

POLICY FORUM: INVITED COMMENTARIES & SIDEBARS

Developmental Disability Long-Term Supports & Services Face Unprecedented Threats in North Carolina

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North Carolina's developmental disability community faces significant cuts to Medicaid-funded long-term support services. This worsens a system already experiencing two long-standing challenges: a long waiting list for services and a paid caregiver workforce shortage. Despite the challenges, there are some reasons to hope the challenges can be overcome.

Recently, 37-year-old Jon D'Angelo was the lead speaker at three notable events, including one at the Governor's Mansion, a legislative event, and a separate gathering of state leaders where he introduced his Congresswoman.¹ Despite having so many connections, Jon is more concerned than ever that he may have to go into a nursing home or leave the state when his aging parents are no longer able to physically care for him. This is because of short-term and long-term threats to Medicaid Long-Term Supports and Services ("LTSS").

Jon has spinal muscular atrophy type 2, which causes him to have little movement below the neck. He needs a paid caregiver or family member to support him with all activities of daily living, including getting out of bed, using the restroom, eating, and working.

North Carolina's LTSS system for people with developmental disabilities (DD) already faced two major challenges going into 2025. Now, these challenges are much more severe due to short-term and long-term funding shortfalls for Medicaid. In North Carolina, there is a critical shortage of paid caregivers, which are called Direct Support Professionals (DSPs), and a massive waiting list of people with DD who need LTSS through the Innovations Medicaid Waiver. In June 2025, the waiting list for the Innovations Waiver was 19,789 people long.² The waiting list itself has "racial, gender, geographic, and age inequities" according to a 2022 study.³

DD advocates have been working since the COVID-19 years to raise the alarm about the growing shortage of DSPs and LTSS challenges. Hundreds of North Carolinians have traveled to the General Assembly at annual listening sessions with the DD Legislative Caucus. They have also shared their stories at meetings with state leaders and through the media.

Going into 2025, North Carolina had made progress on the workforce shortage and waiting list. Legislators and Governor Roy Cooper increased DSP rates for DD Medicaid services in 2023 by appropriating \$176 million in state and federal recurring funds for these rates, which raised rates from approximately \$11.50 an hour pre-COVID-19 on average to approximately \$15.00 an hour on average.⁴⁻⁶ This still did not reduce the workforce shortage as much as needed, but it showed a bipartisan willingness to address the issue. Also, around that time, North Carolina began a new service called 1915(i) Medicaid, which provides limited LTSS, respite, and supported employment for people with intellectual and developmental disabilities (I/DD), as well as other disabilities.⁷ This new service does not have a waiting list but is more limited than the Innovations Waiver. Services through 1915(i) are particularly helpful to individuals with disabilities who have support from family members or at school. As of October 2025, 12,636 individuals with disabilities were receiving services through 1915(i).⁸

The North Carolina Department of Health and Human Services (NCDHHS) also renewed its commitment to increase the quantity and quality of DSPs. NCDHHS and partners issued a critical report on long-term strategies to build a robust long-term workforce.⁹ The recommendations included: higher pay; developing a career path with opportunities for increased responsibilities; better training; and increased recruitment. NCDHHS began to operationalize these DSP recommendations with a new community college training program and with grants to increase recruitment and retention.^{10,11}

The twin challenges of the workforce and waiting list worsened at both the federal and state level in 2025. These new challenges are so severe they could break the systems that the I/DD community relies on. The 119th Congress' House Resolution 1 (HR1), also known as "The Big Beautiful Bill Act," was signed into law on July 4, 2025.¹² The law will have a profound and lasting impact on NC Medicaid, including LTSS. According to the North Carolina Department of Health and Human Services, NC Medicaid is expected to lose about \$49.9 billion over the next 10 years as a result of HR1.¹³

At the state level, North Carolina cut payment rates for Medicaid on October 1, 2025. This was not related to HR1. Instead, the Medicaid cuts occurred because the state underfunded the Medicaid rebase. The Medicaid rebase is the annual amount of funds the state must increase its funding to in order to meet Medicaid expenses. NCDHHS estimated that the funding shortfall was \$319 million for Fiscal Year (FY) 2025.¹⁴

For individuals with developmental disabilities, the Medicaid cuts included a 3% cut to Innovations Waiver services; an 8% cut to personal support services provided through the Community Alternatives Program for Disabled Adults (CAP-DA) and Community Alternatives Program for Children (CAP-C)

programs (LTSS for individuals with primarily physical disabilities); an 8% cut to intermediate care facilities (group homes for individuals with I/DD); and a 10% cut to applied behavior analysis (ABA) therapy (autism behavior therapy) and other research-based behavioral health therapies (RBBHT).¹⁵ Other cuts impacted health providers and other therapies, such as physical therapy and occupational therapy.

The North Carolina Council on Developmental Disabilities (NCCDD) sent out surveys to individuals with I/DD, family members, DSPs, and providers to better understand the impact of the Medicaid cuts. It received over 450 responses. Here is a sampling of some of the survey responses:

- “My main caregiver received a \$3 per hour pay cut. Another backup caregiver quit due to the effects on her reduced hours...If she leaves, I would have to quit my full-time job.”
- “Because of the rate cuts, there are almost no CNAs (Certified Nursing Assistants) in our area...This means that I have to be the sole caregiver, 24/7.”
- “My son’s care team...had their pay cut by \$1.74 an hour! This is roughly an 8% payout for his team.”
- “We have had our funding cut by 3% effective Nov. 1st but recouping back to October 1st...We will not be able to make our budget this year.”
- “Without a reinstatement of Medicaid funds, we may have to cut services for some members, as we will not have the staffing available to support them. I will have to look into taking out a line-of-credit to ensure payroll comes through on time.”
- “These cuts are nothing short of catastrophic for an industry that was already years behind the competitive market.”

While there is a small hope that the current Medicaid cuts may be reversed due to increased funding, litigation, or other actions, the cuts show the fragility of I/DD LTSS Medicaid services. State and federal leaders will have to change course to ensure that people with I/DD do not get hurt.

Although time is of the essence, the I/DD community can still convince state and federal leaders to do what is necessary so LTSS people with I/DD and others have what they need. Here are some small reasons for optimism in this bleak time.

First, all of us have a reason to want to make sure we have a strong LTSS system. This is true whether or not we are connected to the I/DD community. In North Carolina, the number of people over age 85 is expected

to grow by about 114% in the next 2 decades, going from 198,000 in 2021 to 423,000 in 2041.^{16,17} According to the North Carolina Department of Commerce Labor & Economic Analysis Division, of those who are over the age of 65 in North Carolina, 20% have ambulatory difficulty and 12% have difficulty living independently.¹⁸ This compares to 5% of those between the ages of 18 and 65 having ambulatory difficulty and 4% having difficulty living independently. Each of us is aging, as are our parents and loved ones. Thus, we all have a reason to want a strong LTSS system.

As just one example, President George H.W. Bush was motivated in part to sign into law the Americans with Disabilities Act in 1990 because he had an uncle with Polio. Later, though, he benefited from the curb cuts and other accommodations required by the law when he became disabled late in his life.^{19,20} Just like President Bush, all of us may need accommodations and LTSS at some time in our life.

Second, there is reason for limited optimism because the I/DD community has worked hard to develop relationships on both sides of the political aisle in the General Assembly. North Carolina is one of the only states with a bipartisan DD Legislative Caucus.²¹ Many of these legislators have family members with I/DD. The Caucus is co-chaired by Senator Michael Lee (R), Senator Sydney Batch (D), Rep. Mitch Setzer (R), and Rep. Zack Hawkins (D).

Third, LTSS is required by law. The United States Supreme Court's decision in *Olmstead v. L.C.* is often called the *Brown v. Board of Education* decision for people with disabilities.²² This is because it requires every state that provides Medicaid services in institutions and nursing homes to provide equivalent services in the community. The Supreme Court found that forcing people to only receive services in institutions unnecessarily segregates them in settings where everyone else has a disability and cuts them off from many of the benefits of living in the community.

In North Carolina, there is currently a temporary settlement (consent order) in an *Olmstead* case called *Samantha R.*²³ In that case, North Carolina committed to increasing access to direct support professionals (DSPs), the Innovations Waiver, and 1915(i) Medicaid. There is no question that Medicaid cutting rates will diminish that access. Also, Medicaid law requires states to provide adequate and sufficient services. The state cannot provide adequate and sufficient services when it cuts rates so that there are not enough providers for services.²⁴

Finally, there is reason for limited optimism because the disability community has repeatedly overcome the odds to make political progress. This is shown by the successful efforts over the decades to pass the ADA, to later amend the

ADA to strengthen it after courts narrowed its impact, to pass the Individuals with Disabilities Education Act, and to pass Section 504 of the Rehabilitation Act. In North Carolina, the state passed its own version of the ADA.

Conclusion

This is a time of unprecedented threats for individuals with disabilities and their families who rely on long-term services and supports. We have hope, though, because we live in a state that cares about its citizens. Now, it is time to show that we care with action.

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The author's wife leads HOPE NC, a statewide non-profit focused on increased housing for people with developmental disabilities.

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