foster care experience placement instability that can disrupt their medical care, many lack up-to-date evaluations or other medical documentation necessary to demonstrate their disability. Their foster parents and caseworkers may also struggle to get them to medical appointments due to transportation obstacles, their own employment or health, placement changes, or other life disruptions common to this vulnerable population. All of these barriers make preparing for initial eligibility determinations and the currently required redeterminations a challenge for the child welfare system and increase the likelihood that applications will be initially denied. By requiring more frequent redeterminations, the proposed rule would exacerbate these challenges and likely cause many eligible children to lose benefits, which in turn can have a devastating impact on their health and well-being.

The Proposed Rule Undermines the Ongoing Federal Efforts to Address the Special Challenges Facing Youth with Disabilities Who Age Out of the Child Welfare System in, or at Risk of Involvement in, the Child Welfare System.

By making the process to access and retain SSI benefits more onerous, the proposed rule undermines multiple ongoing federal efforts to address the special challenges older youth with disabilities in the child welfare system face as they transition to adulthood. Federal law requires that the child welfare agency work with youth to develop a transition plan that ensures that have a viable plan for thriving outside of the child welfare system. This plan must include “specific options on housing, health insurance, education, local opportunities for mentors and continuing support services, and work force supports and

³ Cheatham, Leah Powell, “Aging Out of Foster Care with Disabilities: Predictors of Educational Attainment and Employment,” *Florida State University Libraries*, 2016. <https://fsu.digital.flvc.org/islandora/object/fsu%3A366042>. Accessed 31 January 2020.

⁴ Turney, Krsitin and Wideman, Christopher, “Mental and Physical Health of Children in Foster Care,” *American Academy of Pediatrics*, 16 August 2016. <https://pediatrics.aappublications.org/content/pediatrics/138/5/e20161118.full.pdf>. Accessed 31 January 2020.

employment services, ...”⁵ Outcomes for youth who age out of foster care are poor in general, but research suggests that youth with disabilities experience even worse outcomes after leaving the system than their non-disabled peers.⁶ Accessing SSI for youth with disabilities is crucial to an effective transition plan and ensuring that the plan includes viable options related to housing, health insurance, and support services. In addition to providing cash assistance that can help pay for housing, SSI is a gateway to other resources for these youth, including Medicaid, food stamps, and many supportive housing programs.

The SSA has already recognized and responded to the administrative challenges youth in foster care experience accessing SSI benefits and the importance of SSI in the transition to adulthood. SSA policy has long recognized that youth transitioning out of foster care “need the income support and health services that result from SSI eligibility to ease the transition to independent living,” and thus allowed youth to apply for benefits before leaving care to try to ensure benefits were in place before discharge.⁷ In 2016, the SSA expanded this policy to allow youth to apply for SSI benefits up to six months before leaving care, regardless of the reason for discharge.⁸ This policy change was made in recognition that the obstacles youth in foster care encounter in receiving needed medical care and evaluations, securing and maintaining medical documentation to demonstrate their disabilities, and submitting an application for benefits can result in an extended application process and delays in eligibility determinations. This policy has been invaluable to ensuring high quality transition plans for youth. By *increasing* the administrative burden associated with maintaining SSI benefits, the proposed rule will substantially undermine the effectiveness of this policy by enhancing the burden of Continuing Disability Reviews after a youth ages out, increasing the likelihood of them losing the benefits they need to survive.

Nationwide, almost 50% of older youth exit the child welfare system without finding permanency and family. As mentioned above in section I, many of these youth have a disability. One study, for example, showed that 45% of older youth surveyed carried a disability diagnosis.⁹ This means that large numbers of young adults will not have the support of family and caring adults to navigate the redetermination process after they leave care. The barriers youth faced to accessing SSI that SSA has reduced while in the system will now occur in subsequent Continuing Disability Reviews that they face on their own. Many young adults who need this important benefit and who have a disability will lose eligibility because they do not have the experience, knowledge or assistance to navigate the redetermination process. The

⁵ 42 U.S.C.A. § 675(5)(H).

⁶ Anctil, Tina M, et al., “Predictors of Adult Quality of Life for Foster Care Alumni with Physical and/or Psychiatric Disabilities,” *Child Abuse and Neglect*, Vol. 31, Issue 10, pp. 1087-1100. October 2007.

<https://www.sciencedirect.com/science/article/abs/pii/S0145213407002414>. Accessed 31 January 2020; Schmidt, Jessica, et al., “Assessing Restrictiveness: A Closer Look at the Foster Care Placements and Perceptions of Youth with and without Disabilities Aging Out of Care,” *Journal of Public Child Welfare*, 2013. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3904544/>. Accessed 31 January 2020.

⁷ POMS SI 00601.011.

⁸ Ibid. See also Press Release, “New Social Security Policy Benefits Youth Leaving Foster Care,” *Juvenile Law Center*, 11 August 2016. <https://jlc.org/news/new-social-security-policy-benefits-youth-leaving-foster-care>. Accessed 31 January 2020.

⁹ Ibid, 3.

additional administrative burdens posed by the proposed rule will result in many of these vulnerable young people losing access to needed benefits, compromising their health and well-being and a successful transition to adulthood.

The Proposed Rule Undermines Ongoing Federal Efforts to Address the Special Challenges Facing Youth with Disabilities at Risk of Child Welfare System Involvement and the Capacity of Families and Kin to Care for Them.

The proposed rule should be withdrawn because it is at odds with existing federal law and efforts that aim to help youth and families access services, supports, and benefits in the community so they can avoid involvement in the child welfare system. The Family First Prevention Services Act (“Family First”),¹⁰ as well as the recently enacted Family First Transition Act,¹¹ are designed to expand the federal resources available to support families and kin so that families can remain together and children can avoid involvement with the costly child welfare system. This proposed rule would make it much more difficult for vulnerable youth and families to access a basic and necessary resource for children with disabilities, and in doing so will frustrate efforts to serve this vulnerable population outside the foster care system. The financial assistance and Medicaid access that come with SSI eligibility can help families struggling to meet the needs of a child with a disability, and in some circumstances can prevent system involvement altogether. It is likely that more children will enter the child welfare system if the process to redetermine eligibility becomes more burdensome and families who are working extremely hard to care for children are not able to jump the hurdles that redetermination puts in front of them. The success of Family First and its effort to build systems that are responsive to children and families in their communities depends on the collaboration of all federal systems and agencies.

Conclusion

CDRs create time and financial burden, stress, unnecessary medical appointments, and hardship for parents of children with disabilities and for children and youth in the child welfare system. Increasing the frequency of CDRs, particularly without clear data about who will be harmed, is unfair and goes against the Social Security Act and the Administrative Procedures Act by not improving outcomes for children and others with disabilities. The proposed rule should be withdrawn. Thank you for the opportunity to comment on the proposed rule.

Respectfully submitted,



Bruce Lesley
President

¹⁰ Public Law No: 115-123.

¹¹ Public Law No: 116-94.