

ADDRESSING THE CRITICAL HOUSING NEEDS OF ADULTS WITH SEVERE/PROFOUND AUTISM

SUMMARY

National Council on Severe Autism (NCSA) urges Congress to initiate a Government Accountability Office (GAO) investigation to evaluate housing options for adults with severe/profound autism, identify regulatory barriers, and propose actionable solutions. This investigation will optimize existing resources, improve outcomes, and ensure fiscal responsibility.

THE CHALLENGE

One in 36 children have autism spectrum disorder (Maenner et al., 2023), with 26.7% classified as having profound autism (Hughes et al., 2023). As these children become adults, our nation faces an unprecedented housing crisis. Despite the surging demand for specialized housing solutions, current options remain severely limited, leaving families without viable alternatives for long-term care.

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BACKGROUND

Adults with severe/profound autism require specialized housing and support that existing models fail to provide. The problem is compounded by conflicting federal regulations:

- The HUD Section 811 Supportive Housing program, while well-intentioned, creates unintended barriers. Its extremely low-income requirements (30% of Area Median Income) and restrictions on specialized group living arrangements often exclude individuals with severe autism who require 24/7 support (HUD, 2025)
- The CMS Home and Community-Based Services (HCBS) Settings Rule, while aiming to promote integration, has created significant limitations for adults with severe autism. According to research published in the *Journal of Intellectual and Developmental Disabilities*, the rule's implementation has created barriers to specialized residential settings that many individuals require for their health and safety (Friedman, 2020)
- These regulatory conflicts between HUD and CMS policies create a fragmented system that restricts innovation in housing development
- Families bear unsustainable caregiving burdens due to the lack of appropriate housing options

“Despite physically relocating *into* the community, many people with intellectual and developmental disabilities (IDD) fail to be meaningfully included *in* the community.”
(Carli Friedman)

WHY CONGRESSIONAL ACTION IS NEEDED

Current federal regulations, while intended to protect vulnerable populations, have created unintended barriers to effective housing solutions. Without congressional intervention, we face:

- Increased reliance on costly hospital care and emergency services
- Growing strain on family caregivers
- Inefficient use of existing federal resources
- Limited development of innovative housing models

A Government Accountability Office (GAO) investigation would provide the data-driven insights needed to improve and optimize these systems.

CALL TO ACTION

We urge Congress to take immediate action to address the critical housing needs of adults with severe/profound autism by initiating a Government Accountability Office (GAO) investigation. This investigation will provide essential insights to identify and resolve the systemic barriers that limit housing options for this vulnerable population. Specifically, we request the following:

1. **Initiate a GAO Investigation**
Direct GAO to evaluate current housing options, identify regulatory barriers, and propose optimized housing solutions for adults with severe/profound autism.
2. **Update Regulatory Framework**
Use GAO findings to:
 - Align HUD and CMS policies to eliminate conflicts
 - Modernize Section 811 requirements to better serve individuals with severe autism
 - Enhance HCBS Settings Rule to ensure it accommodates necessary specialized residential settings
3. **Enable Innovation**
Support public-private partnerships and community-based initiatives that maximize existing resources while meeting specialized care requirements.

EXPECTED OUTCOMES

- Improved quality of life for individuals with severe/profound autism
- Reduced burden on emergency services and hospitals
- Enhanced workforce participation among family caregivers
- Broader economic growth and social stability for families
- More efficient use of existing federal resources
- Development of sustainable, scalable housing solutions

The National Council on Severe Autism (NCSA) stands ready to provide additional information and expertise to advance this critical initiative. Your leadership will help ensure that individuals with severe/profound autism have access to appropriate housing and care, creating lasting positive change for one of our most vulnerable populations.

SOURCES

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