



# ENSURING INCLUSION OF PEOPLE WITH PROFOUND AUTISM

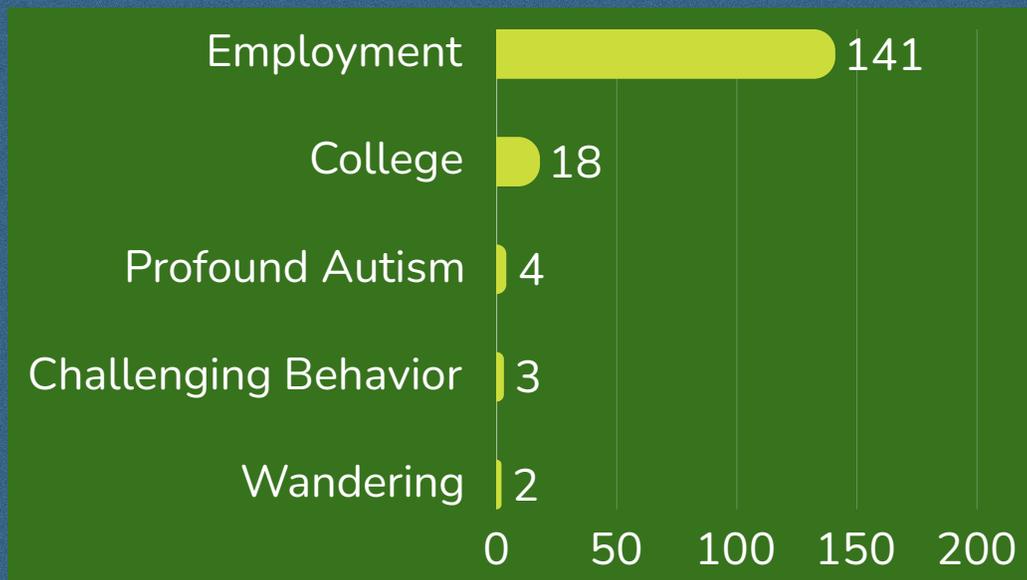
Over time, federally funded autism research and services have become increasingly diluted, with minimal focus on autistic people who require lifetime, 24/7 care.



## Interagency Autism Coordinating Committee's Report to Congress (FY 2019–FY 2023)

### \$198 Million in Autism Funding

*Number of Times Area of Focus Mentioned in Report*



Profound Autism and related issues barely appear

**In FY2026,  
Congress directed  
NIH autism  
research to reflect  
the entire autism  
population,  
including people  
with profound  
autism.**

“  
The Committee urges the Director to ensure that fiscal year 2026 NIH spending on research on Autism Spectrum Disorders [ASDs] meets the authorized funding level set by the Autism CARES Act of 2024, and ensure such research addresses the underlying biology, including genetics, environmental factors and their interaction, co-occurring medical conditions, and treatment and services needs, and includes the entire population of individuals with ASD, **including those with profound autism.**”

## **WHAT WE ARE ASKING FOR - FY26 OVERSIGHT**

- Clear reporting from NIH on how funded research includes people with profound autism
- Meaningful representation of this population in study design, enrollment, and analysis
- Continued use of the term “profound autism” in research and strategic planning

## **LOOKING AHEAD TO FY27**

- Reinforcing NIH reporting expectations in FY27 appropriations language
- Encouraging CDC to ensure autism surveillance and reporting clearly reflect individuals with profound autism

Your leadership is essential to ensuring that people with profound autism remain visible in federal research, policy, and data systems.