

The Families Together 2025 Policy Agenda is created by families and young people with social, emotional, behavioral and cross-systems challenges.

Thank you, Chairs and Members of the Senate and Assembly, for the opportunity to provide testimony today. My name is Paige Pierce. I am the mother of four children and have personal experience navigating multiple systems to meet their needs. I am submitting testimony on behalf of Families Together in New York State (FTNYS), a statewide network of families and young people with lived experience navigating systems such as mental health, addiction, child welfare, juvenile justice, developmental disability, education, and social services.

We also serve as the organizational home of the Family and Youth Peer Support Movement in New York State. Our network includes Family Peer Advocates (FPAs) and Youth Peer Advocates (YPAs) who leverage their own hard-earned lived expertise to support our peers currently navigating the system. Through this lens, we understand intimately what families and young people are going through- many of us continue to navigate systems even as we work to help others find their voice in their service journeys.

We are here today to draw your attention to two concurrent crises: increasing need for youth behavioral health services and a severe lack of access due to workforce shortages and unsustainable funding. While we must acknowledge promising proposals in this year's executive budget such as four Safe Spaces for Youth sites and Teen Mental Health First Aid, we feel they are too limited to address the breadth of our current crisis.

Families and youth across New York State are not just waiting—they are struggling—for resources, treatment, and support. The FTNYS 2025 Policy Agenda, created by families and young people who have firsthand experience with these challenges, outlines the urgent investments necessary to address this crisis. We urge you to prioritize these proposals in the FY 2026 enacted budget.

Proposals for Investment and Action

The following investments are critical to addressing these challenges and ensuring access to behavioral health services:

- 1. Increase Flexible State Aid to Localities for Family and Youth Peer Support Services**
Add an additional \$5.5 million in flexible State Aid to Localities funds under program code 1650 to provide unrestricted support for families and young people, regardless of their insurance status.
- 2. Raise Reimbursement Rates for Peer Support Services**
Align peer support reimbursement rates across all settings, including Child and Family

Treatment and Support Services (CFTSS), with the 150% rate increase provided to clinical settings under the Mental Health Outpatient Treatment and Rehabilitative Services (MHOTRS) Program.

3. Expand Coverage to Families with Commercial Insurance

Require commercial insurers to make the same broad range of services currently available to children, youth, and families with Medicaid insurance accessible to New Yorkers with commercial coverage. This includes CFTSS and Home and Community-Based Services (HCBS).

4. Expand Access to Youth Mental Health Services under Medicaid and Child Health Plus (CHP)

Add \$195 million to rates for outpatient clinics, CFTSS, and HCBS youth mental health services to serve 26,000 additional children, youth, and families.

5. Increase Rates and Contracts for Mental Health and Substance Use Disorder Programs

Add a 7.8% increase to rates and contracts for mental health and substance use disorder programs, reflecting a 2.9% CPI increase (effective July 2024) and the difference between human services COLAs of the past three years (12.2%) and the CPI increases (17.1%) over the same period.

6. Carve Behavioral Health Services Out of Medicaid Managed Care

Carve behavioral health (mental health and substance use disorder) services out of the state's Medicaid managed care program and reinvest the resulting savings to restore the availability of essential services to New York's most vulnerable residents.

This is a Youth Behavioral Health Crisis: Families Need a Workforce, Not Waitlists

We are not exaggerating when we say that families are languishing on waitlists for outpatient and community-based services. Before young people experience crisis, emergency room visits, hospitalization, residential programs or police interactions, they very often experience insufficient access to upstream and preventative services within their home and community. After these crisis and residential experiences, the same difficulty accessing services remains as they transition back home. Increasingly, the New York State mental health system is focusing on reacting to mental health crises rather than proactively building up our community-based array that can serve us before a crisis.

The results are devastating for families. We are forced to wait months or years for mental health and substance use disorder services we desperately need today. As a result, parents are leaving their jobs so they can navigate the mental health system for their children; children are cycling in and out of ERs and hospitals; and young peoples' needs are becoming more acute, complex, and difficult to address as they grow into adults.

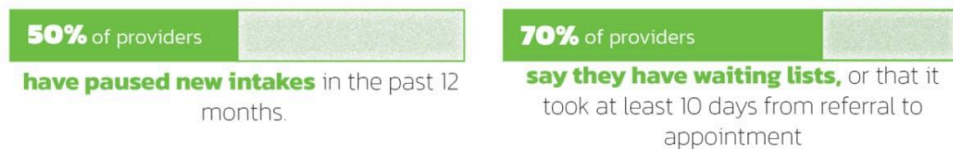
To help policymakers and the public better understand the depth of the waitlist crisis, FTNYS collaborated with the Campaign for Healthy Minds Healthy Kids and provider associations to gather perspectives from families, youth and agencies about their experiences around youth mental health access to better understand the depth of the waitlist crisis. Simultaneously, the campaign commissioned an in-depth needs assessment for the population of children on Medicaid and Child Health Plus.

Provider perspective: We conducted a survey of outpatient and community-based providers across the state. We received a total of 43 responses representing Long Island, New York City, Mid-Hudson, Capital District, Mohawk Valley, Southern Tier, Western New York, Finger Lakes, Central New York, and the North Country (Empire State Development Regions).

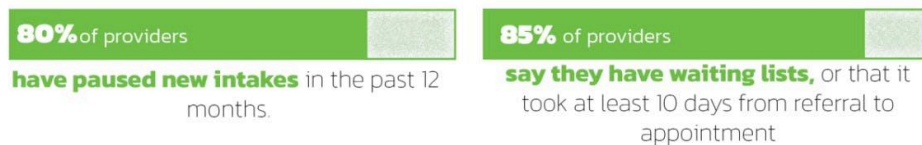
Provider types included the following children’s outpatient services:

- Article 31 Outpatient Clinics
- Children and Family Treatment and Support Services (CFTSS) Therapeutic Services:
 - Psychosocial Rehabilitation Services (PSR), Other Licensed Professional (OLP), and Community Psychiatric Supports and Treatment (CPST)
- CFTSS Peer Services: Family Peer Support Services (FPSS) and Youth Peer Support (YPS)

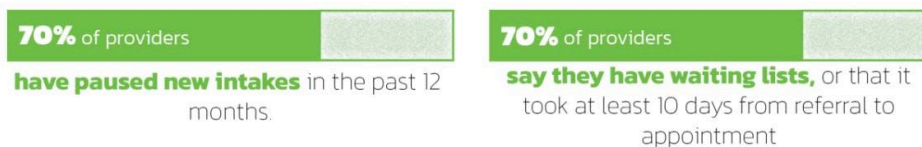
A majority of Article 31 Outpatient Mental Health Clinics report children and families waiting for services:



A majority of Children and Family Treatment and Support (CFTSS) therapeutic service providers report children and families waiting for services:



A majority of Children and Family Treatment and Support (CFTSS) Family and Youth Peer Services providers report children and families waiting for services:



Across all surveyed program types, key barriers to mental health service access are as follows:

- **Staffing Issues:** High turnover and vacancies remain the most significant challenges, with 100% of CFTSS therapeutic and peer services providers reporting these as major concerns.

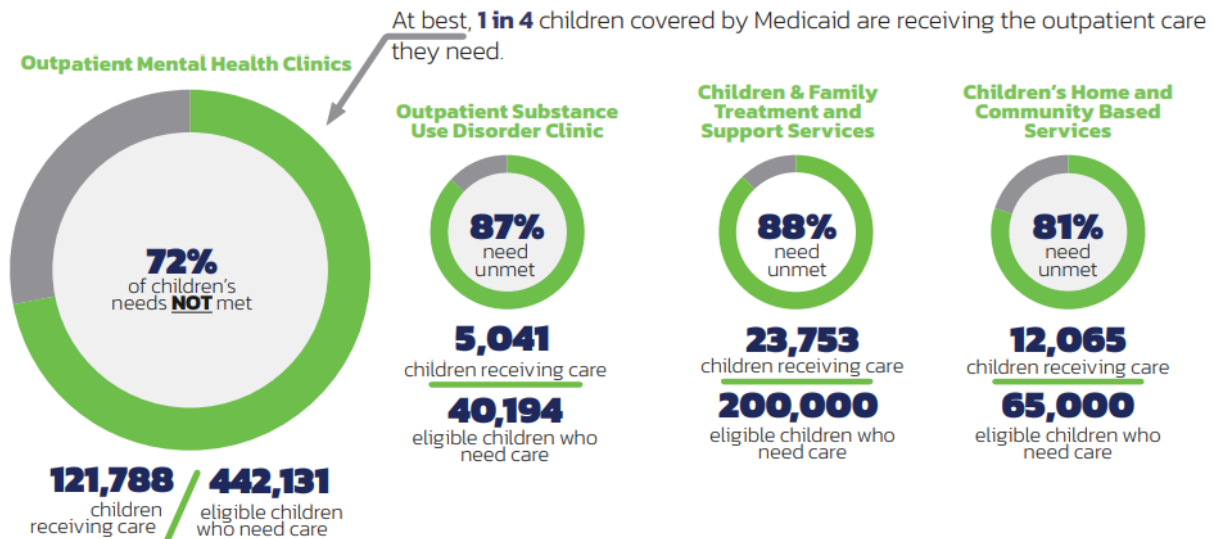
- **Inadequate Reimbursement:** Both Medicaid and commercial rates are widely viewed as insufficient, impeding the ability to provide timely and effective services.
- **Resource Limitations:** A significant portion of providers (50%-60%) in all categories report that they do not have the resources to provide the full range of services necessary for clients.
- **Delayed Service Delivery:** Waitlists and delays are widespread, with many clients waiting 50 days or more for the initial intake, exacerbating the strain on services.

For CFTSS providers, other barriers include:

- Travel Time Compensation: 94.74% of providers rated travel time compensation as inadequate.
- Care coordination activities inadequately compensated: 66.67%.
- Documentation and administrative tasks inadequately compensated: 66.67%.

During this same period, a separate but complementary needs assessment conducted by Health Management Associates (HMA) focused on the population of children on Medicaid and Child Health Plus. Their analysis indicates that, at most, 1 in 4 New York children covered by Medicaid are accessing the outpatient behavioral health (mental health and/or substance use disorder) services they need.

The charts below illustrate the percent of children in New York State who need outpatient services but are not receiving them.



Family and Youth Perspectives: As parents and youth, we recognize our own stories in the data and findings from the provider survey and needs assessments. To make these findings real, we worked with providers, advocates and a group of parent and youth advisors to conduct a children's behavioral health waitlist story collection survey and interview effort.

Through this project, families and young people across New York shared deeply personal stories of waiting for services, sometimes for over a year, and traveling long distances to access care. These stories revealed the critical barriers families face and the devastating

consequences of systemic failures. Below are some snapshots and themes from their responses:

Barriers to Accessing Mental Health Services: Families face extensive delays, unclear communication, and logistical challenges in accessing essential mental health care, often leading to exacerbated crises.

- “The need is there, but the services aren’t. The pay won’t get good people in the door and that is the major issue.” (Western Region)
- “We were on a waitlist, only to be told they didn’t have what we needed to help with the mental health concerns.” (Western Region)
- “From referral to waitlist to actual services it was well over a year, closer to two years. In that time frame, she continued to struggle and it resulted in multiple school displacements; from suspension to home instruction, to being moved from school to school many times.” (Western Region)
- “My son has been on a waitlist for services for years. He has had several inpatient hospitalizations as a result and multiple suicide attempts.” (Western Region)

Inadequate Crisis Support: Immediate crises often result in temporary solutions that fail to address the root causes, leaving families and individuals in distress.

- “Every moment counts when it comes to mental health crises, and the need for immediate assistance is crucial.” (Hudson River Region)
- “Mobile crisis won’t come out to the house until 24 to 48 hours later, which doesn’t help in an emergency situation.” (Long Island Region)
- “Without timely access to care, there is a risk of exacerbating existing mental health conditions.” (Hudson River Region)

Geographical and Systemic Inequities: Families often face significant disparities in access due to geographic location, insurance limitations, or a lack of local resources.

- “We had to travel approximately one hour to a different county to ensure that my child could see a therapist.” (Hudson River Region)
- “The services we desperately needed were unavailable in our county.” (Hudson River Region)
- “The longest we’ve had to travel is 50 minutes for mental health services.” (Western Region)

Long-Term Impact on Children: Delays in care have profound consequences for children, affecting their mental health, education, and overall development.

- “She lost two years of education and opportunities to build and maintain friendships... That cannot ever be replaced.” (Southern Tier Region)
- “My son has been hospitalized multiple times due to delays in care, but he still hasn’t received the services he needs.” (Western Region)
- “My daughter has suffered because of this... a domino effect because her being deregulated causes her to be ineffective in managing her own life.” (Long Island Region)
- “Reflecting on my personal experience, I can relate to the frustration and helplessness that come with being put on a never-ending waitlist after my child’s mental health crisis. Following my child’s attempt, we were thrust into a system where we had to wait for nearly a year to receive the mental health assistance required. This agonizing wait was only exacerbated when we discovered that the services we desperately needed were unavailable in our county.” (Western Region)

Emotional and Physical Toll on Families: Caregivers experience exhaustion, frustration, and financial strain while advocating for their loved ones.

- “I was about to lose my job due to the interruptions and constant phone calls.” (Western Region)
- “By day, I try to do my full-time job and provide for my kids. I drift off to sleep occasionally with exhaustion, from the situation and the system.” (Southern Tier Region)
- “It’s so frustrating. Mobile crisis is supposed to help, but they spend more time asking questions than providing solutions.” (Long Island Region)
- “Yes it takes a village but it shouldn’t be this damn hard!” (Western Region)

Systemic Failures and Misunderstandings: Families often feel unsupported or judged by schools, healthcare providers, and social services, deepening their challenges.

- “Teachers don’t believe me because they don’t see it.” (Southern Tier Region)
- “Mobile crisis workers told me they’re not meant as a crisis hotline, which makes no sense.” (Long Island Region)
- “We have had CPS called 6 times, all unfounded.” (Central Region)

Parent Advocacy as a Lifeline: Families frequently serve as the sole advocates for their children, often at great personal and emotional cost.

- “Mama Bear” has struck again and we might be getting someone for my daughter as of the last email I just received and the copious phone calls and some assistance from my parent support group and some Family Peer Advocates.” (Western Region)
- “I am a seasoned social worker and a solo parent who continues to fiercely advocate for not only my son, but other families that are experiencing something similar.” (Western, NY)
- “By eliminating barriers to seeking help... we can create a society where mental health is prioritized.” (Hudson River Region)
- “Now that our daughter has secured support, we are working to rebuild her self-esteem, self-confidence, social skills, and education.” (Southern Tier)
- “We’ve called mobile crisis countless times, but they’re such a disappointment. I’m done with them.” (Western Region)

One Family's Story

This is a harrowing story that demonstrates the urgent need to require commercial coverage of services currently offered under Medicaid and CHP.

Last year, an upstate parent told us about her struggle accessing ANY mental health services through her private insurance for her teenage son who was struggling with suicidality and several ER visits. While appropriate services exist in her community, HCBS and CFTSS services are only covered for families on Medicaid or CHP, not private insurance. After months of navigating a burdensome application process, a local CFTSS/HCBS provider successfully helped her enroll in those services through a pathway called C-YES.

For a time, her son's condition improved as they accessed peer support and skill builders previously unavailable to them. For the first time in years, they felt hope. Unfortunately, this story does not have a happy ending. You see, enrollment in HCBS for non-Medicaid families is only temporary. After a year of benefitting from those services, his enrollment was discontinued and he could no longer access those supports. Not longer after, she said he lost all hope and he completed suicide. While she says she couldn't possibly know if he'd still be here today if he had

continued access to those services, we know it is injustice enough that she has to wonder. It is an injustice that any families on private insurance like hers can't seamlessly access this service array despite paying both taxes to the government AND premiums to for-profit insurance companies. Situations like hers should never happen again. **With your help, we could change that by introducing language on the one-house budget that requires commercial insurers to cover any behavioral health services currently offered through Medicaid.**

Families and Youth Need Urgent Action

The Families Together network represents those who have lived through the systemic challenges of behavioral health. These proposals are not abstract; they represent the real, urgent needs of New York families. We implore you to fund these priorities by any means necessary, including new tax revenue, reinvestment strategies, or funds recovered from managed care organizations.

Investing in youth mental health now will not only save lives but also reduce long-term costs for the state by preventing more severe crises and enabling young people to reach their full potential.

On behalf of the families and youth we represent, we thank you for your attention to this urgent matter and urge you to act decisively to ensure these priorities are reflected in the upcoming budget.

Sincerely,

Paige Pierce, CEO
Families Together in New York State