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Interagency Autism Coordinating Committee

Dear Members of the Committee,

Congratulations on your appointments and thank you for your willingness to serve in this important role. I appreciate the opportunity to provide public comment and write as cofounder and president of the Profound Autism Alliance, a nonprofit organization focused on improving the health and connection of people with profound autism and intellectual disability through inclusive research and focused advocacy.

People with profound autism typically require continuous supervision and lifelong support. Federal autism research addresses many important issues across the spectrum, yet people with profound autism remain underrepresented in research and federal priorities.

This gap has consequences. When people with profound autism are not included in research, the field lacks evidence needed to advance medical understanding, services, and real supports for a substantial portion of the autism community.

The use of the term “profound autism” is about clarity, not competition. Greater clarity helps researchers, policymakers, and service systems better understand support needs and develop appropriate responses. Recognizing the needs of people with profound autism does not diminish the importance of any other part of the spectrum. Every part of the spectrum matters.

Research indicates that approximately **1 in 4 people with autism meet criteria for profound autism** (Hughes MM, Shaw KA, DiRienzo M, et al., 2023, *Public Health Reports*), yet **only about 6 percent of clinical autism research includes people from this population** (Stedman A., Taylor B., Erard M., Peura C., & Siegel M., 2019, *Journal of Autism and Developmental Disorders*). As a result, many people and families are not represented in the research that informs policy and services.

The disparity also appears in federal reporting. In the **2019–2023 IACC Autism Spectrum Disorder Research Portfolio Analysis Report**, employment was referenced **141 times**, while **profound autism was mentioned only four times**.

Congress has recognized the importance of addressing this issue. Fiscal year 2026 appropriations language tied to the **Autism CARES Act of 2024** directs NIH autism research to reflect the **entire autism population, including people with profound autism**.

To support implementation of this directive, we respectfully encourage the IACC and federal agencies to:

- Provide **clear NIH reporting on how federally funded autism research includes people with profound autism**, including representation in study design, enrollment, and analysis.
- Align research portfolios with the **full range of autism**, including people who require continuous supervision and lifelong support.
- Continue use of the term “**profound autism**” in federal research, strategic planning, and reporting so that this population remains visible in policy discussions and research priorities.
- Encourage ongoing **CDC autism surveillance and reporting that clearly tracks the prevalence and characteristics of people with profound autism**, helping policymakers and service systems better understand population needs.

As the Committee begins its new term, there is an opportunity to translate congressional direction into research priorities, reporting practices, and accountability.

People with profound autism and their families depend on the federal research enterprise to advance understanding of co-occurring medical conditions, challenging behaviors, and long-term support needs. Greater representation in research design, funding priorities, and federal reporting will strengthen the evidence base and help federal autism research serve the entire community.

Thank you for your consideration and for your continued work to improve outcomes for all people on the autism spectrum.

Sincerely,



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