



Advocates for Children of New York

Protecting every child's right to learn

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Re: Comments to Proposed Early Intervention Program Regulations

Dear Ms. Ceroalo:

Advocates for Children of New York (AFC) appreciates the opportunity to provide written comments concerning the proposed changes to the New York State Early Intervention Program regulations. For more than 40 years, AFC has worked to ensure a high-quality education for New York students who face barriers to academic success, focusing on students from low-income backgrounds. Every year, we help thousands of New York City parents navigate the Early Intervention (EI), preschool, and school-aged special education programs. As a result, we are well-positioned to comment on these proposed changes.

We are pleased with a number of proposed changes to the regulations. In particular, we support the proposed repeal of section 69-4.5(a)(6), which prohibits the same provider from being approved as an EI service coordinator and an EI evaluator. This change would help ensure that children receive evaluations in a timely manner. We also support adding section 69-4.7(m), which, in line with state law, would require notification, with parental consent, to the Office of People with Developmental Disabilities (OPWDD) of a child's potential eligibility for OPWDD services; amending the regulations to ensure that federal protections are in place when conducting a screening, such as providing notice to parents of their right to request a multidisciplinary evaluation at any time during the screening process (section 69-4.8(c)); and amending section 69-4.17(g)(3) to provide protections during the mediation process in line with federal regulations, including ensuring that the mediation process is not used to deny or delay a parent's right to an impartial hearing.

However, we have several concerns about proposed amendments that do not comport with state law and would be harmful to children and families. We address these provisions below.



Section 69-4.8 – Assessments for Children with a Diagnosed Condition

We oppose, and state law prohibits, the proposed regulations regarding the 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.

Under the proposed regulations in section 69-4.8, the evaluator would use a child's medical records to establish 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. While we do not object to using medical records to establish eligibility, we are very concerned that, under the proposed regulations, such children would not receive a comprehensive evaluation. Under the proposed regulations, such children would not receive a "multidisciplinary evaluation," an evaluation using a standardized instrument (when appropriate) to identify the child's level of functioning in each area of development. Such children would receive only a "multidisciplinary assessment" to "identify the child's unique strengths and needs."

While these 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 the Early Intervention Program.

Moreover, the proposed changes are not allowed under New York State law. New York State law explicitly entitles all children referred to EI to receive a multidisciplinary evaluation. New York State Public Health Law states: "*Each child* thought to be an eligible child *is entitled to a multidisciplinary evaluation*, and the early intervention official shall ensure such evaluation, with parental consent." PHL § 2544(1) (emphasis added). The law goes on to explain that the "evaluation of each child" shall include an evaluation of the child's level of functioning in each of the developmental areas, as well as an assessment of the unique needs of the child in terms of each of the developmental areas, among other components. PHL § 2544(4)(d). While state law allows the Commissioner to prescribe in regulation *additional* assessments that should be conducted, PHL § 2544(4)(d)(v) (emphasis added), state law does not allow the Commissioner to limit the evaluations that can be conducted for a subgroup of children. State law makes clear that all children referred for an EI evaluation are entitled to a multidisciplinary evaluation and does not allow for an exception for children who have a documented diagnosed developmental delay or condition.



Recognizing the need to change state law in order to effectuate the proposed evaluation system, Governor Cuomo proposed amending the statute with respect to multidisciplinary evaluations as part of his 2016-2017 Executive Budget in the same way the Department is now proposing to amend the regulations. However, the Legislature expressly rejected these changes, refusing to include them in the final budget legislation. As such, state law continues to entitle each child to receive a multidisciplinary evaluation.

Besides being illegal under state law, the proposed change is bad policy. 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.

Given that state law makes clear that every child referred to EI is entitled to a multidisciplinary evaluation, that federal law does not prohibit such a system, and that a multidisciplinary evaluation will help the IFSP team have sufficient information to determine the services that a child needs, **we urge the Department to maintain each child's entitlement to a multidisciplinary evaluation.**

Sections 69-4.1(o), 69-4.1(ad), 69-4.8(a) – Definitions of Evaluator and Multidisciplinary

The proposed regulations to allow only one professional to participate in evaluations of a child referred to EI are a clear violation of state law and must be rejected.

State law defines "evaluator" as "a team of *two or more professionals* approved pursuant to section twenty-five hundred fifty-one of this title to conduct screenings and evaluations." PHL § 2541(10) (emphasis added). While Governor Cuomo proposed changing this statutory definition in his 2016-2017 Executive Budget to allow only one professional to conduct evaluations, the Legislature rejected this proposal.

The proposal to amend section 69-4.1(o) to delete "a team of two or more professionals" from the regulatory definition of "evaluator" and allow only one



professional to conduct evaluations is a clear violation of state law and must be rejected.

Furthermore, the Department has proposed defining a multidisciplinary evaluation or assessment as having “the involvement of two or more qualified personnel from different disciplines or professions listed in section 69-4.1(ak), or only one qualified personnel, if such qualified personnel has a license, certification, or registration in more than one discipline or profession listed in section 69-4.1(ak).” § 69-4.8(a). However, given that an evaluator is a team of two or more professionals under state law, EI evaluations must be conducted by two or more professionals unless and until the Legislature changes state law, regardless of how the regulations define “multidisciplinary.”

While federal regulations allow a multidisciplinary evaluation to be conducted by one professional certified in more than one discipline, federal regulations do not require evaluations to be conducted by only one person. Meanwhile, state law requires *two* professionals to conduct evaluations. In order to avoid confusion, **the Department should reject the proposed definition of “evaluator” in section 69-4.1(o), reject the proposed definition of “multidisciplinary” in section 69-4.1(ad), and delete all references to the concept of multidisciplinary evaluations conducted by only one qualified personnel.**

Section 69-4.11(a)(7)(ii) – Assigning Service Providers

While we continue to have concerns about the impact on the timely delivery of EI services of prohibiting the same agency from evaluating and providing services to a child, we support the proposed amendment to section 69-4.11(a)(7)(ii)(a), which would task the local Early Intervention Official, instead of the New York State Department of Health Commissioner, with responsibility for authorizing services from a service provider who works for the agency that evaluated the child. As we have commented in the past, local official has far more knowledge than the State Commissioner about the availability of local service providers and the specialization of different service providers and is far better positioned to determine if the agency that evaluated the child should also provide services to the child.

Regardless of who authorizes this waiver, the State must ensure that there is a streamlined process that allows children to get services in a timely manner. To this end, **the State should amend, rather than repeal, section 69-4.11(a)(7)(ii)(b), which states the timeline for responding to waiver requests, and should retain,**



rather than repeal, section 69-4.11(a)(7)(ii)(c), which allows for standing waivers, to help ensure that children are not waiting needlessly for services to begin.

We recommend the following language, modeled on the current regulatory language:

(b) Any request for such authorization shall be made by the child’s service coordinator on a form stating the reason for such request. Any request for authorization shall not delay the timely delivery of early intervention services authorized in the child’s IFSP. The Early Intervention Official shall issue a determination upon such a request within ten calendar days after the request is received.

(c) If the commissioner finds there is a shortage of evaluators or approved providers in certain disciplines in a particular region of the state, the commissioner may issue a standing authorization, on such terms or conditions as he or she deems appropriate, which shall remain in effect in such region until such time as the commissioner determines that such shortage no longer exists.

Section 69-4.16(d) – Surrogate Parents

In describing the circumstances when the Early Intervention Official should appoint a surrogate parent when a child’s parent is unavailable, we oppose the deletion of the clause “after reasonable efforts to facilitate their participation and the child has no person in parental relation.” While we understand that section 69-4.16(c) would still require the Early Intervention Official to make reasonable efforts to facilitate the participation of the child’s parent and to ensure that the child has no person in parental relation prior to appointing a surrogate parent, we do not understand why the Department is proposing to remove these important terms from 69-4.16(d) and recommend that the Department retain this important language.

Parent involvement has always been a critical component of the Early Intervention Program. Surrogate parents should be appointed in only a limited number of cases when a child’s parent is truly unavailable and the child has no person in parental relation. Under the federal regulations, the circumstances when a surrogate parent must be appointed include when the “lead agency or other public agency, *after reasonable efforts*, cannot locate a parent.” 34 CFR § 303.422 (emphasis added). As the discussion in the federal regulations explains: “[T]he regulations continue to require that the lead agency make reasonable efforts to discover the whereabouts of a parent before assigning a surrogate parent.” While reasonable efforts continue to be discussed in section 69-4.16(c), we think it is important to retain this requirement in section 69-4.16(d) as well.



Similarly, while section 69-4.16(c)(3) continues to make clear that a surrogate parent should be appointed only when a child has no person in parental relation, we think that the term “and the child has no person in parental relation” should be retained in section 69-4.16(d) as well in order to avoid confusion and make clear the circumstances when a surrogate parent should be appointed.

For consistency and clarity, and to help ensure that parents have an opportunity to participate in the Early Intervention process whenever possible, **we urge the Department to maintain the clause “after reasonable efforts to facilitate their participation and the child has no person in parental relation” in section 69-4.16(d).**

Section 69.4-6(d) – Insurance Information

The proposed regulations would require service coordinators to obtain and update, and parents to provide, any information and documentation necessary to establish a child’s health insurance, including the nature and extent of such coverage, on at least a “quarterly” basis instead of “periodically upon the request of the early intervention official.” Updating insurance information on a quarterly basis would be burdensome for service coordinators who are already tasked with numerous administrative responsibilities.

We recommend changing “quarterly” basis to “two times per year” so that service coordinators may update health insurance information when they speak with families during the six-month IFSP reviews and annual IFSP meetings. As an additional precaution, the State could add language directing service coordinators to ask parents to inform the service coordinator when their health coverage changes.

Section 69.4-6(d)(3) – Medical Necessity Documentation

We are concerned about the proposed regulation to require service coordinators to obtain, and parents to provide, a written referral from a primary health care provider as documentation of the medical necessity of each EI service—a more burdensome requirement than what is currently in state law.

We support efforts to maximize reimbursement for EI services from health insurance companies. We understand that health insurance companies often reject EI reimbursement claims due to lack of medical necessity documentation. We support



amending state statute to require health insurance companies to accept the IFSP as documentation of medical necessity, as Governor Cuomo has proposed in the past. However, parents often struggle to get written referrals from health care providers. While all parents may have difficulty getting referrals for each service from busy health care providers, parents whose primary language is a language other than English, parents with disabilities, parents who are homeless, and parents who are working multiple jobs may encounter even more barriers. Furthermore, there may be times when a doctor does not feel that a particular service is medically necessary; rather, the service is necessary for the child’s development.

At a minimum, to protect children’s right to timely services, **the regulations should state explicitly that the provision regarding written referrals of medical necessity cannot delay the timeline for starting a child’s EI services.** Without such language, we worry that parents will be told that children cannot receive a particular service until they provide documentation of medical necessity, in violation of federal law.

We recommend adding the following clause to the end of section 69.4-6(d)(3): “[.]; provided, however, that such requests for written referrals shall not delay the timely delivery of early intervention services authorized in the child's IFSP.”

Section 69-4.7(g)(3) – Lifetime or Annual Limits

We oppose the proposal to amend the regulations to allow a parent to consent to have their insurance billed for services from an insurance company that will apply EI services to the insurance policy’s annual and lifetime limits. This change is not allowed under state statute and is not sound policy. New York State Public Health Law § 2559(3)(a) states that “the obligation to seek payment [for EI services] shall not apply to a payment from a third party payor who is not prohibited from applying such payment, and will apply such payment, to an annual or lifetime limit specified in the insured's policy.” Section 2559(3)(c) states that payments for EI services “shall not be applied by the insurer or plan administrator against any maximum lifetime or annual limits specified in the policy or health benefits plan.” Furthermore, state regulations make clear that a provider “shall not obtain payment from a third party payor who is not prohibited from applying such payment, and will apply such payment, to an annual or lifetime limit specified in the insured’s policy.” § 69-4.22(a). There is no exception based on parental consent. State law is careful to protect parents who may not realize the harmful impact of having EI services count toward an annual or lifetime limit, limiting the services that their child can get in the future.



We recommend that the Department delete the proposed addition in section 69.4-7(g)(3) of the clause “unless parental consent is obtained to bill their insurer.”

Section 69-4.3(e) - Referrals

We have concerns about the proposed changes regarding referrals in section 69-4.3(e). 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 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 proposed regulations would require that, with parental consent, primary referral sources submit a specific referral form that contains “information sufficient to document the primary referral source’s 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, or the child’s level of functioning in one or more developmental areas, that constitutes a developmental delay 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, we have several concerns with this proposal. Our primary concern is that the proposed language does not state 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 regulations 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.

Too often, we find that children with significant developmental delays miss out on EI services even though their families have encountered primary referral sources, such as homeless shelters, child care providers, doctors, and other social service providers. The State should be working to train primary referral sources on EI, encouraging them to submit EI referrals when appropriate, and making it as easy as possible for them to do so.



We oppose the proposed changes to the referral process. If the Department decides to adopt these changes, the Department should, at a minimum make the following change to the second sentence of section 69-4.3(e):

“The referral form shall [contain information sufficient to document] state the primary referral source’s basis for suspecting the child has a disability or is at risk of having a disability.”

Thank you for the opportunity to submit comments. If you have any questions or would like any additional information, please feel free to contact me at (212) 822-9532 or rlevine@advocatesforchildren.org.

Respectfully submitted,

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