



14 February 2025

The Honorable «First_Name» «Last_Name»
«Albany_Address»

Dear «Title» «Last_Name»,

In OCFS Region 2 and across New York State, children with complex intellectual and developmental disabilities, behavioral health and mental health needs are being hospitalized longer than medically necessary. They languish on waitlists, sit in acute care hospitals or detention, and are often driven into foster care or out-of-state residential placements. The dearth of meaningful and available community-based services and the lack of residential options has resulted in a situation that is not meeting the needs of children, families or the community, adding to overcrowding in our hospital systems, and costing New York taxpayers millions of dollars a year. We can do better.

To keep children in their communities with the supports they need to thrive, we call on you to prioritize three urgent needs in the one-house budget proposals:

1. **BUILD ON the Governor's proposal to fund Comprehensive Clinical Assessment Hubs** by **doubling** the amount to \$2 million and **specifying** that the hubs should be physical locations that include behavioral, developmental, medical, mental health and other interdisciplinary assessments. Medical providers report seeing many children with complex needs for whom treatments and services are not working because diagnoses have been missed. Treatment and services through the Consumer Directed Personal Assistance Program can only have full effect when they are based on full and accurate assessments. This small investment in comprehensive clinical assessment hubs can save New York from far more costly hospitalizations that occur when needs are not met and youth spiral into crisis.
2. **OPPOSE the Governor's proposal to cut Medicaid funding for Applied Behavior Analysis (ABA) services.** Children with complex needs have waited years for the ABA Medicaid benefit. To enact cuts before they have had the chance to benefit from this science-based support will perpetuate long-standing inequities. In 2012, the legislature mandated that commercial insurance plans

cover ABA for children on the autism spectrum, but it was not until 2021 that the same coverage was provided to children covered by Medicaid. The proposed \$9.6 million cut this year and \$19 million cut next year -- before the coverage approved by the legislature has even been fully implemented -- will deprive thousands of children of this life-changing support.

3. **SUPPORT the Governor's \$53 million investment to support minimum wage increases at OPWDD, OMH and OASAS and at least a 2.1% targeted inflationary increase for voluntary operated providers at OPWDD, OMH and OCFS.** We must invest in a skilled workforce so children with complex needs get the care they need, when and where they need it. The challenges in accessing services for children with complex needs are great enough. The last thing they need is to be eligible for a service but not receive it because no provider is available.

The cost of these actions is far less than what New York is already paying:

- A hospital survey done by the Healthcare Association of New York State found medical costs of **\$167 million in a single 3-month period** due to New Yorkers with complex needs being hospitalized in-patient beyond what was medically necessary. This included the costs for 52 children who were hospitalized a total of 5,110 in-patient days. These delayed discharges also have indirect costs due to exacerbating shortages in hospital beds, unnecessarily disrupting the lives of children and their families, and thwarting children's healthy development.
- In 2023, **249 children were sent to out-of-state residential programs** because there was no program available in New York. These placements can cost our departments of social services and committees on special education over **\$1,000 per day per child**.
- Our child welfare system is also experiencing unprecedented impacts. In Monroe County, the number of **youth in child welfare with significant cross-system needs rose over 74% in only two years**. Visits to the hospital by youth in child welfare rose 61%. Even when their needs are known, services are often not available. In Monroe County, 64% of youth in the child welfare system who are eligible for OPWDD services and 57% eligible for OMH services were not able to access them.

Early and accurate diagnosis, equitable Medicaid coverage, and a strong workforce can reduce these costs. Children with complex intellectual and developmental disabilities, behavioral health, and mental health needs must not pay the price. Creating centralized clinical assessment hubs, maintaining Medicaid coverage for Applied Behavioral Analysis, and investing in the frontline workforce that serves these children and families are critical steps toward ensuring children with the greatest needs receive the care they need, when and where they need it.

Sincerely,

AutismUp
City of Rochester, Department of Recreation and Human Services
Empowering People's Independence

Golisano Institute for Developmental Disability Nursing at St. John Fisher University
Mary Cariola Center
Monroe County Department of Human Services
New York Public Welfare Association
New York State Association for Behavioral Analysis
Pathways, Inc.
Rochester Regional Health
Schuyler County Department of Social Services
The Child Advocacy Center of Greater Rochester
University of Rochester Medical Center