

## The Crisis of “Empty Waivers” for the Profoundly Autistic

National Council on Severe Autism (NCSA) advocates on behalf of individuals affected by severe and profound forms of autism and related disorders. This population includes those who require continuous or near-continuous, lifelong services, supports, and supervision. Many are nonverbal or have limited use of language, have intellectual impairments, and, in a significant subset, exhibit challenging behaviors that interfere with safety and well-being.

On a daily basis parents and guardians are spending hours weaving together the medically necessary services to support these individuals with complex care needs. Often two key tasks consume the day:

- **Finding care workers** – a never-ending task given the workforce shortage and low pay
- **Managing fragmented and overwhelmed systems** to arrange for programs, therapy, medical care, respite and insurance coverage.

This is in addition to the basic care duties required of the parents and guardians. While Congress and the Centers for Medicare and Medicaid (CMS) have worked to expand care via a variety of waivers and regulations, the reality is **many are unable to find providers and programs** that accept these clients.

Individuals with severe/profound autism typically require vastly different personnel support and clinical care than others in the autism and disability community. For example, staff must often be able to safely address aggression and self-injurious behaviors and be on constant alert for elopement or ingestion of inedible objects. Therapy programs must be specifically designed and staffed to allow for these individuals to successfully participate and benefit.

So, it is frustrating to the point of exasperation when the common response from therapeutic programs, schools and agencies is: **“We do not accept clients with severe autism or challenging behaviors.”**

Qualifying for an HCBS Medicaid waiver by virtue of having extremely disabling disorder often **does not lead to services actually occurring**. These waivers are often “empty” due to **systemic failure of service development in this area**. It means parents locked in a persistent struggle for care while the children go without necessary supports.

Medicaid is a complex federal-state relationship, but **Medicaid’s failure to require states to equitably serve its most severely disabled children and adults has resulted in vast disparities**. Congress must work to strengthen the requirements and expectations of those providing care via Medicaid — via waivers and otherwise.

Care needed, care promised, is not care delivered.

NCSA looks forward to working with you to enact federal laws that compel states and Medicaid providers to ensure our loved ones are not ignored and receive all the necessary services and staffing. *Cherry picking healthcare recipients has never been accepted, and Congress should not allow it to continue.*

When you have a moment, please contact our policy director Jackie Kancir at [policy@ncsautism.org](mailto:policy@ncsautism.org) to arrange a time to meet and further discuss next steps. Thank you.