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March 24, 2023

Dr. Kilolo Kijakazi
Acting Commissioner
Office of Regulations and Reports Clearance
Social Security Administration
6401 Security Boulevard, 3rd Floor (East) Altmeyer Building
Baltimore, Maryland 21235-6401

Re: Docket No. SSA-2021-0014

Dear Acting Commissioner Kijakazi,

The National Down Syndrome Congress (NDSC) respectfully submits these comments to the Social Security Administration (SSA) in support of the proposed changes to remove food from the calculation of In-Kind Support and Maintenance (ISM). NDSC is the country's oldest national organization for people with Down syndrome, their families, and the professionals who work with them. We provide information, advocacy, and support concerning all aspects of life for individuals with Down syndrome, and work to create a national climate in which all people will recognize and embrace the value and dignity of people with Down syndrome.

We thank the SSA for promulgating regulations to update the definition of income, excluding food from the ISM calculation, and simplifying and shortening the processing requirements for applicants. Our comments are focused primarily on applicants and recipients with Down syndrome.

We strongly support updating § 416.1130 to exclude food from the calculation of ISM. Many individuals with Down syndrome rely heavily on Supplemental Security Income (SSI) benefits, and it is most often their only source of income. Due to costs, SSI recipients are often challenged when purchasing food. Parents and other family members may want to help but because of the ISM rule which counts food as income, they are discouraged. If they choose to help them, then the beneficiary is faced with a reduction in their SSI benefit. The proposal to remove food from ISM calculations would help eliminate the benefit reduction that is currently applied.

We also support the proposed changes to § 416.1131 which clarifies the Value of the One-Third Reduction (VTR). In addition, we support the proposed change to § 416.1102 and the clarification to include "constructive" income. The change would benefit the Down syndrome community by simplifying rules that place a burden on people with intellectual and developmental disabilities (IDD). The changes would reduce the number of program rules individuals with Down syndrome need to comprehend and lessen the amount of information they need to report during the application and post-award reporting processes. In turn, this would shorten processing time, and result in fewer benefit recalculations.

While this rule change is greatly welcomed and needed, ultimately, it would greatly benefit the Down syndrome community if Congress eliminated ISM rules and the marriage penalty altogether in addition to increasing asset limits. As we at NDSC work towards our goal of improving the lives of individuals with Down syndrome, we look forward with hope to these legislative changes.

NDSC appreciates the opportunity to provide this input. We urge SSA to move quickly to make the proposed changes. SSI is a lifesaving benefit, but its rules are outdated. We support efforts to make SSI's financial rules work better for people with Down syndrome, people with disabilities, and older adults. Please contact Chapman Bryant, NDSC Policy & Advocacy Associate, with any questions at chapman@ndscenter.org.

Sincerely,

A handwritten signature in blue ink, appearing to read "Jordan Kough".

Jordan Kough
NDSC Executive Director