



# Advocates for Children of New York

Protecting every child's right to learn

August 31, 2018

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Re: Comments on Revised 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 currently prohibits the same provider from being approved as an Early Intervention (EI) service coordinator and an EI evaluator. This change would help ensure that children receive evaluations in a timely manner. We also support the following changes: 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 (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.

In addition, we are pleased that the New York State Department of Health made several revisions to the proposed regulations that align with the comments we submitted in August 2017. For example, we are pleased that the Department is

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maintaining the current definition of “multidisciplinary” as involving two or more professionals from different professions (revised 69-4.1(ae)); is rejecting the proposed exception that would have allowed parents to consent to bill an insurance company for EI services even though the insurance company would apply EI services to the insurance policy’s annual or lifetime limits (69-4.7(g)(3)); and is maintaining language about the need to appoint a surrogate parent only “after reasonable efforts to facilitate their participation” (69-4.16(d)).

However, we continue to have several significant concerns about the proposed amendments. We address these provisions below.

#### ***Section 69-4.3(e) - Referrals***

We are concerned 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 certainly benefits to having primary referral sources share information, with parents’ consent, about their concerns about the child being referred and while we would support regulations that encourage primary referral sources to share such information, where available and applicable, we have several significant concerns with this proposal.

Federal law and state law require the Department to develop “a comprehensive child find system” that ensures that eligible children in the State are identified, located, and referred for Early Intervention evaluations. 20 U.S.C. § 1435(a)(5); N.Y. Public Health Law § 2542. Yet, 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. As such, the State should be conducting



outreach to primary referral sources and training them on their obligations with respect to EI referrals.

We are concerned that the proposed regulations would make it more burdensome for primary referral sources to refer children for EI evaluations, making it more challenging for the State to comply with its “child find” obligations and making it more likely that children who need EI services will go without them.

First, the proposed regulations would make the referral process more burdensome for primary referral sources by requiring them to submit a written form. Several counties, including New York City, have referral telephone hotlines that have worked well to begin the EI process. Primary referral sources, from child care providers to staff at homeless shelters, are very busy with other responsibilities, and it may be easier and faster for them to make a phone call than to complete and submit a form. We worry that additional administrative requirements, for which they are not compensated, will cause them not to make needed EI referrals. In response to the concerns we raised in our previous comments, the Department responded: “While a municipality is not precluded from taking a referral by telephone, the call must be followed up with written documentation.” However, once the Early Intervention Program becomes aware from a primary referral source of a child suspected of having a disability, the municipality has an obligation under “child find” to reach out to the family regardless of whether the primary referral source follows up with written documentation. **We strongly urge the Department to maintain the option for a municipality to accept referrals by phone from primary referral sources.**

In addition, we are concerned that, under the proposed regulations, children suspected of having disabilities will not move forward to screenings and evaluations in cases where the EIO determines that primary referral sources failed to meet the vague standard of including “information sufficient to document” the concern. Federal law does not allow the EI official to reject a referral for containing insufficient information, but the proposed regulations could be misinterpreted as allowing such a rejection. The proposed regulations do not state the EIO’s responsibilities when the EIO determines that a referral form fails to contain “information sufficient to document” the concern. Primary referral sources, from homeless shelter staff to doctors to child care staff to social workers, are extremely busy with other responsibilities, and following up with them to get additional information about a child’s need for EI evaluations can be extremely time intensive. In response to our prior comments, the Department acknowledged that this proposed regulation could prolong the intake process. However, we fear that, in many cases, the proposed regulation will not only prolong the intake process, but stop the intake process altogether. Particularly given that the proposed regulations do not include any



guidance about the type of follow up that the EIO is required to conduct, we fear that after the EIO rejects a referral for lack of “sufficient” information, the EIO will return the referral form and, in many cases, will never receive additional information from the primary referral source, causing children to miss out on needed evaluations and services.

Prior to requiring a more burdensome process for primary referral sources, the Department should conduct and share an analysis of referrals by primary referral source. We would be interested to know, for example, how many EI referrals are currently received from staff at homeless shelters.

We note that, this year, as in prior years, the New York State Legislature explicitly rejected a very similar proposal to change the EI referral process, removing the proposed changes to the referral process from the 2018-2019 Health and Mental Hygiene Article VII budget bill. The Department cannot use regulations to circumvent the legislative process.

**We oppose the proposed changes to the referral process and ask that the Department maintain the ability of counties to accept EI referrals via phone.**

**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.”

#### ***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, this year, as in prior years, the Governor proposed such changes to state law through state budget legislation. However, this year, as in prior years, the New York State Legislature explicitly rejected this proposal to change the EI evaluation process, removing the proposed changes to the evaluation process from the 2018-2019 Health and Mental Hygiene Article VII budget bill. The Department cannot use regulations to circumvent the legislative process.

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 provide important information to the IFSP team and help the team determine the services that a child needs, **we urge the Department to maintain each child’s entitlement to a multidisciplinary evaluation.**

#### *Section 69-4.8 – Screenings/Evaluations*

We have several recommendations regarding the revised proposed amendments to the regulations regarding screenings and evaluations.

First, in the first sentence of section 69-4.8(b), for consistency and clarity, we recommend replacing the term “evaluation” with the term “multidisciplinary evaluation,” so that the end of the sentence reads “or conduct a[n] multidisciplinary evaluation to determine the child’s eligibility for the Early Intervention program.”

Second, we recommend removing the term “refer” from the screening/evaluation section of the revised proposed regulations, as the referral process has already taken place at this point in the process. The revised proposed amendment states that if the evaluator “does not refer the child to the Early Intervention Program” based on results of screening, the child may still receive a multidisciplinary evaluation upon parent request (69-4.8(b)) and that if, based on the screening the child is suspected of having a disability, the child, shall, with parental consent “be referred to the Early Intervention Program” and receive a multidisciplinary evaluation (69.4.8(b)(6)(i)). In this context, the term “refer” is confusing, as the child’s parent or a primary referral source has already referred the child to the Early Intervention Program at this point in the process. We recommend replacing this language with following language based on the language of the federal regulations, which do not use the term “refer” at this stage of the process (*see* 34 CFR § 303.320(a)(2)).

- 69-4.8(b): ... If the screening indicates that the child is not suspected of having a disability [evaluator does not refer the child to the Early Intervention Program based on results of screening], the child may still receive a multidisciplinary evaluation to determine eligibility for the program upon parent request.



- 69.4.8(b)(6)(i): If, based upon the screening, a child is suspected of having a disability, the child shall, with parental consent, [be referred to the Early Intervention Program and] receive a multidisciplinary evaluation to be conducted in accordance with the procedures set forth in subdivision (c) of this section.

In addition, there is a typo in the cross reference in section 69-4.8(b)(6)(i). Instead of referencing subdivision (c), the proposed regulation should reference subdivision (e), the subdivision that describes the multidisciplinary evaluation process.

Finally, the revised proposed regulations state in section 69-4.8(a)(2) that children whose eligibility for the Early Intervention Program is established based on a review of the child's medical records, without a multidisciplinary evaluation, are entitled to a multidisciplinary assessment and voluntary family-directed assessment, but do not mention that children whose eligibility is established based on a multidisciplinary evaluation are also entitled to these assessments. Federal regulations do not limit multidisciplinary assessments and voluntary family-directed assessments only to children who qualify for the Early Intervention Program *without a multidisciplinary evaluation*. The revised proposed regulations in section 69-4.8 are unclear and inconsistent about which children receive multidisciplinary assessments and voluntary family-directed assessments. We recommend that the Department clarify that multidisciplinary assessments and voluntary family-directed assessments are available to all children who are eligible for Early Intervention services.

#### ***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. This concern is amplified given the breadth of the proposed regulation. The proposed regulation would require referrals for each service in the child’s IFSP, even though doctors tend not to write prescriptions for many EI services, such as special instruction. Regardless of the difficulty a parent may encounter getting this documentation, the Early Intervention Program has a legal obligation to provide a child with the services authorized by the child’s IFSP.

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 69-4.16(d) – Surrogate Parents***

In describing the circumstances when the Early Intervention Official should appoint a surrogate parent when a child’s parent is unavailable, the Department originally proposed deleting the clause “after reasonable efforts to facilitate their participation and the child has no person in parental relation.” While we are pleased that the revised proposed amendments would maintain the clause “after reasonable efforts to facilitate their participation,” we continue to oppose the deletion of the remainder of the sentence (“and the child has no person in parental relation”).

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 who can consent to evaluations and provision of services. While section 69-4.16(c)(3) continues to state 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 “and the child has no person in parental relation” in section 69-4.16(d).**

Furthermore, while we understand that federal regulations require the lead agency to ensure the assignment of a surrogate parent “not more than 30 days” after determining that the child needs a surrogate parent, we recommend that state regulations set a shorter timeframe for the appointment of a surrogate parent. Under New York State special education regulations, the local educational agency must assign a surrogate parent for a school-aged student within 10 business days. 8 N.Y.C.R.R. § 200.5(n)(3)(iv). **We recommend aligning New York State EIP regulations with state education regulations by amending the proposed regulations to require that appointment of a surrogate parent be made within 10 business days after making a determination of the child’s need for a surrogate parent.**

#### *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.



*Finally, we also recommend the following changes:*

- 69-4.5(e)(1)(viii) - In the description of statements required in marketing materials, the proposed regulations include a statement that “authorization from the Early Intervention Official is required for an evaluator, or for an approved agency provider that employs or contracts with such an evaluator, to provide early intervention services to the child.” This proposed regulation contradicts the revised proposed regulation in section 69-4.11(7)(ii), which states that the evaluator who conducts an evaluation, or an approved agency provider that employs or contracts with the evaluator, shall *not* be prohibited from providing EI services unless the EIO documents that this course of action is not in the best interest of the child and family and provides a justification. As such, we recommend deleting the proposed language in section 69-4.5(e)(1)(viii) and maintaining the current language of this section.
- 69-4.8(a)(2) - The proposed language in this section appears to include an incorrect cross reference. Instead of referencing subdivision (h), the regulation should reference subdivisions (f) (multidisciplinary assessments) and (g) (family-directed assessments).
- 69-4.8(i)(5) - In the response to comments, the Department noted that it would be changing the term “partial evaluation.” While in certain places, the Department changed the term “partial evaluation” to “supplemental evaluation,” the term “partial evaluation” still appears in proposed section 69-4.8(i)(5). For clarity and consistency, we recommend changing the term to “supplemental evaluation.”

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](mailto:rlevine@advocatesforchildren.org).

Respectfully submitted,

A handwritten signature in black ink that reads 'Randi Levine'.

Randi Levine, Esq.  
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