

# Testimony to the SFY2025 Joint Legislative Budget Hearing on Health

## Submitted by Brigit Hurley, The Children's Agenda and Kids Can't Wait

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Thank you for this opportunity to submit testimony regarding New York State's Early Intervention (EI) program, which serves approximately 65,000 infants and toddlers and their families every year.

The <u>Kids Can't Wait coalition</u> is led by <u>The Children's Agenda</u>, and is made up of parents, providers, advocates, pediatricians, higher education faculty, and others concerned about the well-being of New York's infants and toddlers. The goal of the Kids Can't Wait coalition is to successfully advocate for reform and improvement of New York's Early Intervention and Preschool Special Education systems, bringing them into compliance with federal law and ensuring that young children with developmental delays and disabilities receive the services and therapy they need in a timely and equitable manner.

The Early Intervention program exists in all 50 states to serve children from birth through two years old with developmental delays or disabilities and their families. Their right to early childhood developmental services is established in federal law through the Individuals with Disabilities Education Act (IDEA) – Part C. IDEA was originally enacted in 1975, to require and govern how states provide free appropriate public education to children with disabilities. The Education of the Handicapped Act Amendments of 1986 established the Early Intervention Program for Infants and Toddlers with Disabilities under Part H (now Part C) of IDEA.

The purpose of the Early intervention program is to identify and meet the needs of infants and toddlers in five developmental areas: physical development, cognitive development, communication development, social or emotional development, and adaptive development. The federal program is designed to support states in developing and implementing a statewide, comprehensive, coordinated, and multidisciplinary interagency system to make early intervention services available for ALL infants and toddlers with disabilities and their families.<sup>1</sup>

Across the state, infants and toddlers with developmental delays or disabilities are waiting weeks and months for their Early Intervention services to begin, meaning that children are languishing or regressing instead of making developmental gains. According to data collected by the New York State Association of County Health Officials (NYSACHO), as of August 2023, 7,360 children across our state are waiting for Early Intervention services, reflecting a 28% increase since 2022 and 500% increase since 2020.

#### SFY2025 Executive budget

The Kids Can't Wait coalition commends Governor Hochul for addressing this crisis by proposing an across-theboard 5% rate increase for Early Intervention services delivered in-person in her SFY25 Executive budget. It is not enough, but it is a first step toward making the investments that are needed to bring New York's Early Intervention program into compliance with federal law. It recognizes that low reimbursement rates are driving providers out of the program, leaving infants and toddlers waiting for and at times denied developmental services because no provider is available.

<sup>&</sup>lt;sup>1</sup> 43rd Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, 2021 (https://sites.ed.gov/idea/2021-individuals-with-disabilities-education-act-annual-report-to-congress/)

We are hopeful that the addition of a 4% rate modifier for rural and underserved areas will help reduce disparities in access to Early Intervention services. However, to be effective, the modifier must also be limited to Early Intervention services delivered in-person. We look forward to learning more details about this proposal to ensure that it can have the intended effect of increasing access to services.

We are opposed to the removal of school psychologists from the list of qualified Early Intervention providers. At a time when we need to grow the workforce, it is irresponsible to take steps to reduce it.

We look to the legislature to hold firm in demanding that the final enacted budget builds on the Governor's proposed investments in the Early Intervention program by:

**Providing an 11% increase in reimbursement rates for all Early Intervention services delivered in person**. We support the addition of a rate modifier designed to expand access to in-person services in rural and underserved areas.

*Funding a reform of the methodology used to determine Early Intervention reimbursement rates, as the current method is outdated and inadequate.* The State should conduct a comprehensive assessment of the methodology used to determine payment for all Early Intervention evaluations, services and service coordination. A report should be released within 12 months recommending new rates that fully cover the costs of delivering services.

**Creating a student loan forgiveness program to attract new Early Intervention providers.** To address the growing waitlists and workforce challenges plaguing Early Intervention, the State should incentivize recruitment of providers by offering a student loan forgiveness program for graduates of higher education institutions preparing Early Intervention professionals. The program should offer loan forgiveness to providers willing to provide inperson Early Intervention services in Medically Underserved (MUA) and/or Health Care Provider Shortage Areas (HPSAs). (A. 8455 - Early Intervention Loan Repayment program)

#### Waiting for Early Intervention services

When parents have concerns about their infants' or toddlers' developmental progress, New York's Early Intervention program should be there to help. Thousands of families are told that help is not available because New York State is not adequately investing in this critical program.

Nearly half of families whose children are evaluated and deemed eligible for Early Intervention services don't receive them within the legally required timelines, delaying and at times denying their opportunity for full development. The New York State Dept. of Health and the state Office of the Comptroller released data showing that wait times are longer for Black and Hispanic children and that this crisis is hitting rural and high-poverty areas of our state especially hard.

Children are waiting because therapists and providers who work one-on-one with families to nurture progress are leaving the Early Intervention program due to state-set payment rates that result in compensation that is far below what their peers earn doing equivalent work in other settings, such as schools or hospitals.

Early Intervention provider rates are lower now (post-2022) than they were in 1994 for both the Basic Home/Community-Based Individual Collateral Rate and the Extended Home/Community-Based Individual Collateral Rate. When considering inflation, 2022 rates for service coordination, screening, and core evaluation would need to increase by, on average, over 90% to have the same spending power as reimbursement in 1994. For basic and extended rates, an increase of about 140% is needed. The consequence of stagnant Early Intervention rates is impacting every region of New York state. While other sectors of New York's health care workforce have received well-deserved rate increases and bonuses over the past three years, Early Intervention therapists have not. It's long past time for recognition of their value to our families, communities and state.

**The crisis is worsening: more children are waiting and in-person services are increasingly scarce** Data from New York's Annual Performance Report State Systemic Improvement Plan presented to the State Early Intervention Coordinating Council on December 14, 2023 show that the percentage of New York families receiving Early Intervention services on time has dropped from 78.3% in 2014-15 to 53.9% in 2022-23.<sup>2</sup>

According to this data report, in the program year 2022-23, the top three reasons why children did not receive timely services were families refusing telehealth service delivery when no in-person providers were available to work with the child (21.25%), provider capacity (13.4%), and provider scheduling problem/wait list (2.25%).<sup>3</sup>

**Parents of children who currently are or recently have been enrolled in the Early Intervention program are voicing their concerns.** They experience the effects of wait lists and provider shortages most directly. Excerpts from their testimonials recorded in the past two months include the following:

A mother of a three-year-old who waited for Early Intervention services: "Developmental milestones could have been met if the services were met in a timely manner. It's a federal right for services to be met in 30 days. So I don't understand why this isn't happening. I just ask you and urge you to think of my son when he wasn't able to get his services for Early Intervention and also countless other families in New York State who are still waiting for these crucial services and how agonizing and frustrating it is when these when they are not able to be met."

A mother of five-year-old twins who benefitted from Early Intervention services: "I am so passionate about these services and fervently believe that my twins are doing as well as they are because of the work that their therapist did with them from when they were only a couple of months old all the way through when they were three. We put in the work. We worked with the therapists and they are doing just exceptionally, exceptionally well. I can't imagine how it would have looked different if we had to wait any longer than we did."

A former Early Intervention service coordinator shared her concerns: "As a service coordinator and a nurse who knows the implications of the lack of services, to go from being able to get who I thought would be the best fit for a family to begging anyone to take them has been a heartbreak that I cannot overstate."

All of New York's children deserve a chance to thrive and grow to their full potential. We are counting on you to stand firmly in supporting substantial new resources for the Early Intervention program and the families it serves.

Again, thank you for the opportunity to speak with you today.

<sup>&</sup>lt;sup>2</sup> P. 19, <u>https://www.health.ny.gov/community/infants\_children/early\_intervention/eicc/docs/2023-12-14\_ann\_perf\_report.pdf</u>

<sup>&</sup>lt;sup>3</sup> p. 20, <u>https://www.health.ny.gov/community/infants children/early intervention/eicc/docs/2023-12-14 ann perf report.pdf</u>