Families 109 2024 Joint Mental Hygiene Hearing Families and Youth Are Waiting. For resources. For treatment. For support.

Families Together in New York State (FTNYS) is a statewide network that represents, supports and advocates for youth and family voice in policy and systems change to ensure an equitable and inclusive journey that fosters belonging, wellness, and empowerment for all.

For over 25 years, Families Together has served as the organizational home to a network of families and youth peers with lived experience navigating systems like mental health, addiction, developmental disabilities, child welfare, juvenile justice and education. As an established peer-run organization, we listen and do hear the needs of families. Each year, the conversation has grown more desperate and with dire urgency.

Students have been talking about their mental health. Parents have been talking about their children's mental health. Educators. Peers. Clinicians. Lawyers. Pediatricians. Attorney Generals. U.S. Surgeon Generals.

And now, thanks to Kathy Hochul, a NY Governor. After decades of observing legislative sessions, advocates know mental health was a rare mention in a NY Governor's State of the State; even rarer, the mention of children.

The silence was deafening. But now, it's clear that Governor's Hochul and the legislature are listening and ready to act. Never has there been more hope that we are witnessing a turning point for children's behavioral health.

Behind a podium marked with the words "Tackling the Youth Mental Health Crisis," Governor Hochul declared "for decades, our mental health system was deprioritized and defunded. Make no mistake: this is the defining challenge of our time." We agree wholeheartedly. And unfortunately, we have a lot of ground to cover. Despite the past few years of initial investments, a much more drastic infusion of resources is necessary to reverse this trend.

Two crises, one Continuum: Rising Demand and Eroding Capacity

For too long, the New York children's behavioral health systems has been experiencing concurrent crises of soaring children's behavioral health needs unfolding in our homes, schools and communities alongside an eroding workforce capacity to meet those needs. Together, the outcome has been disastrous for families who need to access care for their loved ones. New York families and youth desperately need a mental health workforce, not months-long waitlists for services.

First, the growing need for behavioral health among children is well documented.

• In 2021, the U.S. Surgeon General issued an advisory warning of a youth mental emergency and recently renewed those calls in 2022.

- In the fall of 2021, the American Academy of Pediatrics, the American Academy of Child and Adolescent Psychiatry and Children's Hospital Association all jointly declared a national emergency in child and adolescent mental health.
- Importantly, both groups were clear that COVID sharply exacerbated an existing problem.

The probable causes of this growing crisis vary widely and many of these trends are both national and global. All of New York's children and families have experienced great adversity and disruption from multiple sources, but structural inequities have disproportionately impacted children from communities of color.

Unfortunately, our service delivery system is unprepared to meet this growing need. At the center of this capacity crisis are decades of chronic disinvestment through deferred Cost of Living Adjustments for behavioral health agencies, low reimbursement rates for home and community-based services, while simultaneously downsizing beds for children and adolescents- the resources of which failed to be reinvested back into upstream services.

Time moves faster for developing minds and "white-knuckling" through adolescence means growing up under constant duress that can stall healthy growth and development. Yet, families, young people and even service providers throughout the state report 3 to 8 month waitlists for all manner of services.

And that's if they can even find a provider that accepts their insurance. As the Attorney General uncovered in their investigation of health plans in December of 2023, among mental health providers listed in New York health plan directories, 86% did not take in-network patients- the rest being "ghosts," in that they couldn't be reached or weren't actually in-network at all.

Unfortunately, if they do manage to connect with a provider, those connections aren't always stable ones. In addition to vacancy rates, staff turnover is as high as 40% in some programs. Developing a trusting therapeutic relationship can take a long time, and severing that relationship can be devastating for anyone, but especially for adolescents. Unfortunately, this isn't just common, but expected, and often cited as a barrier to young people engaging in services.

Furthermore, due to the lack of community-based services, some children's conditions escalate to emergency rooms and hospitalization but to the lack of availability of beds and without community alternatives, they wait months in hospitals awaiting a more appropriate setting to become available.

One key issue at the center of this backlog is rates. Reimbursement rates for behavioral health services do not reflect the cost of delivering the service. As a study commissioned by

the Campaign for Healthy Minds Healthy Kids revealed, Medicaid APG rates for Article 31 and 32 Outpatient, Child and Family Treatment and Supports Services (CFTSS) and Home and Community-Based Services (HCBS) are simply too low to compensate for the complexity involved in serving children or were built on fallacious assumptions of volume that never materialized. Furthermore, decades of deferred Cost of Living Adjustments (COLA) means that rates have not kept pace with inflation. Indeed, the behavioral health sector has lost nearly \$500M since 2006 despite recent years.

Often, the rates do not cover all the activities actually required to perform a service at all, let alone in a high-quality manner. These rates were built under assumptions that providers would be seeing patients around the clock, every waking moment having facetime with a patient that's time considered billable. One program director in the Hudson Valley reported that only 50% of their staff time is actually spent with people, the rest spent performing administrative tasks like documentation to bill insurance, travel, or coordinating with the constellation of care coordination and ancillary stakeholders involved in the child's life- all activities that are not billable- yet still represent a cost for the provider operating on slim margins, if not deficits. The most immediate consequence of this lack of investment is that programs cannot compensate workers adequate wages which means they cannot easily recruit workers or retain existing ones.

Ultimately, too many families and young people experience this system of care as a theoretical one. As one parent from Long Island puts it- "We have a great [behavioral health] system on paper... I've never experienced it, but I'm told it's there."

Sadly, while Medicaid rates are inadequate, commercial rates are even lower. A survey of mental health providers reported that on average rates of reimbursement from commercial plans were less than 50% of Medicaid rates. Many clinics that do accept both public and private insurance report that they do so out of mission- for these bedrock providers, public mental health rates essentially subsidize commercial rates- many providers do not opt-in to networks or accept insurance at all. Reflecting back on the Attorney General's investigation, one might wonder to what extent the 14% of providers actually in-network and accepting new patients remain so thanks to higher-yet-still-inadequate government rates.

The situation is unsustainable and providers have been sounding the alarm for some time. Instead of substantial investment in the existing continuum, the State continues to roll out a steady stream of new service types which are certainly welcome but most of which are also inadequately resourced and compete with the already limited pool of qualified workers.

New York's families and young people need a workforce, not waitlists.

To meet the growing need of children and their families, New York State must reverse these trends by investing deeply into the children's behavioral health continuum with a special emphasis on upstream, community-based programs that are meant to serve as alternatives

to out of home placements like inpatient and residential programs but were never appropriately invested in.

Allocate \$195M to enhance children's outpatient rates

In the fall of 2023, the Campaign for Healthy Minds Healthy Kids (HMHK)- a group of advocates, clinicians, family and youth peer advocates, parents, caregivers, and young people focused on increasing access to timely and high-quality behavioral healthcare for all New York's children- conducted a rigorous study on outpatient children's rates and issued recommendations that, if enacted, would allow for the hiring of 1,300 additional clinicians and serve of 26,000 more children. The rate reform proposal calls for \$195M to enhance children's outpatient rates for community-based Child and Family Treatment and Support Services (CFTSS), Home and Community-based Services (HCBS), and Article 31 and 32 clinics serving children. Reforms should adjust children's clinic rates to reflect the extra effort children require, add care coordination fees, and adjust to reflect actual volume of children receiving services under CFTSS and HCBS.

Trend rates to keep pace with inflation

Trends maintain, but do not advance, the children's behavioral health delivery system

- 3.2% trend for children's behavioral health clinic services: \$10,749,230
- 3.2% trend for children's HCBS and CFTSS services: \$2,107,748

Establish a care team coordination fee

Providers are responsible for coordinating with a growing array of care managers. They should be compensated for the time it takes to do so.

- \$7.50 Per Served Member Per Month (PSMPM) fee for children's clinics \$12,112,200
- \$7.50 PSMPM for CFTSS and children's HCBS \$8,324,766

Adjust CFTSS and children's HCBS to account for actual volume

Enable providers to expand capacity by acknowledging that the anticipated volume efficiencies have not materialized.

• Increase in CFTSS and children's HCBS rates to reflect the lack of economies of scale \$44,460,329

Adjust children's clinic rates to reflect the extra effort children require

Account for the additional costs of serving children and their families. Enable providers to expand their capacity to meet the need.

• 35% enhancement for clinic visits provided to children \$117,569,701

Pass a 3.2% Cost of Living Adjustment (COLA) and add an additional \$500M in flexible funding to reverse decades of divestment from the community behavioral health system.

Address harmful discrimination of behavioral health by insurance companies:

- Support the Governor's proposal to require commercial insurance to pay at least Medicaid APG rates for behavioral health (Part AA, Health/Mental Hygiene Article VII executive budget bill)
- Require commercial insurance to cover services available under Medicaid such as CFTSS and HCBS.
- Support regulations to improve network adequacy standards by requiring insurance to provide out-of-network coverage at no additional cost if they cannot provide appointments within 10 days.
- Carve behavioral health out of for-profit Medicaid Managed Care contracts and invest hundreds of millions worth of savings back into the system.
- Ramp up enforcement of behavioral health parity by doubling fines and staffing up enforcement agencies
- Make Telehealth Payment Parity permanent.

Fund Family Peer Advocates and Youth Peer Advocates for all:

- Expand flexible State Aid funding for Family and Youth Peer Support by at least \$5.5 million.
- Match current peer rates in all settings to recently enhanced Mental Health Outpatient Treatment and Rehabilitative Services (MHOTRS) Clinic rates to correct disparities between clinical and non-clinical settings who do the exact same home and community-based work.
- Create cross-systems funding for cross-systems work by ensuring all child-serving systems are funding the use of Family and Youth Peer Support.

Students need healing-centered schools.

- Support the Governor's proposal to add \$45M to establish school-based mental health clinics in every school that wants one by investing toward flexible start-up funds, maintaining enhanced rates and requiring insurance coverage.
- Double the Student Mental Health Support Grants to School Districts from \$50 million over 5 years to \$100 million over 5 years to improve student access to mental health resources.
- Dedicate \$105 million to expand community schools and their technical assistance statewide and maintain the current Community Schools Set-Aside of \$250 million to ensure sustainability for current community schools.
- Pass the Solutions Not Suspensions Act (A5691 Solages) to end the reliance on suspensions as the default way to discipline students and establish a framework to instead use proven restorative approaches to inappropriate behavior and discipline.

In addition, we lend our support to the following Executive Budget proposed investments toward children and family behavioral health:

- \$4M Loan repayment for Children's Mental Health Professionals
- \$53,289,000 for home-based crisis intervention program for children

- \$2M for Teen Mental Health First Aid
- \$9.6 million for 12 new Youth Assertive Community Treatment (ACT) Teams
- \$10,000,000 for youth suicide prevention
- \$10,000,000 for high fidelity wraparound services for children
- Includes \$13.9 million in funding to support a 5 percent Early Intervention reimbursement rate increase
- 15 new state-operated psychiatric beds for youth.

Poverty undermines family wellbeing. Invest in improving social determinants of health.

Investments toward improving social determinants of health such as employment, housing, food, healthcare and income are key to healthy development of children. We encourage the legislature to center child and family wellbeing as an additional strategy to reduce adverse childhood experiences and poverty therefore promoting emotional wellbeing, including the following:

- Ensure continuous Medicaid and Child Health Plus health coverage for all enrolled children from birth to age 6.
- Increase the Public Assistance housing allowance to a level that stabilizes housing for more families.
- Add \$250M to create the Housing Access Voucher Program (HAVP) to aid nearly 15,000 families or individuals at-risk or currently homeless.
- Move toward universal child care by creating a permanent state child care fund to increase child care worker compensation and reduce unnecessary barriers to subsidies and access for families who need care outside of 9 to 5, weekday hours.
- Expand and strengthen New York's child tax credit (CTC) and Earned Income Tax Credit to put more financial resources into the hands of families.
- Establish and fund a permanent, statewide Healthy School Meals for All program that provides school breakfast and lunch at no cost to all students in schools participating in the National School Lunch Program.
- Establish the Mothers & Infants Lasting Change (MILC) allowance, S.4578A (Ramos) /A.6197A (Clark) to establish a pilot that provides financial support to parents of infants at a critical period in their lives.