

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.

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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.
- Meaningful funding related to communication needs.
- Clarity in reporting, continued representation, and participation in strategic planning at the NIH.