January 31, 2020

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

RE: Rules Regarding the Frequency and Notice of Continuing Disability Reviews

The Fenway Institute at Fenway Health submits the following comment regarding the Social Security Administration's (SSA) "Rules Regarding the Frequency and Notice of Continuing Disability Reviews." The Fenway Institute is the research, education, training, and policy arm of Fenway Health, a federally qualified health center and Ryan White Part C HIV clinic in Boston. We provide care to 32,000 patients annually, including about 2,200 people living with HIV. Half of our patients identify as lesbian, gay, bisexual and transgender (LGBT). We urge the SSA to reconsider this proposed rule, which could subject beneficiaries to more frequent and burdensome Continuing Disability Reviews (CDRs) leading to loss of life-saving benefits.

The Social Security Disability Insurance (SSDI) program and the Supplemental Security Income (SSI) program provide benefits to millions of Americans with disabilities. In 2016, SSDI provided benefits to more than 10 million Americans. In 2018, SSI provided benefits to more than 8 million Americans. These programs provide life-saving financial support for beneficiaries who may not otherwise be able to work due to disability. This is especially important to us because of the high prevalence of disability in the LGBT community. Analysis of the Washington State Behavioral Risk Factor Surveillance System found that 36% of lesbian women and 36% of bisexual women reported being disabled, compared to 25% of heterosexual women.[1] Similarly, 26% of gay men and 40% of bisexual men reported being disabled, compared to 22% of heterosexual men.[2] These differences in disability prevalence remained statistically significant after controlling for age and other covariates of disability.[3]

The 2015 U.S. Transgender Survey found that 39% of respondents reported having one or more disabilities as defined by the American Community Survey, compared to 15% of the general population.[4] This survey also found that 9% of respondents relied on Social Security income, including SSDI and SSI, as their only source of income.[5] SSI and SSDI also provide important sources of income for people living with HIV who are also diagnosed with other diseases, have functional limitations due to HIV, or experience frequent HIV complications resulting in hospitalization. Transgender Medicare beneficiaries experience multiple chronic conditions at

[1] Fredriksen-Goldsen K, Kim H, Barkan S. (2012 January). Disability Among Lesbian, Gay and Bisexual Adults: Disparities in Prevalence and Risk. *American Journal of Public Health*. 102(1): e16-e21.
[2] *Ibid.*
[3] *Ibid*.
[4] James SE, Herman JL, Rankin S, Keisling M, Mottet L, Anafi M. (2016). *The Report of the 2015 U.S. Transgender Survey*. Washington, DC: National Center for Transgender Equality.
[5] *Ibid*.

higher rates than cisgender Medicare beneficiaries. They are much more likely to qualify based on disability than cisgender Medicare beneficiaries (71% vs. 17%).[6]

Nearly half of people living with HIV in the U.S. (46%) receive federal disability benefits, according to an analysis of data from the Medical Monitoring Project and the National Health Interview Survey. Seventy-nine percent of these have had an AIDS diagnosis. Many people living with HIV, especially those who are older and those who are long-term survivors, experience comorbid conditions such as cognitive impairment, cardiovascular disease, metabolic syndrome, depression, and substance use. As people grow older with HIV, thanks to the availability of antiretroviral medications, they are more likely to experience comorbidities that can impede their ability to work, causing many to go on disability. Sixty-nine percent of those living with HIV who received federal disability benefits in 2009 were age 45 or older. [7]

Currently, people who apply for benefits are sorted into one of three categories: medical improvement expected (MIE), medical improvement possible (MIP), or medical improvement not expected (MINE). These categories determine how often beneficiaries will be subjected to Continuing Disability Reviews (CDRs). For those in MIE, a CDR is conducted once every 6-18 months, in MIP once every 3 years, and in MINE once every 5-7 years. A CDR involves time consuming and burdensome paperwork in order to determine if a beneficiary is still eligible based on disability. Failure to complete a CDR can result in termination of benefits.

This rule proposes the creation of a new fourth category, medical improvement likely (MIL), with a CDR required once every 2 years. If this proposed rule is finalized, beneficiaries who are reclassified from MIP or MINE to MIL would be subjected to much more frequent CDRs. While a requirement to complete paperwork and submit documentation at the risk of losing monetary benefits and health care would be challenging for anyone, it is likely more difficult, stressful, and time consuming for disability beneficiaries, who as a group are older,[8] poorer,[9] and sicker than the general population. Furthermore, beneficiaries often experience other extenuating circumstances, such as unstable housing, limited education, inability to leave their homes, and other barriers to completing and mailing increasingly frequent CDR paperwork. But if beneficiaries do not complete the required CDRs, they will become part of an increasing number

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[6] Dragon CN, Guerino P, Ewqald E, Laffan AM (2017). Transgender Medicare Beneficiaries and Chronic Conditions: Exploring Fee-for –Service Claims Data. *LGBT Health*. 4(6); 404-411.

[7] Huang YA, Frazier EL, Sansom SL, et al. (2015, October). Nearly half of US adults living with HIV received federal disability benefits in 2009. *Health Affairs*. 34(10); 1657-1665. https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2015.0249

[8] More than 75% of SSDI beneficiaries are age 50 or older, over 35% are age 60 or older, and nearly 6% are age 65. https://www.ssa.gov/OACT/ProgData/benefits/da_age201612.html

[9] 71% of Title II disability beneficiaries have household income below 300% of the poverty level; 20% were in poverty. Among SSI recipients, the poverty rate was 34% for children and 43% for adults aged 18-64. https://www.ssa.gov/policy/docs/rsnotes/rsn2015-02.html

and percentage of CDR recipients[10] whose disability benefits are terminated for "failure to cooperate" with the CDR process.

The proposed rule estimates that it will take beneficiaries 60 minutes to complete the full medical CDR form (SSA-454-BK), but it is likely to take some beneficiaries much longer and many are unable to complete the form without significant assistance. The form is 15 pages long, and it requires short essays about the beneficiary's use of assistive devices, daily activities, and hobbies or interests. It also requires a list of all medical providers with their contact information, the dates of the first and most recent appointments, and any treatments provided. All medications and tests, education, and vocational rehabilitation must be listed as well. It is often costly to effectively document all of this information to the degree required for benefits to continue.

The SSA should not be forcing any beneficiaries to experience these burdens more frequently, especially without providing evidence that doing so will improve program integrity and outcomes for beneficiaries. The proposed rule fails to include any criteria or scientific evidence the agency used to identify the impairments that would be classified under the newly created MIL category. The proposed rule mentions that disabled children and step 5 beneficiaries—a category of beneficiaries with a combination of disabilities who are typically older, in poor health, and lacking the education or job skills necessary for the current job market—would likely end up in the new MIL category. However, it does not share the data, evidence, or studies that were used to make this determination. The proposed rule also fails to state the CDR categories that would be used for many of the most common impairments, making it impossible to determine what changes would occur, what the rationale is for them, and what the effect would be on disability beneficiaries and others.

It would be dangerous to finalize a rule that could result in loss of benefits for many beneficiaries without data to support the proposed changes or evidence that it will improve outcomes for beneficiaries. We strongly urge the SSA to reconsider this proposed rule.

Sincerely,

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[10] According to SSA's annual CDR reports to Congress, in 2013 there were 2,256 failure to cooperate (FTC) terminations, reflecting less than 2% of all terminations after CDRs. By 2016, these had increased to 9,956 FTC terminations, 5.1% of all CDR terminations.

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