



January 31, 2020

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

Submitted via www.regulations.gov

Re: Notice of Proposed Rulemaking on Rules Regarding the Frequency and Notice of Continuing Disability Reviews, Docket No. SSA-2018-0026, RIN 0960-AI27

Dear Commission Saul:

Thank you for the opportunity to comment on the proposed rule revisions.

The Wisconsin Board for People with Developmental Disabilities (BPDD) is concerned that the proposed changes will disproportionately and negatively impact people with intellectual and development disabilities (I/DD) and their families.

Intellectual and developmental disabilities are permanent conditions. The underlying diagnosis is not subject to change. More frequent re-evaluation will not result in a different diagnosis. More frequent review for this population only increases administrative burden, confusion for the person and/or families navigating often multiple complex systems, creates more challenges (transportation, health care access) to overcome in order to meet new requirements, and puts this population at risk of losing eligibility for critical health care and other public supports.

Many people with I/DD rely on Medicaid for health care they can't get at all or in the amount they need on the private insurance market. Medicaid is also the only place people with I/DD can access long term care services that keep them in their homes and out of costly Medicaid-funded nursing homes or other institutions. Eligibility for Medicaid waiver programs is often dependent on disability determination..

Losing access to these supports can spin individuals and families into a crisis. It is inevitable that administrative mistakes and/or misinterpretation of requirements will result in people with I/DD being disenrolled and losing access to benefits. Rectifying these mistakes will be time consuming, stressful-inducing, and may result in loss of housing, income, or medical care for the person. Many will have difficulty or find it impossible to navigate how to re-enroll.

Many people with I/DD may not be able to read or understand what information is needed to complete complicated forms or complete multi-step processes. Particularly concerning is that both forms—full medical review and mailer form—require detailed information that may rely on multiple parties (employer, health care staff) providing data.

The full medical review form requires interaction with health care professionals in order to complete paperwork. We are concerned that burdening health care facilities with appointments unrelated to medical care will make it difficult for people to obtain required paperwork. Medical professionals are not paid for time spent on completing these sorts of forms which compounds the problem. BPDD has consistently objected to changes that require a doctor's signatures or exam solely for the reason of fulfilling an administrative process; in our experience this invariably results in people being unable to complete requirements and lose benefits.

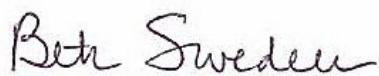
Many people with I/DD face challenges—lack of transportation, literacy, computer skills, lack of people/family members who can support them as they fill out paperwork--that become logistical barriers to completing required paperwork.

Many people with I/DD are participating in the workforce—Medicaid and Vocational Rehabilitation often fund supports to help people work—we are concerned that the mailer form will confuse people and send a signal that any work is a threat to continued benefits. The Social Security Administration has been working to change that perception. Wisconsin is one of six states that received a federal PROMISE grant specifically targeting youth with disabilities on SSI and finding strategies that help people learn they can work without losing benefits. This rule undermines these efforts and reinforces the fears families have that any work will equate with benefit loss.

We encourage the Department to not require increased or more frequent reviews of people with I/DD.

BPDD is charged under the federal Developmental Disabilities Assistance and Bill of Rights Act with advocacy, capacity building, and systems change to improve self-determination, independence, productivity, and integration and inclusion in all facets of community life for people with developmental disabilities.

Sincerely,

A handwritten signature in dark ink that reads "Beth Swedeen". The signature is written in a cursive, flowing style.

Beth Swedeen, Executive Director, Wisconsin Board for People with Developmental Disabilities