80th Anniversary

CP State

Driving the Disability Movement Since 1946

TESTIMONY

SUBMITTED TO THE NEW YORK STATE LEGISLATURE

Joint Hearing of the
Senate Finance and Assembly Ways and Means Committees

2026-2027 Executive Budget
Health & Medicaid

Presented by
Cerebral Palsy Associations of NYS (CP State)

Cerebral Palsy Associations of NYS (CP State) was founded in 1946 by parents of children with cerebral palsy looking for services. Today it is a broad-based, multi-service organization with 30 Affiliates across the state and 19,000 employees providing support, services and programs across the lifespan for over 100,000 individuals with developmental disabilities and their families. CP State was founded and has worked for the past eighty years to enhance the rights of and services for individuals with disabilities and their families.

The family of CP Affiliates have filled a niche time and again – when services were unavailable, our Affiliates stepped up. When there were no clinical services or therapies, CP worked with families to establish clinical services in every part of the state; when Willowbrook closed, CP was the leading agency to ensure the State safely transitioned people to homes in our Affiliates and we even began a new residential program in NYC to meet the need. Today, our Affiliates are the leaders in providing complex care to medically fragile New Yorkers as well as nationally and internationally recognized innovators in supporting autism spectrum disorders and medical complexity.

With that history and context, we appreciate the Legislature's support of clinical services for New Yorkers with intellectual and developmental disabilities (I/DD) but much more needs to be done in order preserve critical Early Intervention program services and to ensure that our State truly offers equitable access to quality health care for people with I/DD.

HEALTH EQUITY: SUPPORT CLINICS THAT SERVE PEOPLE WITH DEVELOPMENTAL DISABILITIES

Universally, people with disabilities are underserved. When people with disabilities access health care, they often experience stigma and discrimination and receive poor quality service. Evidence suggests that people with disabilities face obstacles in accessing the health and rehabilitation services they need. One result of this inequity is increasing numbers of people with multiple, complex and often preventable, chronic conditions, and a health care system that is insufficiently funded and is educationally and structurally unprepared to recognize and address those needs. Ensuring health equity for people with IDD in NYS is not only the right thing to do, it is also the smart thing to do from a fiscal and public policy perspective.

We applaud Governor Hochul for including initiatives to address the health care needs of individuals with disabilities. Past budgets included: funding to address mobility/wheelchair maintenance, etc.; capital funding for Article 28 and Article 16 clinics serving individuals with disabilities; enhanced rates for dental services; and a 30% increase above the base rate for Article 28 clinics serving people with IDD. However, there is more work to do.

For almost fifty years, New York State has counted on clinics supporting patients with significant disabilities to fill an essential gap in the service delivery system, one which otherwise would lead to expensive and unnecessary services delivered in emergency rooms and acute care settings. Over time, the CP State Affiliates and voluntary agencies supporting people with disabilities have stepped up to ensure their access to health services, across the State, through Article 28, FQHC, and Article 16 clinics. These clinics have evolved to become true specialty service providers, serving patients with the highest needs but often with conflicting regulations.

The following recommendations will assist in reaching the goal of health equity for people with disabilities.

IMPLEMENT THE ARTICLE 28 INCREASE FROM THE SFY2025 ENACTED BUDGET

We were extremely appreciative of the SFY2025 enacted budget's inclusion of a 30% increase above the base rate for Article 28 clinics "who treat people with physical, intellectual, or developmental disabilities" effective 10/1/2024. However, due to multiple delays, providers have yet to see this increase in their rates. Therefore, we recommend that the SFY2027 enacted budget **fund the State share of the 30% increase to Article 28 clinics supporting patients with IDD retroactive to 1/1/25**.

ARTICLE 28 AND ARTICLE 16 CLINICS JOINT LICENSURE

Our clinics have evolved to become true specialty service providers, serving patients with the highest needs across New York State. Article 16 and 28 clinics both serve people with IDD but operate under two different state agencies with conflicting regulations. We urge the Governor and the Legislature to create a joint license for Article 16 and Article 28 clinics, as was authorized for the OMH Article 31 clinics and the OASAS Article 32 clinics in the SFY2024 state budget and reiterated in the SFY2027 state budget details on the promulgation of regulations. Just as it was recognized that jointly licensing Article 31 and Article 32 clinics would improve access, coordination, and clinical outcomes for behavioral health services, providing joint licensure for Article 28 and Article 16 clinics will promote health equity by eliminating redundant and conflicting regulations and improve quality of health care for New Yorkers with IDD. Therefore, **we recommend joint licensure for Article 28 and Article 16 clinics that serve individuals with IDD**.

EXEMPT LONG-TERM THERAPIES FROM MEDICAID MANAGED CARE

A proposed change to the OPWDD Article 16 Part 679 regulations would prevent individuals with an IDD diagnosis who do not meet the stringent criteria for OPWDD eligibility from receiving treatment in Article 16 clinics. Many of these children and adults are enrolled in Medicaid Managed Care (MMC) plans, which do not recognize the difference between long-term care therapies needed by individuals with IDD, and short-term rehabilitative therapies. Article 16 services are carved out of MMC because of the recognition that these therapies are needed to maintain a person's level of functioning. Because Article 28 MMC does not recognize the difference between long- and short-term therapies, individuals with a diagnosed IDD who are not OPWDD eligible will have their prescribed, medically necessary long-term therapies terminated prematurely, resulting in the loss of essential functions required for independence, such as swallowing, ambulating, and toileting. Therefore, we recommend that **Article 28 long-term therapy services be exempt from Medicaid Managed Care for individuals with an IDD diagnosis.**

EARLY INTERVENTION – INVEST NOW OR PAY LATER

The financial needs of the NYS Early Intervention System have been severely neglected over the past three decades, leading to a capacity crisis that threatens the viability and availability of EI services for the nearly 70,000 infants, toddlers, and families who depend on them. The Early Intervention (EI) Program, authorized under Part C of the federal Individuals with Disabilities Education Act (IDEA), provides critical services for children, with disabilities and developmental delays from birth to three years of age, and their families. Research shows that EI services, when provided in a comprehensive, coordinated, and collaborative manner, are cost-effective and successful in improving long-term prognoses, significantly reducing the need for life-long services. Two thirds of infants and toddlers who participate in EI substantially improved their social-emotional skills, knowledge, and behaviors[1] and 42% of program participants did not need special education services by the time they reached Kindergarten.[2] Despite clear evidence, instead of recognizing the efficacy and future savings made possible by an investment in Early Intervention, New York State is ranked 48th of the 50 states for failing to meet its legal obligation to ensure access to timely evaluations and services for infants and toddlers with developmental delays.

A recent letter sent to the Governor's Office by the Statewide Early Intervention Coordinating Council (SEICC) describes a system that is compromised on all sides by long- and short-term systemic underinvestment and profound structural changes. The SEICC highlights that the stability of the EI program has been fundamentally shaken by a "sweeping package" of regulatory shifts and the rollout of the EI-Hub, a billing system implemented without key functionality that has significantly increased administrative burdens on already strained staff. Given these disruptions, the Council has formally requested a moratorium on any new regulatory or administrative changes in the coming budget cycle to allow the program the necessary time to stabilize. **We support the SEICC's request for a stabilization period by halting any planned regulatory or administrative changes in the upcoming fiscal year that could further restrict service access or program funding.**

Despite the promise of ensuring real and lasting improvements for infants and toddlers with disabilities who are served by the program, Early Intervention providers are forced by economic realities to leave the field to earn significantly more in other settings. As reflected in a recent Article 78 lawsuit filed this past fall, many reimbursement rates for providers are lower now than in the 1990s when the program first started. This pattern of inadequate compensation has led to a wave of program closures and created a critical shortage of EI providers, resulting in service delays across the state. Too many infants and toddlers with developmental disabilities and delays never receive the recommended services they need.

New York State must accept its responsibility to the infants, toddlers, and families who are counting on their representatives to ensure access to Early Intervention services and a brighter future that their youngest constituents deserve. **Therefore, New York State must:**

- **Increase reimbursement rates by 8%** to begin to approach actual service costs and to stabilize the NYS EI system.
- **Include A.283-A (Paulin)/S.1222-A (Rivera)** in the final budget directing DOH to conduct a comprehensive review of the Early Intervention system, analyzing service delivery models, reimbursement rates, and program efficacy.

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[1] Early Childhood Technical Assistance Center (ECTA), (2022): https://ectacenter.org/~pdfs/partc/PartC-IndicatorAnalysis-FFY2020.pdf

[2] K. Hebbeler, et al (2007). Early intervention for Infants and Toddlers with Disabilities and their Families: Participants, Services, and Outcomes. Link: https://www.sri.com/wp-content/uploads/2021/12/neils_finalreport_200702.pdf

2025 introduced significant revenue challenges for EI providers, including a 10-22% reduction in reimbursement for telehealth services, just as promised rate increases were delayed, and changes and reductions to group services and evaluations were implemented. The SFY2025 enacted budget included a 5% rate increase for all in-person EI services effective 4/1/2024. However, due to delays, EI providers are still waiting for the promised 5% rate increase almost two years later. Given the gravity and severity of the Early Intervention crisis, **New York State must immediately begin to implement the state share funding of the approved 5% increase, retroactive to October 1, 2024.**

FUND THE CENTERS OF EXCELLENCE IN THE CARE AND TREATMENT OF CHILDREN WITH ASD AND OTHER COMPLEX DISABILITIES

Students with complex disabilities who require clinical and instructional expertise and behavioral support beyond what is possible in their local school district or an 853-school day program, are referred by the Committee on Special Education (CSE) to a residential 853 school. New York State SED/OPWDD Children's Residential Projects (referred to as "CRPs") are residential 853 schools where the residential component is operated as an OPWDD Intermediate Care Facility (ICF) with federal and state Medicaid reimbursement and the 853-school component is funded by SED and the local school district. Because resources allocated to the CRPs have not kept pace with the more intensive service needs of these students, those with the highest needs are often placed in more expensive out-of-state settings where the state receives no federal funding (Medicaid or otherwise) to offset state and local costs.

Three New York State CRPs piloted a cost-effective and research-based model, *The Centers of Excellence in the Care and Treatment of Children with Autism Spectrum Disorders and Other Complex Disabilities*, (COEs) that improved New York State's ability to support students with complex needs within the state, simultaneously enhancing the quality of care and achieving significant state and local budget savings. This approach, which employs specialized multi-disciplinary teams working intensively on a short-term basis, is the result of an analysis of what NYS residential schools lacked when compared to the out-of-state schools that are enrolling New York students.

Overall, the average annual tuition and maintenance costs for placement of students in out-of-state programs exceed placement costs in the CRP programs by $229,532 per student annually. This substantial differential represents the opportunity for federal Medicaid funding and savings by investing in NYS-based CRP programs. Such an investment would improve the long-term outcomes for these students while simultaneously building capacity to fully meet their needs within New York State.

The COE pilot was successful and met all its goals. Therefore, we urge re-funding *The Centers of Excellence in the Care and Treatment of Children with Autism Spectrum Disorders and Other Complex Disabilities* (COEs) to improve New York State's ability to support students with complex needs right here at home. The COE Program would require an initial investment of $2 million (including federal and state Medicaid funding) for the establishment of the three COEs to serve an anticipated 18 students, generating a net savings of nearly $120,000 per student per year, for a total savings of $2.1 million per year. The program can be scaled to expedite the repatriation of students currently enrolled in out-of-state schools and will reduce the reliance on out-of-state placements for new students coming into the system.

In addition to the significant fiscal savings, the Centers of Excellence will improve the quality of care, keep resources in New York State, and provide services for students and their families closer to home. The COE model is truly a win–win for all.

Therefore, we urge the inclusion of $2 million (including federal and state Medicaid funding), in the final state budget, to establish *The Centers of Excellence* *in the Care and Treatment of Children with Autism Spectrum Disorders and Other Complex Disabilities* which will generate more than $2.1 million in state savings and improve the quality of care for students with complex developmental disabilities in New York State.

CP State and all our Affiliates across the state would like to thank the Legislature for all your years of support, and we look forward to working with you to provide health equity and opportunities for individuals with developmental disabilities.

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