Testimony

presented for the

Joint Legislative Budget Hearing

on

Health & Medicaid

Submitted by
Winifred Schiff
CEO
and
Kate Hoy, LMSW
Vice President for Children's Services
on behalf of

Inter Agency Council of Developmental Disabilities Agencies, Inc.

150 West 30th Street
New York, NY 10001
(212) 645-6360
kate@iacny.org
wini@iacny.org

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The Inter Agency Council of Developmental Disabilities Agencies, Inc. (IAC) is a non-profit membership organization serving the New York City metropolitan area, Long Island, the Hudson Valley, and regions throughout New York State. We represent a diverse coalition of over 200 member agencies, including voluntary providers, specialized 4410 and 853 special education schools, early intervention programs, family groups, and independent practitioners dedicated to supporting children and adults with intellectual and developmental disabilities (IDD). Our mission is to ensure that people with IDD have the resources, services, and opportunities they need to live full and productive lives. **IAC appreciates the many years of support and partnership with the Legislature, without which, we would not be able to create better futures for the children and adults with disabilities in our care.**

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 educationally and structurally unprepared to recognize and address those needs. *Ensuring health equity for people with IDD in NYS is not only the moral thing to do, it is also the prudent thing to do from a fiscal and public policy perspective*.

We applaud Governor Hochul for promoting initiatives to address the healthcare 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 a critical gap in the service delivery system, one which otherwise would lead to expensive and unnecessary services delivered in emergency rooms and acute care settings. IAC members have stepped up time and again to ensure statewide access to essential health services through Article 28, FQHC, and Article 16 clinics. *Implementing the following recommendations will assist in reaching the goal of health equity for people with IDD*.

- **Implement the Article 28 Increase in 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**.

- **Create a Joint Licensure for Article 28 and Article 16 Clinics**
  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 Governor's SFY2027 proposed budget. 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 healthcare 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 in Article 28 Specialty Clinics**
  An upcoming change to the OPWDD Article 16 Part 679 regulations will 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 therapies needed by individuals with IDD, and short-term rehabilitative therapies. Article 16 services are carved out of MMC because on-going therapies are needed to maintain a person's level of functioning. Without the exemption for long term therapies from MMC in Article 28 Clinics, individuals with a diagnosed IDD who are not OPWDD eligible, will suffer early termination of their prescribed, medically necessary long-term therapies, *resulting in the loss of essential functions required for independence, such as swallowing, ambulating, and toileting*. To preserve function and independence, and prevent the need for expensive 1:1 staffing for activities of daily living, 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 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 of real and lasting improvements for infants and toddlers with disabilities who are served by the program, and instead of capitalizing on the future savings made possible by an investment in Early Intervention, our inaction has caused New York State to be ranked 48th of the 50 states for failing to meet its legal obligation to ensure access to timely evaluations and services.

- **Increase reimbursement rates by 8% to stabilize the NYS EI system**
  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. Early Intervention providers are forced by economic realities to leave the field to earn significantly more in other settings. An increase in reimbursement rates would allow us to increase salaries for therapists who are critical to the program

- **Honor the Promise – Implement the State Share of the 5% Increase Approved in the FY2025 Budget**
  2025 introduced significant revenue challenges for 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.**

- **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**
  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. This bill would analyze service delivery models, reimbursement rates, and program efficacy and produce recommendations to strengthen the program.

- **Impose a Moratorium on Any New or Planned Regulatory or Administrative Changes to Allow the Program the Necessary Time to Stabilize**
  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.