

Smart Choices, Bold Voices,



Testimony to the SFY2026 Joint Legislative Budget Hearing on Health Submitted by Brigit Hurley, The Children's Agenda and Kids Can't Wait February 11, 2025

Thank you for this opportunity to submit testimony regarding New York State's Early Intervention (EI) program, which serves approximately 70,000 infants and toddlers and their families every year.

The Kids Can't Wait coalition is led by The Children's Agenda, and is made up of parents, early childhood and disability advocates, pediatricians, El providers, 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is established in federal law through the Individuals with Disabilities Education Act (IDEA) - Part C. IDEA was originally enacted in 1975, to require and govern how states provide free appropriate public education to children with disabilities.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.1

New York's Early Intervention Program

Unfortunately, New York State's Early Intervention program is not fulfilling its purpose. New York State is currently the lowest ranking U.S. state for timely delivery of El services – 50th in the nation. According to the U.S. Department of Education's Office of Special Education Programs (OSEP)², the Office of the NYS Comptroller³, and the State Early Intervention Coordinating Council⁴, approximately half of eligible children are not receiving their services on time.

¹ 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/)

https://www.ed.gov/sites/ed/files/fund/data/report/idea/partcdmsrpts/dms-ny-c-report-final-02-29-2024.pdf

³ https://www.osc.ny.gov/state-agencies/audits/2023/02/28/oversight-early-intervention-program

⁴ https://www.health.ny.gov/community/infants_children/early_intervention/eicc/docs/2023-12-14_ann_perf_report.pdf, p. 19

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. Some are getting only a portion of the therapy deemed appropriate in their Individualized Family Service Plan (IFSP). Many age out of the program at age three having received no assistance at all.

Racial, geographic and economic disparities make this situation even more challenging for some families. 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.

El families and providers were grateful when the SFY25 budget included a 5% rate increase for El services, effective April 1, 2024, coupled with the promise of an additional 4% rate modifier for services delivered in underserved areas of the state to be effective April 1, 2025. This signaled support for the program and the children it serves.

It's troubling that at this time we must discuss the state budget that passed 10 months ago.

- The 5% rate increase has not been implemented despite the effective date of April 1, 2024.
- We understand that the Medicaid State Plan Amendment (SPA) for the 5% rate increase approved in April 2024 was submitted to the federal government on December 31, 2024. Because of the late date of submission, Medicaid will not cover the additional 5% on services delivered prior to October 1, 2024. We call on the state to cover the full cost of the rate increase from April 1 through October 1 to make good on the promise that was made.
- With a new federal administration, approval of the SPA request is in question.
- The SPA includes a significant reduction in telehealth rates (22% in NYC, Westchester, Poughkeepsie, and Long Island and 10% in the rest of the state) that was not expected, again disrupting the plans of providers and families. Even more providers will leave EI, resulting in more children going without therapies they
- There has been no mention of the 4% rate modifier for rural and underserved areas and it does not appear to be funded in the Executive budget. Though small in scope, this provision in the enacted SFY25 budget was a start toward addressing the racial, geographic and economic disparities that are well documented in New York's EI program. It must be funded in this year's budget and be implemented starting April 1.

These delays in investment after decades of stagnant rates – and the resulting impact on infants and toddlers and their families - is unacceptable. 85% of brain development occurs before children reach age four. Neural circuits that create the foundation for learning, behavior and health are most changeable during the first years of life. Delays or lack of access to EI services negatively impacts children throughout their schooling and their life. A few months don't mean much in the state budget cycle, but they are critically important to infants and toddlers in need of therapies.

The primary cause of these failures is inadequate investment by the state in the EI program, with low and stagnant reimbursement rates leading to an exodus of therapists to other settings where they can make significantly higher income. In 2024 the provider shortage was exacerbated by a problematic launch of the EI Hub, a new platform designed to manage child information, provider data, claims, billing and payments. When providers faced multiple challenges with the new system and had to wait weeks for payment, some left EI to go to higher-paying positions.

According to a February 2024 monitoring report released by the U.S Department of Education's Office of Special Education Programs (OSEP), New York not only fails to provide services to all children in a timely manner and in all geographic areas of the state as required under Part C of the Individuals with Disabilities Education Act (IDEA), but New York also lacks adequate systems for processing parent complaints and for mediation and fair hearings. New

York State Department of Health (NYSDOH) staff acknowledged there are not mechanisms in place to track the implementation of due process hearing decisions by municipalities, contracting agencies, or providers. OSEP also found that NYSDOH does not ensure hearing officers possess adequate knowledge of IDEA Part C.

Why is Early Intervention important?

There is ample evidence that when infants and toddlers with developmental delays and disabilities access EI therapies and assistance, it often changes their life trajectory. This can be as simple as resolving a mild to moderate speech issue before entering Pre-K, or as impactful as making mobility and communication an option for a child with severe disabilities. TCA works with parent advocates who have struggled to receive the services their children legally have a right to access. We bring policymakers together with parents who tell their first-person experiences of waiting for EI services - parents like Kim who has shared her reason for continuing to advocate for EI event after her daughter aged out – when we first met her she said, "This is my daughter, Vivian. Early Intervention is the reason she can SEE. Early Intervention is the reason she can COMMUNICATE. Early Intervention is the reason she can EAT and DRINK. Early Intervention is the reason she can WALK, RUN, JUMP, and PLAY. Early Intervention is the reason she is THRIVING in today!

These services make a real difference for kids, and we have to ensure that every child who needs them has access to EI services in a timely manner.

Research has resulted in the following findings:

- One in three infants and toddlers who receive Early Intervention services do not later present with a disability or require special education⁵
- El results in reduced special education costs by 55-100% for autistic children⁶
- State estimates of annual cost avoidance for each child who avoids special education services vary from \$4,536 (Illinois) to \$14,397 (Michigan), with the average at \$9,369.
- El reduces the need for special education services by one-third: In a longitudinal study, the rate of special education placement was one-third lower in the early intervention group (12.5% for EI children compared to 18.4% for the control group)8
- Participation in EI services leads to consistent improvement in cognitive domains: Cognitive domains include "intellectual ability (IQ), standardized academic achievement tests, standardized tests of school readiness, promotion to the next grade level, and decreased placement in special education classes because of learning problems"9
- Mothers of premature infants who received EI services scored significantly higher on measures of maternal self-confidence and satisfaction.

These short- and long-term gains produce savings for state governments. A recent analysis of six states found that Early Intervention services helped between 760 and 3,000 children per state to avoid special education services at age 3, with a 1-year cost avoidance of between \$7.6 million to \$68.2 million depending on the state. ⁴ Three-year

⁵ What is Early Intervention and Why is it Important, Utah State University, January 2024, https://idrpp.usu.edu/files/policy/what-is-EI-why-important-for-web.pdf

⁶ Cooper, M. (2022). Reducing special education costs by providing early intervention for autistic children. Behavioral Interventions, 37(2), 397-414. https://doi.org/10.1002/bin.1839

⁷ Unpublished report provided by Start Early

⁸ Conyers, L. M., Reynolds, A. J., & Ou, S.-R. (2003). The Effect of Early Childhood Intervention and Subsequent Special Education Services: Findings from the Chicago Child-Parent Centers. Educational Evaluation and Policy Analysis, 25(1), 75-95. https://doi.org/10.3102/01623737025001075

Anderson, L. M., Shinn, C., Fullilove, M. T., Scrimshaw, S. C., Fielding, J. E., Normand, J., & Carande-Kulis, V. G. (2003). The effectiveness of early childhood development programs: A systematic review. American Journal of Preventive Medicine, 24(3), 32-46. https://doi.org/10.1016/S0749-3797(02)00655-4

cost avoidance estimates, which accounted for children re-entering special education services after an initial exit, still projected substantial cost savings. The Prenatal to Three Policy Impact Center produces a state policy roadmap that summarizes research on EI and other early childhood programs.

SFY2026 Executive budget

We look to the legislature to prioritize EI children and their families in upcoming budget negotiations. We understand that there are limited resources and many needs, but this programs and the very vulnerable young children it serves have been waiting too long for recognition and additional investments. We strongly recommend that the final enacted budget includes:

- An additional 5% increase in payment rates for Early Intervention services (in addition to the 5% rate increase from the SFY25 budget), which could be funded through an increase in the Covered Lives Assessment;
- Funding for a comprehensive review of New York's Early Intervention funding, program model, and regulations, culminating in a report with recommendations for innovative solutions to bring the program into compliance with federal law (A.283/S.1222); and
- A student loan forgiveness program for graduates with relevant degrees willing to provide Early Intervention services in Medically Underserved (MUA) and/or Health Care Provider Shortage Areas (HPSAs). (A.1974)

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