

**Testimony for the Joint Legislative Public Hearing on the
2018-2019 Executive Budget Proposal: Health**

Re: Early Intervention Program

February 16, 2018

Winning Beginning New York, the statewide coalition working to ensure access for all of New York's children to a continuum of high-quality learning and development from prenatal to eight years of age, appreciates the opportunity to submit comments on the 2018-2019 Executive Budget proposal regarding the Early Intervention (EI) Program.

We urge the Legislature to:

1. Reject the Executive Budget proposal to restructure the EI referral, eligibility determination, screening, and evaluation process. This proposal does not comport with federal requirements, would have a harmful impact on children, and may not yield any cost savings.
2. Begin restoring EI reimbursement rates by increasing the current rates by at least 5% this year. The Executive Budget proposal of a 2% increase on the condition that providers pursue appeals of private health insurance claim denials is insufficient even to cover the cost of this new proposed responsibility, much less to address the shortage of high-quality EI providers.
3. Modify the Executive Budget proposal to increase health insurance reimbursement for EI services in order to ensure it does not delay evaluations or services for children and does not drive away more EI providers.

1. Reject the Executive Budget Proposal to Restructure the EI Referral, Eligibility Determination, Screening, and Evaluation Process

Mandatory Screenings

The Executive Budget proposes that evaluators perform a screening on each child who is referred to EI because of a suspected disability prior to evaluating the child. This proposal fails to include federally required protections for children and families, would likely disproportionately harm children from low-income backgrounds, and may not yield any cost savings.

It is important to note that, currently, New York State law *allows* evaluators to perform a screening prior to evaluating a child. Section 2544(3) states:

- (a) To determine eligibility, an evaluator shall, with parental consent, either (i) screen a child to determine what type of evaluation, if any, is warranted, or (ii) provide a multidisciplinary evaluation. In making the determination whether to provide an evaluation, the evaluator may rely on a recommendation from a physician or other qualified person as designated by the commissioner.
- (b) If, based upon the screening, a child is believed to be eligible, or if otherwise elected by the parent, the child shall, with the consent of a parent, receive a multidisciplinary evaluation. All evaluations shall be conducted in accordance with the coordinated standards and procedures and with regulations promulgated by the commissioner.

The Executive Budget proposes taking away the evaluator's current authority to determine whether or not a screening is appropriate for an individual child and requiring evaluators to screen every child who is referred to EI because of a suspected disability. An evaluator may only proceed to evaluate a child if, based on the screening, the child is suspected of having a disability or if the parent requests an evaluation.

Administering a screening, instead of fully evaluating a child, comes with the risk that a child who is eligible for the EI program will fail to be identified. Therefore, any proposal for increased screenings must have clear provisions that protect the rights of parents and children. We are concerned that the proposed Article VII changes do not comport with the federal regulations regarding parents' rights to an evaluation. The federal regulations (34 CFR § 303.320(a)(1)) require states that choose to adopt screening procedures to provide parents with notice of the intent to screen the child and "include in that notice a description of the parent's right to request an evaluation under § 303.321 at any time during the screening process." The commentary to the federal regulations explains that this language was added "to clarify that parents have an ongoing right to request an evaluation before, during, or after their child is screened."

With regard to a parent's right to evaluations, the proposed Article VII language merely states: "If, based upon the screening, a child is not suspected of having a disability, an evaluation shall not be provided, unless requested by the parent. The early intervention official shall provide the parent with written notice of the screening results, which shall include information on the parent's right to request an evaluation." This language implies that a parent does not have the right to request an evaluation until the screening has been completed and that a parent will not receive notice of the right to an evaluation until the screening has been completed. The current Article VII legislation fails to comport with the federal requirement that parents receive notice of the intent to screen their child and their right to request an evaluation at any time during the screening process.

While we are not opposed to the concept of screenings, it is also important to consider whether the purported benefits of mandatory screenings outweigh the costs. The Administration has explained that requiring screenings will streamline the evaluation process and save money. However, screenings also come with costs. For children who will ultimately receive an evaluation, a screening does not save any money and, assuming the State will pay evaluators to perform screenings, will cost additional money for each child who is evaluated. Given that any

family can request an evaluation regardless of the outcome of the screening, it is hard to predict how many fewer evaluations the EI program will have to perform as a result of mandatory screenings.

There are several categories of children for whom screenings do not appear to have any benefits. First, in cases where parents request an evaluation prior to a screening, the State will not save any money or achieve any efficiencies by conducting an additional screening.

Second, some children are referred to EI because they are suspected of having a disability based on the result of a screening. For example, pediatricians or Early Head Start programs may perform developmental screenings and make referrals to EI based on the results of such screenings. The State will not save money or streamline evaluations by conducting a screening on a child referred to EI because the child is suspected of having a disability based on the results of a prior screening. In addition, asking children to perform the same tasks for multiple screenings or evaluations can have a “performance effect,” making the subsequent screening or evaluation invalid.

Third, some children are referred to EI because of documented significant concerns about delays in their development. The Article VII bill requires primary referral sources to provide documentation of their concerns and to provide records or reports pertinent to the child’s developmental status or disability, with the parent’s consent. When these records indicate that children are experiencing significant delays, evaluators know that an evaluation is needed without performing a screening, and a screening will not save money or streamline the evaluation process.

In cases where children are going to be evaluated, mandatory screenings not only cost more money but also pose an additional hurdle to families. New York State is already out of compliance on the indicator of holding IFSP meetings within the required 45 days from referral. In fact, the most recent data available show that one out of every six children eligible for EI services in New York does not have an IFSP meeting within 45 days from referral. Adding another step to the process will only exacerbate this problem, and lead to delays in children receiving services at the time when these services can have the biggest impact. This extra step would be particularly burdensome for families with low incomes. Families with low incomes may not be able to afford to take off an extra day from work for this additional appointment or may have difficulty affording the transportation costs of going to this additional appointment.

Furthermore, EI services are cost-effective. If children are improperly screened out because the screening tool does not capture as much information as the full evaluation, the State will have to pay more money later on when the children need more intensive services as a result of failing to address their delays early in life.

We recommend that, instead of amending the law to require screenings for every child, the law continue to allow evaluators the flexibility to use their informed clinical opinion to determine whether or not a screening would be appropriate for an individual child. We understand that, currently, the State does not pay evaluators to perform screenings in cases in which evaluations are also performed. The State pays for screenings only in cases in which the screening is the

only assessment. Thus, there is a financial incentive for evaluators to skip the screenings – since there is a good chance they will not be paid for them. Perhaps if the State *paid* evaluators to perform screenings and outlined factors that evaluators should consider and discuss with parents in determining whether or not a screening is appropriate, we would see an increase in the use of screenings. The State should also conduct an in-depth analysis of the impact on children and costs of the mandatory screenings proposal before implementing it.

We urge the Legislature to reject the mandatory screenings provision.

Assessments for Children with a Diagnosed Condition

We oppose the Executive Budget proposal regarding the abbreviated evaluation process for children who have a documented diagnosed developmental delay or a documented diagnosed condition that has a high probability of resulting in a developmental delay.

The Executive Budget proposes to use a child’s medical records to establish a child’s eligibility for EI for children who have a documented diagnosed developmental delay or a documented diagnosed condition that has a high probability of resulting in a developmental delay. Such children would not receive an “evaluation of the child’s level of functioning in each of the developmental areas” based on an evaluation instrument. Rather, they would receive only an “assessment for the purpose of identifying the child’s unique strengths and needs in each of the developmental areas,” a family-directed assessment, and a transportation assessment.

For a child who has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay, we agree that an evaluation is not necessary *for the purpose of determining eligibility*. However, without evaluating the child’s level of functioning in each of the developmental areas, it is unclear how an IFSP team would determine the type and amount of services appropriate to meet a child’s unique needs. The fact that a child has a diagnosis likely to result in delays does not give sufficient information to determine appropriate services. Two children with the same diagnosed condition may have widely varying degrees of need.

While the proposed changes are allowed under federal regulations, they are not required under federal regulations. Federal regulations do not prohibit states from conducting comprehensive evaluations (i.e., evaluations using a standardized instrument to identify the child’s functioning level in each area of development) for each child referred to EI.

We recommend continuing to require that children referred to EI because of a diagnosed condition receive an evaluation of the child’s level of functioning in each of the developmental areas. We urge the Legislature to reject the abbreviated evaluation proposal.

Referrals

Currently, unless a parent objects, primary referral sources, such as doctors, child care providers, and homeless shelters, are required to refer an infant or toddler to EI for a screening/evaluation if they suspect that the child has a disability. Counties have developed different referral

procedures, including phone hotlines, to help facilitate these important referrals. The Executive Budget proposal would require that, unless a parent objects, primary referral sources submit a referral form that “contains information sufficient to document the primary referral source’s concern or basis for suspecting the child has a disability or is at risk of having a disability, and where applicable, specifies the child’s diagnosed condition that establishes the child’s eligibility for the early intervention program.”

While there are benefits to having primary referral sources share information, with parents’ consent, about their concerns about the child being referred, there are several concerns with this proposal. Our primary concern is that the proposed language is vague on what happens if the EI official determines that a referral does not contain “information sufficient to document” the concern. Federal law does not allow the EI official to reject a referral for containing insufficient information, but the Executive Budget proposal could be misinterpreted as allowing such a rejection. In addition, several counties, including New York City, have referral telephone hotlines that have worked well to begin the EI process. Primary referral sources are very busy with other responsibilities, and we worry that additional administrative requirements, for which they are not compensated, will cause them not to make needed EI referrals.

It should be noted that a screening/evaluation does not take place automatically upon referral. Rather, once a referral is submitted, parents have the decision of whether or not to move forward with a screening/evaluation. A screening/evaluation cannot take place without parental consent. Presumably, parents do not consent unless they are concerned about their child’s development. Thus, concerns about primary referral sources making unnecessary referrals seem unwarranted.

We urge the Legislature to reject the proposed new referral process.

Finally, we note that some of the proposed definitions in the Article VII EI proposal (e.g., the definition of “multidisciplinary”) do not comport with federal definitions.

We stand ready to work with Governor Cuomo’s staff and the Legislature on legislative proposals that would help strengthen Early Intervention services for children. However, the Article VII proposal regarding referrals, eligibility determinations, screenings, and evaluations does not comport with federal requirements, would harm children, and may not produce any cost savings.

The Legislature wisely rejected very similar Executive Budget proposals multiple times in the past. **We urge the Legislature to reject the Article VII EI proposal to restructure the referral, eligibility determination, screening, and evaluation process.**

2. Increase EI Reimbursement Rates by At Least Five Percent

Since 2010, state funding for Early Intervention has decreased significantly. The State cut the EI service rate for home- and community-based services by ten percent in April 2010 and cut the

reimbursement rate for all EI services by an additional five percent in April 2011. Meanwhile, the State implemented a new process for seeking reimbursement, placing significant administrative burdens on EI service coordinators and programs.

As a result, experienced, high-quality EI providers have shut their doors or stopped taking referrals, making it difficult for children to access much-needed high-quality services in a timely manner in certain areas. For example:

- In Franklin County, an established agency shut down its EI program in June 2016 due to inadequate reimbursement rates, leaving dozens of children and families without services.
- In New York City, in June 2017, an agency that was providing EI service coordination to 2,400 children ended its 24-year EI program because the program was not financially viable.

Restoring reimbursement rates is necessary to support recruitment and retention of high-quality professionals, to cover the burden of recently increased administrative costs, and to build ongoing quality improvement efforts into the program.

The Executive Budget proposal of a 2 percent increase on the condition that providers pursue appeals of certain private health insurance claim denials is insufficient even to cover the cost of this new proposed responsibility, much less to address the shortage of high-quality EI providers.

We urge the Legislature to begin restoring reimbursement rates by increasing the current rates by at least five percent this year.

3. Modify the Executive Budget Proposal to Increase Health Insurance Reimbursement for EI Services

One strategy for helping to fund EI is to maximize reimbursement from health insurance companies. As the EI State Fiscal Agent found, private health insurance companies often deny claims for reimbursement of EI services based on lack of documentation (despite having EI documents) or due to reasons such as services taking place in the home or the EI provider not being in the insurer's network. In fact, in FY 2017, 82 percent of claims submitted to private insurers were denied.

While we support measures to require health insurance companies to contribute their fair share to the cost of EI, we are concerned about two provisions of the Executive Budget proposal regarding health insurance reimbursement for EI services.

First, we want to ensure that children's evaluations and services are not delayed due to the proposed requirement to obtain additional medical documentation regarding EI evaluations and services. The Executive Budget proposal would require the parent to provide documentation from the child's doctor or nurse of the medical necessity of EI evaluations or IFSP services or written consent to contact the child's doctor or nurse for purposes of obtaining this documentation. Children have the right to receive EI evaluations if their parents suspect that

they have a developmental delay or disability, regardless of whether or not a doctor signs off. Furthermore, if their evaluations show they have a developmental delay or disability, children have the right to receive EI services in a timely manner, whether or not their doctor signs off. Early Intervention services are part of the Individuals with Disabilities Education Act (IDEA), a federal education law. An IFSP team may determine that a child needs certain services through EI to help with the child's development, even though a doctor does not deem these services to be medically necessary.

Furthermore, particularly for children from low-income families, reaching a doctor and getting written consent for evaluations or services can be an extremely difficult, lengthy, and time consuming process. While we are not opposed to asking parents to obtain or consent to having EI providers obtain documentation of medical necessity, the law should state explicitly that children's evaluations and services may not be delayed due to lack of medical documentation.

Second, we are concerned about the proposal to require providers to submit appeals of denials of certain health insurance reimbursement claims prior to getting paid. We are worried that additional burdens on EI providers and additional delays in payment to EI providers will exacerbate the shortages of providers we are seeing in various parts of the State, resulting in children unable to access the services they need.

Thank you for considering our testimony.