

Autism: The Direct Care Workforce Crisis

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.

More often than not, our families must rely upon a direct care workforce, also known as Direct Support Professionals (DSPs) to assist with the daunting care-giving needs of both our minor and adult children. However, with the complex systems of Medicaid and Medicare often providing care “on paper” and not in reality, guardians struggle to find reliable access to trained caregivers.

By not addressing this workforce shortage, the government is leaving families in crisis mode and forcing parents out of the workforce to become the sole caregiver for their child. This is not acceptable. It is not sustainable.

Based on CDC data, over the past 20 years, autism rates in children have risen from .67% to nearly 3% — with no sign of a plateau. These alarming numbers include those with severe/profound autism and require near constant care and supervision. CDC data also concludes that roughly one-third of those with autism also have at least one additional intellectual disability — further complicating their medical needs.

Workforce shortages in other sectors can cause delays and hardship. But delays in care for this community are of another magnitude, they can lead directly to emergency room visits, crisis intervention, and escalation of dangerous behaviors including self-injury, aggression and elopement, to state just a few examples.

There is legislation before Congress that begins to bend the curve, [S. 1298](#) — Supporting Our Direct Care Workforce and Family Caregivers Act would improve the federal government’s ability to support training and education for DSPs and improve the grant process further expand federal awards benefiting the DSP workforce and those in their care. [H.R. 2941](#) & [S. 1332](#) — Recognizing the Role of Direct Support Service Professionals — would establish a specific occupational category to allow for better data collection and streamline processes to improve federal support for DSPs, ideally leading to higher wages.

To be clear, the data shows that with the increasing numbers of individuals with severe/profound autism, ignoring the DSP workforce shortage will betray their very fundamental needs, and reduce the quality of life and services available to this community.

NCSA urges you to actively work to pass these bills as incremental steps in ensuring individuals with severe and profound autism receive the quality care they require and deserve. Parents and family members cannot and should not be providing professional care — around the clock — for their loved ones who require services from those with medical or behavioral training. Emergency rooms should not be filled with these individuals because care was lacking, or non-existent.

Please reach out to our policy director, Jackie Kancir, at policy@ncsautism.org with any questions you may have regarding the legislation above or to further discuss the impact the workforce shortage is having on our community.