



ENSURING INCLUSION OF PEOPLE WITH PROFOUND AUTISM

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



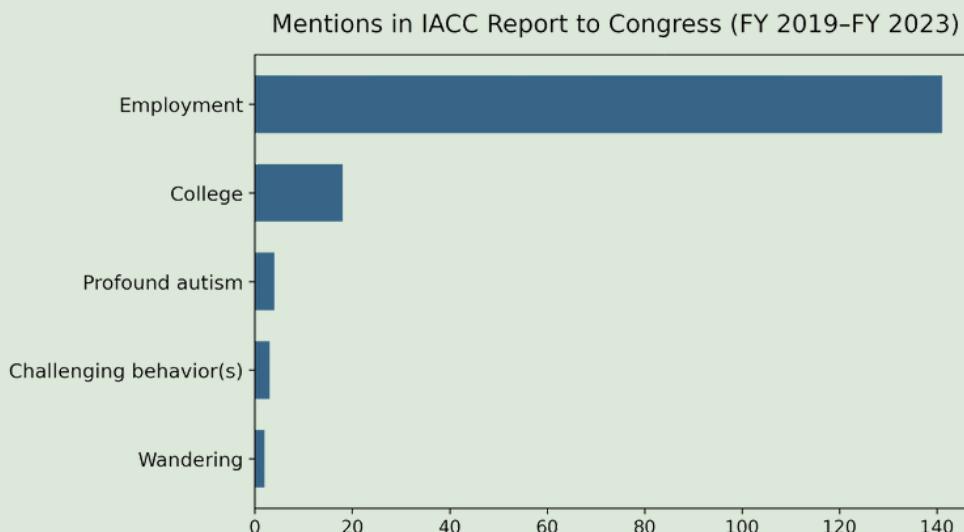
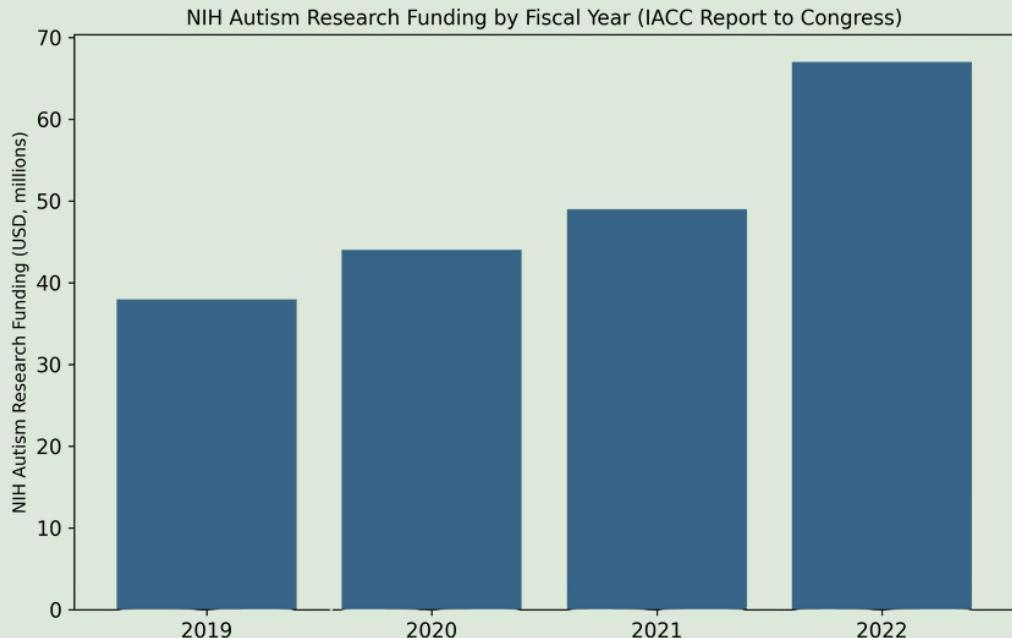
We are grateful that the 2024 version of Autism CARES included language to remedy this:

“ inclusion of the entire spectrum in research, specifically stating: reflects the entire population of individuals with autism spectrum disorder, including those individuals with co-occurring conditions and the full range of needs for supports and services, including such supports and services to ensure the safety, and promote the well-being, of such individuals.”

Our work is just beginning. Now that Autism CARES is signed into law, we need to ensure that its intent is appropriately implemented through:

- Appropriate representation in funded research.
- This leads to fiscally appropriate allocation of resources.
- Clarity in reporting, continued representation, and participation in strategic planning at the NIH.

Interagency Autism Coordinating Committee Report to Congress Covering Fiscal Years 2019 through 2023



Your leadership is needed to ensure the ongoing inclusion of our population and the term that describes them - profound autism.