



July 13, 2026

The Honorable Russell Vought
Director
Office of Management and Budget
725 17th St NW
Washington, DC 20503

Re: Regulation for Federal Financial Assistance Proposed Rule (Docket No. OMB-2026-0034)

Dear Director Vought:

The National Down Syndrome Society (NDSS) works to create a world where individuals with Down syndrome thrive. On behalf of the Down syndrome community, we appreciate the opportunity to comment on the recent proposed rulemaking that would revise several parts of the OMB Guidance for Federal Financial Assistance located in title 2 of the Code of Federal Regulations (CFR).

Research has dramatically improved the health, longevity, and quality of life of individuals with Down syndrome. Continued progress depends on a strong and stable research environment that encourages scientific collaboration and supports long-term investment. We are concerned that several provisions in the proposed rule would create new barriers that could slow or discourage this important research. We respectfully urge OMB to withdraw the proposed rulemaking. Please see specific concerns outlined below:

[200.205]

Federal Agency Review of Proposals

OMB proposes to revise requirements around agency merit review and establish a new pre-issuance review process. Senior political appointees would conduct these reviews and would consider factors such as whether discretionary awards advance the President's policy priorities. The revisions also state that peer review recommendations will "remain advisory" and are not to be "routinely deferred to" by senior appointees.



NDSS is concerned that making political review a formal and mandatory component of the award process complicates the issuance of awards and could halt or slow critical research, including research into Down syndrome or associated medical conditions such as Alzheimer's disease. In addition, these revisions insert a worrying unpredictability into the award process while diminishing the importance of scientific peer review, which has long served as the foundation for identifying and supporting the most promising research.

[200.205]

Indirect Cost Rates

While OMB is not proposing changes to indirect cost rates, the proposed changes do establish a preference for grantee institutions with lower indirect cost rates. Indirect costs cover expenses related to conducting research. Indirect costs cover essential infrastructure required to conduct research and vary considerably based on geography, research areas, and facility types. This change would put certain institutions conducting high-quality research into Down syndrome, including major medical centers and leading research institutions with higher fixed costs, at a competitive disadvantage. The Down syndrome community depends on these institutions to advance our understanding of the medical conditions associated with Down syndrome and to develop new approaches to care and treatment.

[200.218] [200.300(b)]

Restrictions on Disparities Research

OMB proposes a new § 200.218 that would establish a government-wide policy prohibiting federal awards related to “disparate-impact liability.” In addition, OMB proposes changes to § 200.300 to restrict federal awards related to “diversity, equity, and inclusion” (DEI) or “diversity, equity, inclusion, and accessibility” (DEIA).

We are concerned that these changes create significant uncertainty about allowable research activities for researchers and institutions. This would have a significant chilling effect on research into disparities faced by particular populations, including individuals with Down syndrome. Individuals with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer’s disease, childhood leukemia, and thyroid conditions. Research into disparities related to education, employment, and community participation also expands understanding of the Down syndrome community and informs evidence-based solutions that promote health, well-being, independence, and inclusion.



[200.220]

International Collaborations

OMB proposes to establish a government-wide prohibition on the use of federal funds to support bilateral or multilateral collaborations, agreements, programs, or activities with “covered foreign countries” or “covered foreign entities” unless expressly authorized by federal statute or approved by the federal agency. NDSS recognizes the importance of safeguarding U.S. national security interests. At the same time, these broad restrictions could undermine international collaborations that are vital to advancing research in many areas, including Down syndrome.

Multi-national studies are especially important for Down syndrome research, allowing for larger sample sizes, more robust data, and more insight into how environment, quality of care, and demographic differences are influenced by or influence study outcomes. These collaborations have played an important role in advancing scientific knowledge and improving care for individuals with Down syndrome.

[200.340]

Expanded Termination Authority

OMB proposes revisions that would expand the authority of a federal agency to terminate a federal award, including in cases where it determines that the award “does not effectuate program goals, Federal agency priorities, or the national interest as they exist at the time of the termination.”

These changes would create substantial uncertainty for grantees. Researchers and institutions may be especially unwilling to take on the significant financial and legal risks associated with multi-year research initiatives that could have funding terminated based on fluctuating administration priorities or interpretations of the “national interest.” This uncertainty could discourage research associated with smaller patient populations. This is of particular concern when considering the need for robust clinical trials and longitudinal studies that are needed to increase our understanding of Down syndrome and accelerate the development of treatments for associated conditions such as Alzheimer's disease.

[200.421] [200.432] [200.461]

Scientific Communication

Grantees are obligated to provide public access to the results of publicly funded research. OMB proposes to revise requirements related to advertising and public relations, conference attendance, and publication and printing costs. The new rules create hurdles to the dissemination of scientific knowledge, prevents collaborations that improve the quality of research through data-sharing and operational efficiency, and would hamper the ability to



translate research results into evidence-based solutions and improved outcomes for individuals with Down syndrome.

Individuals with Down syndrome, their families, clinicians, and educators rely on the timely sharing of scientific information in order to make informed decisions and follow practices that promote better health outcomes.

Thank you for the opportunity to provide feedback on these proposed changes. Individuals with Down syndrome have benefited tremendously from decades of federally supported research. Continued progress depends on a stable, collaborative, and scientifically driven research environment. NDSS is concerned that the proposed rulemaking would create significant uncertainty and impede this essential research. We respectfully urge OMB to withdraw the rule and to preserve policies that support continued scientific progress for the Down syndrome community.

Sincerely,

A handwritten signature in black ink that reads "Kandi Pickard". The signature is fluid and cursive, with a large, looping "O" at the end.

Kandi Pickard
CEO
National Down Syndrome Society