Impact of Cuts to Medicaid in North Carolina

A Summary of Community Voices

345 Survey Responses 10/1/25 -10/18/25

Survey and Report provided by the North Carolina Council on Developmental Disabilities

*All images were submitted by survey responders of people impacted by the Medicaid cuts.



I. Executive Summary

This report summarizes the experiences of hundreds of North Carolina residents—individuals with disabilities, family caregivers, Direct Support Professionals (DSPs), and service providers—regarding the recent Cuts to Medicaid. The responses reveal a system under strain, with families fearing the loss of essential services, DSPs facing wage reductions, and providers struggling to maintain operations. While some respondents have not yet experienced direct impacts, the overwhelming majority express anxiety, frustration, and a sense of abandonment. The Report used Microsoft Co-Pilot AI to summarize the information provided in the 345 survey responses between October 1st and 18th.

II. Current Situations: Who Responded

Respondents fall into several categories:

- **Family caregivers**
- **Individuals with disabilities**
- **Direct Support Professionals (DSPs)**
- **Provider agency staff and administrators**
- **Concerned community members**



Types of Disabilities

Respondents reported a wide spectrum of disabilities, including but not limited to:

- **Autism Spectrum Disorder (ASD)** – including Level 3 autism, nonverbal autism, and co-occurring conditions like OCD, anxiety, and eating disorders.
- **Intellectual and Developmental Disabilities (IDD)** – ranging from mild to profound, often with additional diagnoses.
- **Cerebral Palsy (CP)** – including spastic quadriplegia, requiring full-time care and mobility support.
- **Genetic and Rare Disorders** – such as Rett Syndrome, Down Syndrome, Prader-Willi Syndrome, Fragile X, Cornelia de Lange Syndrome (CdLS), Turner Syndrome, and Creatine Transporter Deficiency.

- **Neurological Conditions** – including epilepsy, traumatic brain injury (TBI), hydrocephalus, and anoxic brain injury.
- **Medically Complex Conditions** – such as tracheostomy and g-tube dependence, chronic lung disease, and metabolic disorders.
- **Mental Health Disorders** – including schizophrenia, PTSD, bipolar disorder, and depression.
- **Sensory Disabilities** – including blindness, deafness, and sensory processing disorders.

Many individuals have **multiple co-occurring disabilities**, making their care needs especially complex and intensive.

Services

Many families rely on Medicaid-funded services such as:

- Innovations Waiver
- 1915(i) services
- Community Alternative Program Children/Disabled Adult (CAP-C and CAP-DA)
- Intermediate Care Facilities (ICFs)
- Private Duty Nursing (PDN)
- ABA therapy
- Occupational, Physical, and Speech Therapy
- Respite and Community Living Supports (CLS)

III. Key Themes and Findings

1. Immediate Financial Impact on Families and DSPs

- **Wage cuts of 3–10%** are already in effect for many DSPs and Medicaid services.
- Some caregivers are **leaving the field**, unable to survive on reduced wages.

"My pay has been cut by 8%. I work 36–40 hours a week caring for a medically fragile child. I can't afford to get a second job, and I don't want to leave this family."
— Paid caregiver

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2. Medicaid as a Lifeline

- Nearly every respondent emphasized that **Medicaid is essential to their survival and quality of life**. Without it, many would be unable to afford the care, therapies, and equipment their loved ones need. Several families noted that Medicaid services have allowed their children or adult dependents to thrive, gain independence, and participate in their communities.
- Medicaid services **enable individuals with disabilities to live in the community, attend school, work, volunteer, and build social connections**. These supports foster independence, self-esteem, and a sense of belonging. Without them, many would face isolation, regression, or institutionalization.



"Without Medicaid, my daughter would be institutionalized. She requires 24/7 care, and I am her only caregiver."

"We waited 11 years for the Innovations Waiver. It changed our lives. My son now has friends, goes out in the community, and is learning life skills."

"I'm a DSP. I love my job, but I can't afford to keep doing it if the pay is cut again. Families will be left without help."

"My son has severe autism and epilepsy. Medicaid pays for his therapies, medications, and equipment. We couldn't do this without it."

3. Disruption of Services and Supports

- Families report **loss of therapies**, **reduced support hours**, and **discontinued medications**. While respondents reported various issues, only coverage for GLP-1 medications used specifically for weight loss has been discontinued due to cuts to Medicaid. NCDHHS has emphasized that other medications should not be affected and encourages individuals to escalate any issues with medication access. Some children and adults with disabilities are **missing critical appointments** due to provider shortages or unaffordable out-of-pocket costs.
- **Community-based programs** like day supports and vocational services are being scaled back or closed.

"My daughter's therapy clinic had its reimbursement rate cut by 3%. It's one of only two clinics in our area that can treat her."
— Parent

"We're looking at selling our thrift store to keep day services running."
— Provider



4. Workforce Crisis and Provider Instability

- Providers are **losing staff** and **struggling to recruit** due to uncompetitive wages.
- Many agencies report **financial instability**, with some considering **layoffs, property sales, or closure**.
- The **Direct Support Professional (DSP) crisis** is worsening, with turnover disrupting care continuity.
- A recurring concern is the **shortage of Direct Support Professionals (DSPs)** and the low wages they receive. Families and providers alike worry that further Cuts to Medicaid will worsen this crisis, making it even harder to find and retain qualified caregivers.
- Several responses came from professionals—DSPs, therapists, agency directors—who serve individuals with disabilities. They described the challenges of operating under tight budgets, delayed reimbursements, and increasing demands. **Many fear that continued cuts will force them to reduce services or close entirely.**

"We can't compete with Sam's Club. A DSP candidate turned us down because she makes $23/hour there."
— Provider in Asheville

"We've had to cut activities and community outings. Our clients are isolated."
— DSP in Mitchell County

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5. Emotional and Mental Health Toll

- Families express **fear, anxiety, and exhaustion**.
- Many caregivers feel **abandoned by the system** and **worried about institutionalization** for their loved ones.
- The **uncertainty** around future cuts is causing widespread distress.

"We are elderly parents and fear for our 50-year-old son. Will he be forced into a nursing home?"
— Parent

"This is devastating. We're being punished for having medically complex children."
— Parent of child with spina bifida



IV. What People Want Decision-Makers to Know

Respondents shared heartfelt pleas and recommendations:

- **Protect community-based services** to avoid institutionalization.
- **Restore and increase DSP wages** to stabilize the workforce.
- **Ensure continuity of care** for medically fragile individuals.
- **Communicate clearly and honestly** with families and providers.
- **Recognize the human cost** behind budget decisions.

"Behind every service hour lost is a person—a son, daughter, neighbor, or friend."
— DSP, Mitchell County

"These cuts are not just numbers. They are lost opportunities, diminished independence, and increased isolation."
— Parent

V. Conclusion

The Cuts to Medicaid in North Carolina are already having a profound impact on individuals with disabilities, their families, and the professionals who support them. While some respondents have not yet experienced direct effects, the overwhelming majority report reduced wages, disrupted services, and emotional distress. The system is at a tipping point.

This summary is a call to action: to listen, to lead with compassion, and to protect our North Carolina children and adults with disabilities.

