



*Coalition Of Provider Associations*

**Members:**

**Alliance of Long Island  
Agencies, Inc.**  
Seth Stein, Esq.  
Executive Director &  
General Counsel

**Cerebral Palsy Associations  
of New York State**  
Susan Constantino  
President & CEO

**Developmental Disabilities  
Alliance of WNY**  
Rhonda Frederick  
President

**InterAgency Council of  
Developmental Disabilities, Inc.**  
Tom McAlvanah  
Executive Director

**New York Association of  
Emerging & Multicultural  
Providers, Inc.**  
Yvette Watts  
Executive Director

**TESTIMONY SUBMITTED TO THE  
NEW YORK STATE LEGISLATURE**

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

**2019-2020 Executive Budget  
Health & Medicaid**

**Presented by**

Barbara Crosier  
Vice President, Government Relations  
Cerebral Palsy Associations of NYS

Winifred Schiff  
Associate Executive Director for Legislative Affairs  
The InterAgency Council of Developmental Disabilities Agencies

JR Drexelius  
Government Relations Counsel  
Developmental Disabilities Alliance of Western NY

**For the Coalition of Provider Associations**

**February 12, 2019**

***Representing More Than 250 Providers in New York State***

COPA ♦ 3 Cedar Street Extension, Suite 2 ♦ Cohoes, NY 12047 ♦ 518.436.0467 ♦ info@copanys.org ♦ www.copanys.org

The Coalition of Provider Associations (COPA) is pleased to submit these comments on the Governor's Budget Proposal for Health and Medicaid. COPA consists of five associations – the Alliance of Long Island Agencies, Inc. (ALIA), Cerebral Palsy Associations of New York State, Inc. (CP of NYS), the Developmental Disabilities Alliance of Western New York (DDAWNY), the InterAgency Council of Developmental Disabilities Agencies, Inc. (IAC), and the New York Association of Emerging and Multicultural Providers (NYAEMP) – which came together because people with disabilities, their families, and the organizations that support them recognized the need to unify in our efforts to preserve and enhance services for New Yorkers with I/DD and their families. COPA represents over 250 not-for-profit agencies across New York State which provide supports and services to over 100,000 New Yorkers with I/DD and employ more than 120,000 dedicated professionals with combined annual operating budgets of nearly \$5.2 billion.

## **EARLY INTERVENTION**

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 and their families. Research has shown that EI services, provided from birth to three years of age, in a comprehensive, coordinated and collaborative manner (as intended by law) are cost-effective and successful in improving long-term outcomes and minimizing the need for life-long services. **An investment in EI is clearly both fiscally and socially prudent.**

Over the past 25 years, the New York State Department of Health (DOH) has made EI rate adjustments that have resulted in millions in savings for the program – community-based providers are being paid less today than when the program began in 1994. The rate for home and community based individual visits, by far the most frequently delivered EI service, actually decreased in all areas of the state by an average of 6-8%. Therefore, with rates based on pre-1993 cost data and several re-calculations resulting in decreases in some rates since that time, the reimbursement is significantly below costs for salaries, benefits, and other fixed costs that have skyrocketed in the last 25 years.

While all other comparable service systems have received continuing trend factors and cost of living adjustments over these past 25 years, the financial needs of the Early Intervention service system have been ignored, discouraging providers and compromising the quality and availability of services for children and families. The Governor's proposal includes a 5% increase for PT, OT and SPL services but not for the remaining 40% of services provided under the EI program. There is a shortage of EI services in general and overall rates should be raised by 5%, not just for these therapies.

## **SUPPORT A "COVERED LIVES" METHOD OF INSURANCE PARTICIPATION IN THE EARLY INTERVENTION PROGRAM**

The Early Intervention program was established under the Public Health Law and the federal Individuals with Disabilities Education Act (IDEA) to enhance the development of infants and toddlers from birth to age three who have a significant developmental delay or disability, as well as enhance the capacity of families to meet their children's special needs. All EI services must be provided to eligible children at no cost to their families. The EI program is financed through a

combination of state and county funds, Medicaid and commercial insurance. Although Public Health Law and IDEA mandate that public and private commercial insurance be maximized in financing EI services, reimbursement from third party payers, other than Medicaid, has been minimal, leaving the cost of this entitlement to be paid by state and municipal tax dollars.

Recognizing that the current structure of financing EI costs is inadequate, COPA supports a different approach to funding; the creation of a statewide Early Intervention services pool, created through the current covered lives assessments, from which municipalities and the State would be allocated funds to pay EI costs. For the first year, an amount of \$15 million would be paid into the pool. This amount is based on the approximate percentage commercial insurers currently pay of total EI program costs (utilizing data from the 2012-13 program year) increased by the estimated amount paid by commercial insurers related to mandated coverage for autism spectrum disorder. Allowing for the direct allocation of funds to municipalities from the statewide pool will eliminate the unwieldy and inefficient step of requiring EI providers and municipalities (in the case where the insured is not eligible for Medicaid) to seek reimbursement, first from third party insurers, including time consuming appeals of denied claims, and then, only upon denial or other disposition of the claim, from the State. In cases where the insured is eligible for Medicaid, municipalities will remain obligated to seek reimbursement from Medicaid first. Making funds readily available and streamlining the process by which the funds are distributed to municipalities and the State will provide vital relief to EI providers, the State and the municipalities and improve our ability to more effectively administer EI to children who need those services. It will also result in administrative savings for health insurers.

### **CONSUMER DIRECTED PERSONAL ASSISTANCE PROGRAM (CDPAP)**

New York's CDPAP program has been a national model by enabling consumers with disabilities to direct their own care. CDPAP began in the 1990s with a number of COPA agency members as the original fiscal intermediaries (FIs) and CDPAP has provided Medicaid cost savings while providing independence. The CDPAP program allows people to hire and manage their own caregivers. They choose who to interview and hire and make decisions about scheduling and even termination. The program's flexibility accommodates people who do not fit the costlier home care model. Research proves that CDPAP works. The ability of the participant to hire the person of their choice and not be assigned staff by an agency, promotes a better quality of life, less stress than having a stranger in their home and at a lower cost.

**Consumer Directed Personal Assistants can help with an array of home-care needs, including:**

- Dressing
- Bathing and toileting
- Medication administration
- Meal prep
- Light housework
- Transportation to doctor's appointment
- Insulin injections

**The CDPAP program allows individuals to live in their own homes longer, be more independent and manage their own care leading to:**

- High satisfaction
- Greater independence
- Improved physical and mental health
- Lower cost for New York State vs. home health care agency (NP duties)
- Individuals getting the care they need quicker
- Stability in staffing

The Executive budget proposes wholesale changes to the CDPAP program that threaten access to consumer-directed services both by drastically reducing the number of CDPAP fiscal intermediaries (FI), and by reducing the payment to CDPAP FI's. If payment is inadequate, FI's will close – including those with extensive experience and track records of providing excellent services. CDPAP FI's do much more than cut checks and manage paperwork including:

- Provide weekly orientation for new hires to ensure they know what tasks can and can't be completed.
- Conduct annual in-person visits with participants
- Provide referrals to other community-based programs
- Deliver needed medical equipment
- Provide tuberculosis testing of staff
- Assist in staff recruitment when requested by participant
- Promotes best practices
- Protect tax payer funds by auditing timecards to limit errors and fraud attempts
- A Quality Assurance team conducts regular audits to ensure quality
- Staff are local and build relationships with participants to learn their needs
- Training participants on employment law

In the 2017 State Budget a new authorization process for FI's was established requiring all FI's to apply to the Commissioner for an operating license. Nearly two years after enactment, applications have been filed and the first authorizations are just being issued. This licensing process should be given a chance to continue and winnow the number of FI's and close those that fail to meet the criteria. This is a far more rational process of selection than what is now proposed – which would allow only a few of the arbitrarily selected existing FI's to survive.

Especially upstate, where the home care worker shortage is most severe, CDPAP has played a critical role for MLTC plans to staff authorized home care for members. There is a well-known shortage of both licensed agencies and workers in rural areas and small towns. MLTC plans even pressure members to accept CDPAP when they would prefer traditional care, because the plans simply cannot provide the staff. Reducing the number of CDPAP FI's in these areas would lead to reduced access for home care services.

If CDPAP ceased to exist, clients would wind up in nursing homes, group homes, institutions, or left to fend for themselves. The Executive proposal would decimate the CDPAP program and would steal independence from individuals with disabilities and increase Medicaid cost. Therefore, COPA requests that the Legislature reject the Executive CDPAP proposal.

## **MEDICARE PART B COST SHARING**

More than 50% of individuals with developmental disabilities have both Medicare and Medicaid. Because individuals with developmental disabilities are considered dependents, they automatically become Medicare eligible when their parents are Medicare eligible. Low income Medicare beneficiaries are covered by either the Qualified Medicare Beneficiary (QMB) programs or Medicaid, which used to assure meaningful access to Medicare services by paying the Medicare deductibles and cost-sharing, as well as for Medicare Part B premiums. Federal law allows states to limit their cost-sharing assistance by paying the “lesser-of” Medicaid or Medicare rates, which New York has done since 2015. Federal law also bars providers from “balance billing” QMB enrollees for any unpaid cost-sharing. As a result, a provider has to absorb the loss from unpaid Medicare coinsurance. This leads many providers to refuse to serve Medicaid recipients or QMBs, thereby reducing access to routine and specialty health care among QMB and Medicaid enrollees.

Now the Governor proposes to cut NYS Medicare cost-sharing assistance even more. Each year, a Medicare beneficiary must first meet the Part B deductible. This means that Medicare will not begin paying any doctor’s or other Part B bills until the beneficiary has incurred bills for which the Medicare approved charges total **\$185** (2019). The beneficiary is liable for 100% of the Medicare approved charge until the deductible is met. In the example above, if this service was the first one received in the calendar year, Medicare would not pay any of the bill. The bill meets the Part B deductible of \$185, so Medicare would start paying subsequent bills. Currently, NYS Medicaid pays the entire Medicare approved charge of \$185, so that the beneficiary meets the annual deductible, and the provider is paid in full.

Under the proposed change, Medicaid would pay only the Medicaid approved rate of \$100. While the Part B deductible is met by the Medicare approved charge of \$185, even if unpaid, the provider must absorb the loss of \$85. This loss may lead providers to refuse to accept all Medicaid patients.

Therefore, COPA requests that the Legislature reject the Executive proposal to reduce Medicaid benefits for low-income Medicare beneficiaries who rely on Medicaid or Qualified Medicare Beneficiary (QMB) benefits to make Medicare affordable; cuts will reduce access to preferred providers because fewer will accept Medicaid.

## **ELIMINATION OF SPOUSAL/PARENTAL REFUSAL**

The Governor’s proposal would limit spousal refusal only to married members of MLTC plans or other waivers (who are already entitled to it under federal law). Chronically ill children and low-income seniors also need Medicaid for costly medical treatment, to help with Medicare out-of-pocket costs, or for home care outside of an MLTC plan or waiver. The Medicaid income limit for adults is so low – 17% below the Federal Poverty Level – that a spouse’s moderate income or assets can easily disqualify a vulnerable person for health care. While children may have higher limits under the Affordable Care Act, there are those few for whom treatment of severe chronic conditions is so expensive that their parents cannot afford it. Only if the parent or spouse lives apart from their loved one could spousal or parental refusal be used. COPA opposes the requirement that families split up – or be forced to place a sick spouse in a nursing home – in order to obtain Medicaid for these vulnerable individuals and avoid impoverishment for a “well” spouse.

Therefore, COPA urges the Legislature to preserve “Spousal” and “Parental” refusal to ensure access to health and long-term care for vulnerable spouses and children.

### **MAINTAIN PRESCRIBER PREVAILS**

COPA members provide medical care for well over 100,000 individuals with disabilities and their families. The Executive has proposed the elimination of a physician or prescriber’s determination as to which medication is best for his or her patient, also known as prescriber prevails. This proposed elimination of the “Prescriber Prevails” medication management for seven classes of medications, particularly seizure, epilepsy, and endocrine medications, in Medicaid fee-for-service, will result in costly, unintended consequences including delays in treatment (due to appeals), sub-optimal substitutions, and increased acute care utilization by patients who had been previously stable on a medication regimen.

This proposal will directly impact one of the most vulnerable New York State populations, those with developmental disabilities who receive care in Diagnostic and Treatment Centers (Article 28) and Article 16 clinics. Individuals with developmental disabilities have a higher risk of seizure disorders and hospitalization if not controlled by the most appropriate seizure or epilepsy medication.

Specialty providers who treat individuals with developmental disabilities are in short supply. The addition of a labor-intensive appeals process to this already scarce resource is not a judicious use of medical practitioners’ time. Our practitioners have demonstrated significant Medicaid cost savings to New York State Medicaid with reduced acute care utilization and minimal hospitalizations of the most medically complex and behaviorally challenged developmentally disabled populations in New York.

Therefore, we strongly urge that Prescriber Prevails be maintained.

### **CLINICS SERVING INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES**

For almost forty 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 room and acute care settings. Over time, nonprofit agencies supporting people with disabilities have stepped up to ensure their access to health services across the State through an array of Article 28 & 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 OPWDD/DOH rate reform removing any surpluses in other programs, which had helped providers to subsidize these clinics, the insufficient funding of disability clinical services has been glaringly exposed. The annual 20% losses on Article 28 clinic operations can no longer be sustained and Boards across New York State are facing tough decisions about the future of these clinics.

To date, when Boards choose to close clinics, patients, in most instances, have no good option. In the absence of primary care, dental patients are forced to seek treatment in the ER or schedule operatory time for procedures that easily could have been avoided. Generally, clinic visits are replaced with ER visits for untreated conditions that may not require, but almost always generate, MRI and other expensive diagnostic tests because the patient is unable to communicate and has no previous relationship with the ER physicians. This situation is leading us in exactly the opposite direction from the one New York State has been promoting. In order to prevent New York State from incurring unnecessary Medicaid costs, we recommend the State invest in these specialty clinics and recognize them as an essential part of the service delivery network.

## **CONCLUSION**

With your support, including investment in critical Medicaid and healthcare programs, we can accomplish our mutual priority of maintaining and enhancing healthcare for New Yorkers with disabilities and their families. We can continue to redesign the healthcare system, create efficiencies, provide necessary supports to people when and where they need them and continue to be known as one of the best states in the country for all people, including those with intellectual and developmental disabilities. COPA would like to thank the Legislature for its ongoing support, and we look forward to continuing to work with you on behalf of all New Yorkers.