

TESTIMONY SUBMITTED TO THE NEW YORK STATE LEGISLATURE

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

2023-2024 Executive Budget Health & Medicaid

Presented by Cerebral Palsy Associations of NYS Cerebral Palsy Associations of NYS (CP State) is a statewide, family-founded organization with more than 75 years of advocating for and supporting people with CP and other significant developmental disabilities across the State. Our Affiliates employ almost 20,000 people, but most importantly we support close to 100,000 people with I/DD and their families through OPWDD, SED, DOH, OMH, and OCFS programs. 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 these critical services and to begin to provide health equity for people with I/DD.

People with disabilities face many obstacles in accessing their health and rehabilitation services in most traditional settings. At the same time, people with I/DD are being denied equitable access to care, and the cost of care for their complex needs far exceeds any investment in preventive, primary, or specialty care. Simply put, people with complex needs, different needs, and/or higher needs than the typical Medicaid population require more time, expertise, follow up and care integration. These essential factors are not accounted for in a meaningful way under current Medicaid payment methodologies. There currently is a rapidly diminishing number of clinics offering the vital specialty services to meet the needs of people with I/DD. As a result of that failure to support clinics specializing in I/DD services, a growing number of people with disabilities, who do not have or have lost access to primary and preventive care end up in Emergency Rooms and inpatient hospitals at a significantly higher cost to Medicaid and a significantly lower quality of care and quality of life. Ensuring health equity for people with I/DD in New York State is not only the right thing to do, but it is also the smart thing to do from an economic and public policy perspective. (The CP State report on health equity and a full list of recommendations to improve access to care for people with I/DD can be found at: Health Equity - Cerebral Palsy Associations of New York State (cpstate.org).

While we ask that you look at the full report and recommendations for the long term, we ask that you take the following simple steps in the 2023-2024 state budget to address immediate needs that exacerbate health inequity for people with I/DD and will realize significant Medicaid savings. As you negotiate the 2023-2024 budget, we urge the Legislature to work with the Governor to:

- Provide financial stability for clinics that serve people with developmental disabilities by increasing the current Article 28 APG add-ons for patients assigned code 95 (I/DD) or code 81 (TBI) by providing an additional 30% to cover the true cost of providing services.
- Provide telehealth parity reimbursement for all telehealth services in the Article 28 clinic regardless of the location of the clinician and patient with I/DD (Code 95 and Code 81).

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- Provide funding to continue the statewide triage/on call telehealth services for people with developmental disabilities.
- Include an 11% Early Intervention rate increase.

Provide Financial Stability for Clinics that Serve People with Developmental Disabilities

For more than forty years, New York State has counted on clinics that support 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 room and acute care settings. Over time, the CP State Affiliates and voluntary agencies supporting people with disabilities have stepped up to ensure access to health services across the State through their Article 28, FQHC and Article 16 clinics. These clinics have evolved to become true specialty service providers, serving patients with the highest needs and often at a financial loss. With rate rationalization removing any OPWDD surpluses, to help providers to subsidize these clinics, the insufficient funding of clinical disability services has been glaringly exposed and compounded by the fact there has been no significant rate increase in 15 years. A CP State 2022 survey of clinic operations shows a 35% loss on Article 28 clinic operations across the State. These losses can no longer be sustained, and Boards statewide are facing tough decisions about the future of their disability services.

To date, when Boards choose to close these Article 28 clinics, whose primary mission is to serve individuals with I/DD, most patients have no good option. In the absence of primary care, patients show up in the ER and operatory procedures are required for issues that easily could have been avoided with timelier primary and preventive care. Clinic visits are replaced with ER visits for untreated conditions that may not require, but almost always generate, MRIs and other expensive diagnostic tests because the patient is unable to communicate and has no previous relationship with the ER physicians. This scenario would lead us in exactly the opposite direction from the one that New York State has been moving toward.

Clinics serving people with I/DD provide a critical piece of the health system. These clinics accommodate the unique needs of people with I/DD allowing extra time for patients to feel comfortable, including techniques to minimize behaviors, extra time to share information, desensitizing techniques and other accommodations. Current rates do not cover actual costs associated with this specialty care.

In March of 2018, NYS DOH and OPWDD jointly established the *Clinic/APG Base Rates Workgroup* to address the concern that Article 28 and Article 16 clinics operated by OPWDD nonprofit agencies would cease to exist due to fiscal difficulties and operating shortfalls. The DOH/OPWDD *Clinic/APG Base Rates Workgroup* recommended increasing the APG add-on for patients assigned Code 95 (I/DD) or Code 81 (TBI) by 10%. Since 2018 our clinics have further deteriorated and require a more significant increase in the base rates.

For Article 28 clinics to continue to serve people with developmental disabilities and complex needs, the current Article 28 clinic APG add-ons, for patients assigned code 95 (I/DD) or code 81 (TBI), must be increased by an additional 30% to cover the true cost of providing services.

<u>Provide Permanent Telehealth Flexibilities for Clinics that Serve People with Developmental Disabilities</u>

The Covid-19 pandemic wreaked havoc on health care services especially for individuals with I/DD. The one positive aspect of the public health emergency (PHE), however, was that telehealth became the norm for providing health care services and a lifeline for people with I/DD. The telehealth flexibilities allowed by Medicare and Medicaid during the PHE enabled clinics to use telehealth technology in the most efficient and effective manner for people with I/DD. With the end of the PHE, many of the telehealth flexibilities will be continued. However, there are some that will not. When services are provided via telehealth and both the clinician and patient are located outside the Article 28 clinic, clinics will not be paid their full APG rate. Rather, the facility fee will be deducted from the payment. Deducting the facility fee will cause clinics that are already fiscally struggling to lose even more money. Even when both the clinician and patient are offsite, the facility costs are still incurred – the rent or mortgage, gas and electric, salaries and all other overhead must still be paid. There are no costs that the clinic won't need to pay simply because a service is provided via telehealth. The clinic buildings will not close when services are provided via telehealth and therefore costs are still being incurred.

In addition, it is very difficult for our Article 28 clinics, whose primary mission is to serve individuals with I/DD, to hire clinicians – particularly specialists. Allowing clinicians to work remotely has been extremely helpful in obtaining clinicians to work for our clinics and providing access to care. If clinics need to have specialists come to the clinic site in order for clinics to be paid their full rate, clinics will again be unable to hire specialists. If clinics allow clinicians to work remotely, they will then need to require patients to come into the clinic for a telehealth visit in order to be paid their full rate. This negates the benefit of telehealth for the most vulnerable patients and limits their access to healthcare.

Therefore, in order to preserve access and prevent further financial erosion, telehealth parity reimbursement must be included for all Article 28 clinic telehealth services, for patients with I/DD (Code 95 and Code 81), regardless of the location of the clinician and patient.

Provide Permanent Reimbursement for Triage/On Call Telehealth Services for People with Developmental Disabilities

Individuals with I/DD have traditionally utilized the ER/Urgent Care/Hospitals at much higher rates than the general public. This is due, in part, to the complex health issues many individuals with I/DD have, coupled with OPWDD regulations for certified residences.

CP State is in the fourth year of a telemedicine triage grant (provided through Statewide Health Care Transformation Program II) which provides real time virtual visits 24/7 365, with an ER physician trained in treating individuals with I/DD, for any and all urgent issues. The grant began in March 2020 right at the start of the pandemic, and, to date, has saved the Medicaid system more than \$90 million dollars by avoiding trips to the ER/Urgent care/Hospitals for approximately 8,300 individuals. All of these individuals live in OPWDD certified residences.

The service allows direct support professionals to reach out (via an app on a tablet) to the physician who can then virtually examine the individual, using a high-resolution camera, pulse oximeter, stethoscope, and other equipment to determine the next step in the health care for the individual. In 94% of virtual visits, the physician can take care of the individual in place, so trips to the

ER/Urgent Care/Hospital are avoided. This program not only saves significant Medicaid dollars, but also provides better health care to the individual with I/DD and a better quality of life.

The grant funding ends in April 2024, and it appears it will take significant time to establish reimbursement for this program. Therefore, in order to ensure over 8,300 people with I/DD continue to receive this service, and that this program continues save the Medicaid system significant dollars while providing individuals with I/DD better health care and quality of life, we ask that a two-year program be funded to continue the coordination and provision of this service until CMS, with the input of OPWDD and NYS DOH, can approve a permanent reimbursement mechanism.

For SFY'24, the cost would be for one month, with the expectation that the program be funded through the SFY'25 and SFY '26 budgets at the rate of \$250,000 per month (\$29.75 per person/per month). The annual cost of this is approximately \$3 million with an annual Medicaid savings of more than \$31 million a year. This is a win-win – saving more than \$10 for every \$1 spent and providing better health care and quality of life for the most vulnerable New Yorkers.

Therefore, we urge you to include \$250,000 in the SFY'24 budget to ensure over 8,300 people with I/DD continue to receive this service and that this program continues save the Medicaid system significant dollars, while providing individuals with I/DD better health care and quality of life

PROVIDE 11% INCREASE TO EARLY IINTERVENTION REIMBURSEMENT RATES

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 has shown that EI services, provided in a comprehensive, coordinated and collaborative manner as intended by law, are cost-effective and successful in improving long-term prognoses and minimizing the need for life-long services. *Investment in EI is clearly both fiscally and socially prudent*.

The financial needs of the Early Intervention service system have been neglected over the past three decades, leading to a capacity crisis that threatens the viability and availability of EI services to the nearly 70,000 toddlers and their families who depend on them. Community-based EI provider reimbursement rates are about the same as when the program began in 1994. Early Intervention providers are leaving the field to earn significantly more in other settings despite the promise of real and lasting improvements for the infants and toddlers with disabilities who are served by the program. This pattern of inadequate compensation has led to a critical shortage of EI providers, which has resulted in delays in service delivery across the state. New York State is failing to meet its legal obligation to ensure access to timely evaluations and services for infants and toddlers with developmental delays.

NYS DOH and its Early Intervention Coordinating Council (EICC) have recognized the dire need to increase reimbursement rates and stop the hemorrhaging of EI providers. The NYS EICC passed a resolution calling for an 11% rate increase to be included in the SFY'24 Executive Budget proposal. Unfortunately, once again, the Executive did not include an Early Intervention rate increase, leaving Early Intervention rates the same as they have been for almost 30 years.

This is despite the fact that Governor Hochul signed the Early Intervention Covered Lives Legislation into law in 2021, which has saved the state \$28 million annually by requiring commercial insurance companies to cover their fair share of EI costs. These savings, which would cover the vast majority of the state share of the 11% increase, have not been reinvested into the EI program.

Therefore, if the NYS Early Intervention program is to survive, the SFY'24 budget must include an 11% rate increase.

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 for individuals with developmentally disabilities.

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