

April 22, 2025

The Honorable Marvin L. Abney  
Chair, Senate Committee on Education  
State House  
Providence, RI 02903

Re: Testimony in SUPPORT of H-5462, The Early Intervention Continuity and Access Act

Dear Chairman Abney and honorable members of the House Finance Committee:

Thank you for taking the time to review my testimony. My name is Crystal Greene and I live in Exeter. I am the parent to four neurodivergent children; an Assistant Professor at the University of Rhode Island focusing on Health Communication and Public Policy; a Parent Leadership Training Institute cohort member at Rhode Island Parent Information Network and former President of the Down Syndrome Society of Rhode Island. I am here in support of The Early Intervention Continuity and Access Act (H5462/S247) both personally and professionally.

#### **Clarity of Issue**

Bill H5462/S247, The Early Intervention Continuity and Access Act, modifies Section 23-13-22 of the General Laws in Rhode Island to strengthen the early intervention program for developmentally disabled infants by allowing them to remain in early intervention services until the September after turning three, if the child remains eligible for services. The amendment addresses the service gap from turning three and entering preschool and highlights the importance of early identification and efficient referral processes to ensure timely access to services for developmentally disabled infants. The act is set to take effect immediately after passing, highlighting the urgency of improving services for children with special healthcare needs.

Comprehensively, Rhode Island Parent Information Network (RIPIN) in their April 2025 Strengthening Preschool Special Education in Rhode Island report, recommends:

1. Create and Early Intervention (EI) extension option through the September after a child's third birthday.
2. Continue to focus on transitions from EI to preschool special education, making transitions smoother and more efficient for service providers, educators and families.
3. Refresh teacher certification to make the preschool special education certification more attractive.
4. Update RI's school funding formula to better support the unique needs of preschool special education.
5. Strengthen Rhode Island Pre-K by making it more inclusive for children with disabilities.

#### **Impact on Family Well-being**

The transition process from EI to preschool special education is complicated, confusing, messy and not seamless, especially for non-English and English as second language speakers.

Service gaps of many months exist. Missing services at this critical neurodevelopmental time can delay progress and impact long-term development.

With a collaborative yearlong effort from policymakers, educators, families and advocates, families will be supported by closing the gap in services when children age out of EI at age three. The fight to retain services will no longer be the parent's responsibility. Timely and maintained services for youth with disabilities will support family well-being by helping the child catch up with their peers, reduce the need for services later, and increase their chance of success in and beyond grades K-12. The policy change allows the student to enroll and enter the school year with their peers and ensure continuity of care with their trusted EI providers.

Today's testimony is specifically for our youngest son, Benjamin Greene, who currently has 38 on his care team, of which 27 are Boston Children's Hospital (BCH) staff. Ben's portal at BCH lists 31 active and current health issues ranging from Down syndrome, Autism, conductive hearing loss, Cortical vision impairment, cleft palate, Epilepsy, Hypothyroidism and Immunodeficiency disorder. Ben was hospitalized twice since December of 2024 for the Norwalk virus leading to dehydration and causing uncontrolled Epileptic seizures.

I mention Ben's long list of providers and conditions to highlight his need for consistent, effective and reliable Early Intervention services and specialized medical care since birth. Ben entered Early Intervention at 6 months and received EXTRAORDINARY speech, physical therapy, occupational therapy and family sign language support. Supports were first in person, then online, due to COVID procedural changes. Ben's care was managed under the compassionate, experienced and always professional care of his Service Coordinator, Nicole Lynn Pallett of the J. Arthur Trudeau Center.

Under the Olmstead ruling, states have a legal obligation to have the supports in place for individuals with disabilities to live, work, and receive services in the community in the least restrictive setting permitted by their disabilities. Specifically, the United States Supreme Court requires states to have supports in place for people with disabilities in community settings, rather than in institutions, whenever treatment professionals determine that such placement is appropriate, the affected persons do not oppose such placement, and the state can reasonably accommodate the placement, taking into account the resources available to the state and the needs of others with disabilities.

Once Ben aged out of Early Intervention at 3, I advocated fiercely for appropriate preschool placement. After two years of homeschooling due to Ben's medical fragility and our local districts inability to provide safe and adequate pre-school services, we finally were awarded placement at Meeting Street.

However, Ben never received an education at Meeting Street due to a lack of "appropriate staffing" and was dismissed. If H5462/S247, The Early Intervention Continuity and Access Act was passed, Ben would have had continued, uninterrupted access to safe PT, OT, SLP and sign language services instead of going without for 2.5 years at such a crucial time for developmental skills, milestones and opportunities to create lifelong learning pathways.

Since 5.5 years of age, Ben's immune system is supported with monthly IVIG therapy to allow him to attend school. Ben was accepted into and has received extraordinary services from the Sargent Rehabilitation Center in Warwick. I hope that no child has to go through this same gap when aging out from EI, but fear it in light of the ongoing lack of compensation causing lack of staffing of medical professionals and service providers. The current Political climate only further compounds these issues and is causing even greater shortages, divisiveness and lack of diversity, equity and inclusion possibilities for many, including those in the special needs community.

### **Approach Using Family Impact Lens**

The bill affects all three types of family structures; all developmental phases or stages in the family life cycle; all income and educational levels; and diverse sexual orientation, ethnic, racial and cultural backgrounds. RIPIN's yearlong research and community engagement process for the bill with more than twenty listening sessions, key informant interviews, and meetings with more than one hundred families and other key stakeholders (parents, educators, administrators and policymakers) addresses all five principles of the family impact analysis, family: responsibility, stability, relationships, diversity and engagement.

From RIPIN's Fall 2023 Policy Forum gathered input from the community about their general challenges and asked what could be potential solutions. RIPIN's yearlong analysis of preschool special education in RI examined why these issues are occurring to create policy recommendations to improve the system. A family impact analysis was conducted in this process when interviewing dozens of families, hosting roundtables and interviews with more than 100 families, stakeholders, policy leaders and experts.

Their summary of findings is that families struggle to access services. RI has many strengths to build on. School districts face serious resource constraints. Transitions from EI to preschool special education remain challenging. RI Pre-K faces inclusion challenges. Best practice itinerant or embedded service models need new support post COVID. Language access remains a barrier for many families. The special education funding framework is not designed to promote access.

### **Considerations for Policymakers**

Funding is the main cause of issue with this policy. RIPIN's report states that thirty-six states include special education in their primary funding model. RI does not. The bill's fourth recommendation is to strengthen State funding formula to better support special education.

To remedy this, the bill recommends the following changes to its funding formula with respect to preschool special education.

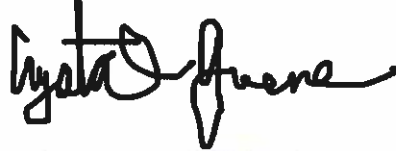
1. "Clarify that preschoolers receiving special education services in a Head Start or other community setting count in a district's average daily membership for the purposes of the funding formula.
2. Include students receiving special education in RI Pre-K classrooms in a district's average daily membership for the purposes of the funding formula".

Questions that policymakers should ask when making decisions on this policy focus on funding and cost. Based on RIPIN's April 2025 report, EI funding comes from 60% Medicaid and 40% private insurance, so what is delaying the acceptance of this since it is primarily not State funded? Since every \$1 spent by RI brings in \$3 in federal and private insurance funds, what is the issue? With the estimated state cost being only between \$300,000 -\$600,000 per year when fully funded, how many policies are passed weekly that incur a higher cost to the state than this and what are the topics that those policies focus on? If EI extension states receive mandatory additional federal EI funding, what is stopping this policy from becoming a law? My final question is why preschoolers requiring special education are treated lesser than their typical peers.

Thank you for your time and the opportunity to testify in favor of H-5462 which is a crucial step in preventing service gaps for children with special needs. I urge you to vote in favor of bill H-5462 to support my son Ben, and all of his buddies. To all of the parents sitting here today, remember one thing, NEVER let a broken system convince you that you have a broken child.

Crystal Greene

Respectfully submitted,



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