

January 27, 2020

Office of Regulations and Reports Clearance
Social Security Administration
3100 West High Rise Building
6401 Security Boulevard
Baltimore, MD 21235-6401

Re: Notice of proposed rulemaking (NPRM): “Rules Regarding the Frequency and Notice of Continuing Disability Reviews”
DOS Docket Number: SSA-2018-0026

To Whom It May Concern:

Thank you for the opportunity to comment on the Social Security Administration’s (SSA) notice of proposed rulemaking (NPRM) on “Rules Regarding the Frequency and Notice of Continuing Disability Reviews” published on November 18, 2019. On behalf of Children’s HealthWatch, a network of pediatricians, public health researchers, and policy and child health experts, please accept these comments and our opposition in the strongest possible terms to this rule change that will threaten the health and well-being of thousands of people with disabilities, including children and families.

Children’s HealthWatch is committed to improving children’s health in America. Every day, in urban hospitals across the country, we collect data on children ages zero to four, many of whom are from families experiencing economic hardship. Over the past 20 years, we have surveyed more than 70,000 caregivers. We analyze our data and release our findings to researchers, legislators, and the public to inform public policies and practices that can give all children and their families equitable opportunities for healthy, successful lives.

Social Security disability benefits are an essential support for individuals and children with disabilities in families with low incomes.

According to the United States Department of Agriculture, it takes roughly \$240,000 to raise a child from birth to age eighteen; for a child with a disability, those expenses can quadruple as the unique medical and educational expenses add staggering amounts to the average cost of raising a child.^{1,2} These include costs of taking a child to medical and educational appointments, home modifications, and out-of-pocket medical expenses.³ Research from Children’s HealthWatch and others demonstrates that, as a result, households with children with special health care needs (SHCN), with or without disabilities, have higher rates of poverty and are more likely to experience significantly greater odds of financial and material hardship, including housing and food insecurity.^{4,5,6,7,8} Previous research shows that young children, whether with or without SHCN, whose families experience any of these hardships may suffer more negative health outcomes, including fair or poor health, increased hospitalizations, and developmental delays than children in families not experiencing these hardships.^{9,10,11,12,13,14} These hardships, however, rarely occur in isolation as families struggle to juggle competing expenses for food, rent, and utilities while also caring for children, especially those with SHCN.¹⁵

Decades of research, including our own, demonstrate that Social Security disability benefits, including Supplemental Security Income (SSI), are an effective tool for offsetting the cost of raising a child with

disabilities and in turn has been shown to reduce hardship and improve health across the lifespan. Our work at Children’s HealthWatch focuses on infants and toddlers during a critical window of brain and body development. In these early years, SSDI and in particular SSI – the only federal income support targeted to low-income families caring for children with disabilities – protects the health of young children and sets them on a course toward a healthier future by providing financial resources to cover basic needs for families that are financially hindered by a child’s disabilities. Through receipt of this support, families with children with disabilities may be able to meet their child’s health and education needs while also avoiding the health costs of material hardships – such as housing instability, food insecurity, and energy insecurity – described previously. For example, compared to children with SHCN that do not receive SSI, our research found that that children with SHCN that do receive SSI are 25% less likely to be behind on rent in the previous year and 25% less likely to report one or more adverse housing conditions. Furthermore, affirming the expressed goal and legislative intent of SSI as a program, our research found that SSI can help offset the medical expenses of a child with SHCN.¹⁶ In order to maintain this ability and program intent, changes should not be made to further restrict SSI access.

If passed, the proposed rule would exacerbate challenges of low-income families of children with disabilities to pay for healthcare and basic needs, and would push thousands of children into or deeper into poverty:

Applying for Social Security benefits is already a rigorous procedure; the proposed rule would add to this difficulty, and make the application process unattainable for those who need it most. The questionable proposal to include an additional diary category – Medical Improvement Likely (MIL) – and review period would result in an estimated 4.4 million more continuing disability reviews (CDR) over a ten year period, and an expected \$2.8 billion reduction in benefit spending when people are cut from the program. Despite the SSA’s claim that the NPRM would not change whether or not someone should keep their disability benefits, but just how soon that determination is made,¹⁷ the reality is that thousands of people living with a disability would lose benefits each year, even though they did not experience any medical improvement, as a result of inability to navigate and comply with the overly complicated and burdensome process. This premature cut-off would exacerbate challenges faced by low-income families to afford basic needs such as food, housing, and utilities by drastically changing the income available to them. This proposal would also predominantly target children, by establishing CDRs at the age of six and twelve years old, in addition to the new MIL category that would include disabled children. Without benefits, in particular SSI, thousands of children with disabilities or recovering from disabilities would be forced into poverty; SSI benefits lifts half of otherwise-poor child beneficiaries out of poverty, in addition to lifting nearly 200,000 children out of deep poverty.¹⁸

For many disabling impairments, including those identified under the proposed MIL diary category, receipt of treatment is essential for medical improvement; when people do not receive adequate treatment, however, medical improvement may not occur for MIL conditions when otherwise expected. The SSA states that “this is particularly significant in light of the data documenting the percentage of individuals with unmet healthcare needs.” In the general United States population in 2016, 43% of low income adults and 32% of all other adults reported unmet healthcare needs due to cost.¹⁹ People with disability, likely as a result of increased healthcare needs and simultaneous financial loss and hardship, report even greater rates of unmet needs.²⁰ Accessing healthcare for a disabled individual or child can be challenging due to barriers beyond cost as well, such as time burden and transportation. In 2015, 31.4% of people with two or more chronic conditions delayed or did not obtain needed medical care due to cost or other non-cost reasons, even if they had health insurance.²¹

The SSA acknowledges that scheduling a CDR under the Medical Improvement Expected (MIE) category may be premature when medical improvement does not occur as expected due to unmet healthcare needs, and suggests that the additional MIL diary category (and subsequent proposed CDR timeframe of 2 years) would allow for more accurate assessment of medical improvement after beneficiaries are able to benefit from access to healthcare. This is problematic, however, as research above demonstrates that people with disabilities, even those with health insurance, may face barriers to accessing healthcare, and therefore not obtain the medical care necessary for medical improvement. This may result in a beneficiary being placed in an inappropriate category or cut off from benefits due to expected medical improvement, when in reality the beneficiary may not be accessing medical care necessary for improvement. Furthermore, even if treatment necessary for medical improvement is obtained – through a combination of earnings, health insurance, and SSDI/SSI benefits – families that are then cut off as a result may struggle to continue to maintain medical care, as well as afford other basic needs that impact health and financial stability. In other words, their improvement may be contingent on continuing to have access to health care and support from benefits. Removing the benefits could put their health at risk again, causing children’s health to suffer. Our research has found that children in families that reported not paying for rent, utilities, transportation, food, or other basic needs in order to pay for medical care or prescriptions were more likely to be in fair or poor health, be at risk for developmental delays, be food insecure, have mothers experiencing depressive symptoms, and have parents in fair or poor health.²²

Instead of cutting off beneficiaries as a result of unjustified additions to the medical diary categories and frequencies of CDRs, the SSA should focus on expanding and improving SSDI and SSI to lift children out of poverty:

Stable housing, access to healthcare, and food and energy security are critical for optimal health in early childhood and are especially necessary for children with disabilities and/or SHCN. Raising a child with disabilities and/or SHCN, regardless of severity, brings greater costs for their families and places them at greater risk of material hardships.¹⁸ These families have greater medical and education costs and parents may have to cut work hours to care for their children, both of which can create strain on family budgets, especially for families with low incomes who struggle to make ends meet.²³ One recent study, supported by the SSA through a grant to the National Bureau of Economic Research, found that ten years after onset of chronic and severe disability, respondents had on average experienced a 79% drop in earnings, 35% drop in after tax income, and 22% drop in food consumption.²⁴ For families of children with disabilities with very low incomes, SSI is a critically important resource, as it helps buffer them from these hardships. While research supports the importance of SSI for low-income families raising children with disabilities, the bar for receiving SSI is very high, and leaves out millions of children and families that may then face a lifetime of health, financial, and material hardships.

As discussed previously, these hardships have devastating impacts on families with children and entire communities. For example, Children’s HealthWatch estimated total US health, education, and lost productivity costs of food insecurity – which, as stated previously, occurs even more frequently in low-income households with people with disabilities – across all age groups at more than \$178 billion in 2014 alone.²⁵ In a complementary study, another group of researchers, Berkowitz et al., showed that people with food insecurity have significantly greater health care expenditures - an extra \$1,863 per year - totaling to \$77.5 billion annually.²⁶ By expanding SSI and other disability supports, rather than

shrinking them, the SSA can reduce these long term costs and improve the physical and financial health of society overall.

The proposed rule would deny benefits to those that need it most, including families of disabled children, with limited evidence or data to justify such consequential changes. Furthermore, the proposed changes would unfairly target children and increase the frequency and amount of burdensome CDRs resulting in the cutoff of thousands of beneficiaries from critical supports. For this reason, it is essential that the SSA maintain and expand SSI and disability benefits for children and families at increased risk for hardships and poor health and financial outcomes.

Our future national prosperity depends on the well-being of our nation's children and their families. As those who care for the health of America's children, we strongly oppose any administrative action that would harm the health of children, particularly the youngest, and their families and urge the administration to withdraw this proposal in full immediately.

Sincerely,



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- ¹ U.S. Department of Agriculture. The Cost of Raising a Child. 2017. Available at <https://www.usda.gov/media/blog/2017/01/13/cost-raising-child>
- ² Guillot C. The Cost of Raising a Special Needs Child. MintLife. July 23, 2013. Available at <https://blog.mint.com/planning/the-cost-of-raising-a-special-needs-child-0713/>
- ³ Hogan D. Family Consequences of Children's Disabilities. A volume in the American Sociological Association's Rose Series in Sociology. Russell Sage Foundation, New York. 2012.
- ⁴ Parish S, Roderick RA, Andrews M, Grinstein-Weiss M, Richman EL, Dababnah S. Material hardships in the US families raising children with disabilities: Research summary and policy implications. University of North Carolina School of Social Work. March 2009. Available at: <http://www.realeconomicimpact.org/data/files/reports/outside%20reports/material%20hardship%20children%20with%20disabs.pdf>.
- ⁵ Rose-Jacobs R., Fiore J, Ettinger de Cuba S, Black MM, Cutts DB, Coleman SM, Heeren T, Chilton M, Casey PH, Cook JT, Frank D. Children with special health care needs, receipt of Supplemental Security Income, and food insecurity. *J Dev Behav Pediatr.* 2016;37(2):130-147.
- ⁶ Fujiura GT & Yamaki K. Trends in demography of childhood poverty and disability. *Exceptional Children.* 2015;66:187-199.
- ⁷ Ghosh S, Parish SL. Deprivation among US children with disabilities who receive supplemental security income. *Journal of Disability Policy Studies.* 2015;26(3):173-83.
- ⁸ Rose-Jacobs R, de Cuba SE, Bovell-Ammon A, Black MM, Coleman SM, Cutts D, Chilton M, Heeren T, Casey P, Ochoa E, Frank DA. Housing Instability Among Families With Young Children With Special Health Care Needs. *Pediatrics.* 2019;144(2):e20181704.
- ⁹ Rose-Jacobs R, Black MM, Casey PH, et al. (2008) Household food insecurity: Associations with at-risk infant and toddler development. *Pediatrics.* 121(1):65-72.
- ¹⁰ Cutts DB, Meyers AF, Black MM, Casey PH, Chilton M, Cook JT, et al. (2011) US Housing insecurity and the health of very young children. *Am J of Public Health* 101(8): 1508-1514
- ¹¹ Cook JT, Frank DA, Casey PH, Rose-Jacobs R, Black MM, Chilton M, et al. (2008) A brief indicator of household energy security: Associations with food security, child health, and child development in US infants and toddlers. *Pediatrics.* 122:e-867-e875.
- ¹² March E, Ettinger de Cuba S, Cook JT, Bailey K, Cutts DB, Meyers AF, et al. (2011) Behind Closed Doors: The hidden health impact of being behind on rent. *Children's HealthWatch.* Retrieved from: http://www.childrenshealthwatch.org/wp-content/uploads/behindcloseddoors_report_jan11-.pdf.
- ¹³ Jeng K, Ettinger de Cuba S, March EL, Meyers AF, Cook JT, and Coleman S. (2009) Affordable Health Care Keeps Children and Families Healthy. *Children's HealthWatch.* Retrieved from: http://www.childrenshealthwatch.org/wp-content/uploads/AffordableHealthCare_brief_July2009.pdf
- ¹⁴ Cook, JT and Frank, DA. (2008) Food security, poverty, and human development in the United States. *Annals of the New York Academy of Sciences.* 1136:193-209
- ¹⁵ Frank, DA, Casey PH, Black MM, Rose-Jacobs R, Chilton M, Cutts DB, et al. (2010) Cumulative hardship and wellness of low-income, young children: Multisite surveillance study. *Pediatrics,* 125(5):1115-1123.
- ¹⁶ Children's HealthWatch. Children with Special Health Care Needs and Disabilities: Solutions for Stable Homes. Policy Action Brief. April 2018. Available at <https://childrenshealthwatch.org/wp-content/uploads/CSHCN-and-Housing.pdf>
- ¹⁷ Social Security Agency. Notice of Proposed Rulemaking, Rules Regarding the Frequency and Notice of Continuing Disability Reviews: Overview. Supporting document contained in SSA-2018-0026. Available at <https://www.regulations.gov/document?D=SSA-2018-0026-0856>
- ¹⁸ Romig K. SSI: A Lifeline for Children with Disabilities. Center for Budget and Policy Priorities. May 2017. Available at <https://www.cbpp.org/research/social-security/ssi-a-lifeline-for-children-with-disabilities>
- ¹⁹ Commonwealth Fund. 2016 Commonwealth Fund International Policy Survey of Adults. November 16, 2016.
- ²⁰ World Health Organization. Disability and health. January 2018. Available at <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>
- ²¹ National Center for Health Statistics. Barriers to Health Care for Adults with Multiple Chronic Conditions: United States, 2012-2015. NCHS Data Brief No. 275. March 2017.
- ²² Children's HealthWatch. Affordable Health Care Keeps Children and Families Healthy. Policy Action Brief. June 2018. Available at <https://childrenshealthwatch.org/wp-content/uploads/CHW-Affordable-Care-Brief.pdf>

²³ Center for Budget and Policy Proposals. Chart Book: Social Security Disability Insurance. September 6, 2019. Available at <https://www.cbpp.org/research/social-security/chart-book-social-security-disability-insurance>

²⁴ Meyer BD, Mok WK. Disability, earnings, income and consumption. *Journal of Public Economics*. 2019;171:51-69.

²⁵ Cook JT, Poblacion A. Estimating the Health-Related Costs of Food Insecurity and Hunger. In Bread for the World 2016 Hunger Report. Available at www.hungerreport.org

²⁶ Berkowitz SA, Basu S, Meigs JB, Seligman HK. Food insecurity and health care expenditures in the United States, 2011–2013. *Health services research*. 2018;53(3):1600.