Testimony

of

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before the

New York City Council Committee on Mental Health, Mental Retardation, Alcoholism, Drug Abuse and Disability Services

on

Oversight: Updates to New York City's Early Intervention Program

October 3, 2012
250 Broadway, 14th Floor Committee Room
New York, NY

Good morning Chairperson Koppell and members of the Committee on Mental Health, Mental Retardation, Alcoholism, Drug Abuse and Disability Services. I am Dr. Marie Casalino, Assistant Commissioner of the Bureau of Early Intervention at the New York City Department of Health and Mental Hygiene, and I am joined here today by Anthony Faciane, Senior Director for Revenue at the agency. On behalf of Commissioner Farley, we would like to thank you for the opportunity to testify.

The Early Intervention Program serves approximately 35,000 children per year under age 3 with developmental delays, who require developmental interventions such as speech therapy, special instruction, and physical and occupational therapy. The program incurs costs of more than $400 million per year and is the single largest expense for the Health Department, comprising more than 30% of the total budget.

The Governor's 2012-2013 budget introduced mandate relief to municipal governments with the stated goals of reducing administrative burden, providing fiscal relief to counties, and establishing a State Fiscal Agent under the authority of the State Department of Health. Establishing a State Fiscal Agent is expected to increase insurance revenues, achieve efficiencies, and improve accountability in fiscal operations statewide. Today I will describe its anticipated effect on DOHMH, the provider community, and most importantly the children and families who are or will be receiving services through this essential program.

During the transition period of January 1 through April 1, 2013, all provider agencies currently in contract with DOHMH will be required to enter into new agreements with the State Department of Health to deliver evaluation, service coordination, or early intervention services. Then, as of April 1, 2013, DOHMH will no

longer have the authority to enter into contracts with providers of early intervention services, with the exception of transportation and respite services.

In addition, all early intervention providers will be required to initiate claiming and receive payment through the State's billing system and Fiscal Agent for all services provided under the Early Intervention Program. Providers will replace DOHMH as the providers of record for billing purposes, not just for service delivery.

DOHMH continues to be responsible for the administration of key programmatic aspects of the Early Intervention Program, including accepting and managing referrals, designating the Initial Service Coordinator, and ensuring that evaluations and eligibility determinations for the Early Intervention Program are in compliance with State regulations and clinical practice guidelines. Most important, DOHMH continues to convene the Individualized Family Service Planning meetings and ensures that high quality service plans are developed for each child and family as required by State regulation.

In addition, as of April 1, 2013, DOHMH will have enhanced provider oversight authority. DOHMH may request that parents select a new service coordinator if that person fails to meet his/her regulatory and statutory responsibilities, or require that the service coordinator find a new service provider if services are not provided as authorized by the IFSP. The new law also expressly articulates that municipalities have the authority not only to audit but now to also monitor providers, including site visits, in accordance with State Department of Health regulations and guidance documents. DOHMH currently monitors early intervention provider agencies based on provisions in the municipal contract with providers and will continue to do so.

Although the 2012-2013 Early Intervention reforms affect the administrative and business processes of municipalities and providers, the family experience in the Early Intervention Program will not change. Children continue to enter the program via a referral to DOHMH, where the early intervention process begins with the assignment of the initial service coordinator. Families continue to choose their child's evaluator and ongoing service coordinator. Services continue to be authorized based on the individual needs of the child and family at an individualized family service planning meeting and are delivered at no cost to families.

Thank you again for the opportunity to testify. We would be glad to take your questions.

TESTIMONY TO THE NYC COUNCIL

Committee on Mental Health, Mental Retardation, Alcoholism, Drug Abuse *and* Disability Services
Wednesday, October 3rd, at 1 p.m. in the 14th Floor Committee Room
250 Broadway, New York, New York
Chairman G. Oliver Koppell

Testimony Of Leslie Grubler On Behalf Of ***The United New York Early Intervention and Related Service Providers with Parents as Partners,*** *Before The New York City Council Committee on Mental Health, Mental Retardation, Alcoholism, Drug Abuse and Disability Services.*

Good afternoon, my name is Leslie Grubler. I am a Speech-Language Pathologist and have been working as a sub-contractor in NYC Early Intervention since 1998. I am on the faculty of Queens College in their Department of Linguistic and Communication Disorders as an Adjunct Lecturer where I teach both *Introduction to Communication Disorders* to students entering the major of Speech-Language Pathology as well as *Child and Adult Language Disorders* to upperclassmen. I am also the Founding Director of the ***United New York Early Intervention and Related Service Providers with Parents as Partners*** with close to 30 years of Staff Training and Development experience and a background in Employee Relations and Labor Relations.

I would like to thank the City Council Committee on Mental Health, Mental Retardation, Alcoholism, Drug Abuse and Disability Services for extending an invitation to UNYEIP to provide testimony today and, for providing all us the privilege to address the issue of Embedded Coaching in NYC Early Intervention, as part of the democratic processes of the responsibility of government.

UNYEIP is a grassroots coalition of parent and professional volunteers, formed on April 15, 2010 to represent the needs of parents and their children, and providers inclusive of independent contractors and small agencies, as they move through the New York State Bureau of Early Intervention. UNYEIP charges no fees and accepts no membership dues. At present, we have nearly 2500 members statewide with approximately 30% residing in NYC. Since our inception, we have been at the forefront of advocating for meaningful reform. Our frequent visits to Albany inclusive of meetings with the DOH Bureau of Early Intervention, the Deputy Secretary of Health, James Introne, the Department of Budget, the Office of the State Comptroller as well as our frequent presentations to the State Early Intervention Coordinating Council underline our commitment to ensuring that decisions made that impact our state's most vulnerable children are made with *minimizing and/or eliminating* **ANY** unintended consequences. Our mission has always been to provide policymakers with vital input that they often do NOT readily have, that is, data from the primary stakeholders -- those on the frontlines, both parents and providers. *[See Appendix #1 for Mission Statement].* In order to appropriately share our position on this initiative of NYC DOH MH EI, it is important that we frame it in the context of the following: IDEA Part C, the structure of NYC DOH MH EI, a brief but relevant history of EI in NYC as well as the initial implementation of Embedded Coaching, relevant definitions, and summary recommendations.

i. Responses to a UNYEIP survey issued last week are voluminous and 75 pages in length. Our providers have pointed to both concern and also meaningful possibilities in the utilization of Routines-Based Intervention if managed appropriately. Given the aforementioned points, UNYEIP has no confidence, however, that this initiative will be managed productively in the future. I will make this document available to the council upon request with anonymity of provider names if requested.
j. Upon review of all literature of Embedded Coaching offered by NYC DOH MH, it is apparent that it is an adapted version of that found in the literature and, any attempt to apply the research to an adapted rather than a pure program would be false and, therefore, not be considered "scientific-based research" as is required by IDEA Part C. **[Appendix #4]**

IV. Definitions of Independent Contractor

a. Federal Definition via the IRS: You are not an independent contractor if you perform services that can be controlled by an employer (what will be done and how it will be done). This applies even if you are given freedom of action. What matters is that the employer has the legal right to control the details of how the services are performed."
b. NYS Definition via the Department of Labor: "Independent contractors are free from: a. Supervision b. Direction and c. Control in the performance of their duties."

V. SUMMARY and RECOMMENDATIONS

1. The title "Learning Collaborative" is a misnomer for this initiative. All reports from those attending the 'collaborative' have reflected that **trainers are dismissive with an expectation of non-democratic compliance.** Ie. Feedback provided in sessions by participants has NOT been responded to democratically or used to assist in shaping the program to **this** municipality's BEI.
2. An IFSP in NYS and in the US must be **individualized** to meet the specific needs of the child. NYC is attempting to apply a cookie cutter in the treatment of children in Early Intervention. NYC is seeking to implement a comprehensive approach to working with every child in Early Intervention which does not comply with IDEA Part C and the nature of the IFSP. NYC DOH MH EI has implemented a plan in the largest municipality in the state, impacting 37000 families WITHOUT consultation or input from frontline providers and without any beta-testing.
3. **Frontline providers in NYC Early Intervention are independent contractors. They cannot be told by NYC or their contracting agency by Federal and State Law "HOW" to do their jobs.** Providers from each discipline have been trained, educated and licensed in their professions. Is NYC DOH MH BEI also attempting to operate ABOVE and/or AROUND the law? UNYEIP will NOT stand by idly.
4. Innovators in Embedded Coaching as noted have provided statements that negate the manner in which implementation in NYC is operating which further diminishes the credibility of the program.
5. NYC DOH MH began the implementation of Embedded Coaching without consensus from its Provider Agencies or its frontline providers of supportive services. This explains the necessity to offer agency "incentives" for engagement. That is, it is seemingly **NOT** supported by the provider community.
6. Routines-Based Interventions have been in existence for nearly a decade and have value. There are many meaningful interventions utilized by providers in Early Intervention at present. Choice must be valued and has been the cornerstone of Early Intervention Services in NYS.
7. Professionals who work in NYS Early Intervention are licensed by the state in their Professional Discipline. There are NOT licensed as an Interventionist.
8. NYC DOH MH must apply for CEU status from each National Provider Association to ensure that Providers of Support Services receive appropriate Continuing Education Credits for licensure for any future training opportunity they would like to offer the independent contractors in NYC Early Intervention.
9. Besides all important points mentioned, the lack of support that this initiative is garnering has everything to do with how and when this initiative was implemented by NYC DOH MH. This NYC BEI must increase its awareness of organizational psychology and implement change not at a time when providers are reeling from rate reductions and reductions in caseload, but with discussion, consultation, and compromise with frontline providers inclusive of families and providers. NYC must begin to initiate ongoing meaningful

consultations with frontline providers to achieve meaningful, cost-effective reform ie. initiate the effort to open the dialogue rather than a non-democratic top-down approach.
10. While NYC DOH MH has indicated that the decision to implement Embedded Coaching has NOTHING to do with cost-savings, their alignment of reduced service authorizations with this initiative as well as their financial documents issued to the Assistant Commissioner in July of 2011, reflect the opposite.
11. Consistently throughout our Survey issued last week, providers report that incorporating and training parents and/or caregivers (for parents who cannot be home with their children) has been ongoing since the inception of Early Intervention in 1993 in NYS.
12. Consideration should be given to using this methodology as an introductory training for new independent contractors because of its emphasis on family involvement but not as a pervasive methodology.
13. Choice is critical in the therapeutic process from the perspective of both parents and providers. The imposition of this initiative has not allowed for this democratic freedom. The NYC DOH MH BEI must gain skill in consensus-building.

APPENDIX

I. UNYEIP Mission Statement:

a. Ensure that children with special needs, ALL children, from ALL religious, cultural, and socio-economic groups, of NYS are prioritized
b. Ensure that the children with special needs of NYS Early Intervention and Special Education receive not only individualized services but frequency and duration of services that are meaningful in relation to their delay or disability
c. Ensure that ONLY those children who are ELIGIBLE to receive services are those that do receive services
d. Improve communications amongst the stakeholders of New York State Early Intervention and NYSED
e. Improve transparency in Governmental Relations with the Bureau of Early Intervention and NYS Special Education statewide
f. Encourage participation in the Statewide Early Intervention Coordinating Council and the Local Early Intervention Coordinating Councils
g. Enable collegial sharing amongst professionals
h. Enable support amongst family and caregivers
i. Develop meaningful relationships with our governmental representatives and New York State Legislators
j. Encourage Lobby Day Involvement of all members inclusive of Parents and Professionals
k. Coordinate Rallies in support of children with special needs as needed
k. Enhance communication throughout New York State between Agencies, Municipalities, and Independent Contractors
l. Preserve and protect the provision of services to children with special needs so that it is maintained as the Premier State in NYS Early Intervention

2. March 2012 Minutes of the LEICC Meeting:

"Linda Silver, Chair, Programs and Services Committee
• The Programs and Services Committee's mission has been to focus on Embedded Coaching in service provision. Its focus has been on changing session and progress note forms to reflect

Embedded Coaching principles, including functional outcomes, natural routines, observations, and learning activities.

• The Committee's next topic will be how Provider Oversight will monitor providers on their use of Embedded Coaching.

• Another goal of the Committee is to develop literature about Embedded Coaching for parents.

• Nancy Calderon-Cruz remarked that a one (1) sheet session note is of great concern and asked if the form can have two (2) session notes per page.

Embedded Coaching

• BEI continues to expand its efforts to promote Embedded Coaching, the standard of care, and has commenced Phase Two of the Learning Collaborative. Phase Two will allow agencies to train more interventionists. There will be two (2) content trainings in June and July. BEI is working on a stipend for agency participation."

3. From Embedded Coaching Literature of NYC DOH MH:

RESPONSIBILITIES of the INDIVIDUAL PARTICIPANTS (To Be Signed By the Interventionist)

1. Fully participate in the program for the duration. Attend all four (4), half-day content-based sessions, as well as three (3) intervention observations with the practice mentor, and complete those observations and reflections.
2. Participate in nine (9) small group trainings/discussions, as directed.
3. Meet with the practice mentor for follow-up and feedback, as directed.
4. Allow the practice mentor to complete pre and post-Performance Assessments and review a summary of the finds for the purpose of individual professional growth and development.
5. Participants will not share information about the performance of any other participant in the Learning Collaborative with anyone outside the Learning Collaborative.
6. All confidentiality requirements regarding families in NYCEIP are applicable to the Learning Collaborative.

4. ON SCIENTIFICALLY BASED RESEARCH FROM IDEA PART C

IDEA PART C – on Scientifically Based Research -- Section 303.32 provides that scientifically based research has the meaning given the term in section 9101(37) of the ESEA.2 2 The term "scientifically based research" under the ESEA—

(A) means research that involves the application of rigorous, systematic, and objective procedures to obtain reliable

and valid knowledge relevant to education activities and programs; and (B) includes research that—

(i) employs systematic, empirical methods that draw on observation or experiment;

(ii) involves rigorous data analyses that are adequate to test the stated hypotheses and justify the general conclusions drawn;

(iii) relies on measurements or observational methods that provide reliable and valid data across evaluators and observers, across multiple measurements and observations, and across studies by the same or different investigators;

(iv) is evaluated using experimental or quasi-experimental designs in which individuals, entities, programs, or activities are assigned to different conditions and with appropriate controls to evaluate the effects of the condition of interest, with a preference for random-assignment experiments, or other designs to the extent that those designs contain within-condition or across-condition controls;

(v) ensures that experimental studies are presented in sufficient detail and clarity to allow for replication or, at a minimum, offer the opportunity to build systematically on their findings; and

(vi) has been accepted by a peer-reviewed journal or approved by a panel of independent experts through a comparably rigorous, objective, and scientific review.

(20 U.S.C. 7801) **********

Advocates for Children of New York
Protecting every child's right to learn

Testimony to be Delivered to the New York City Council Committee on Mental Health, Mental Retardation, Alcoholism, Drug Abuse, and Disability Services

Re: Early Intervention

October 3, 2012

Thank you for the opportunity to discuss the New York City Early Intervention Program's embedded coaching model. My name is Randi Levine, and I am an attorney and Project Director of the Early Childhood Education Project at Advocates for Children of New York. For more than 40 years, Advocates for Children has worked to promote access to the best education New York can provide for all students, especially students of color and students from low-income backgrounds. Every year, we help thousands of parents navigate the Early Intervention, preschool, and school-aged special education programs.

Research shows the efficacy of engaging parents in their children's learning beginning at an early age. Teaching parents how to work effectively with their infants and toddlers when therapists are not present can have a lasting impact on a child and can ease a family's life by giving the parent techniques to help with a child's daily routines. However, embedded coaching must enhance services provided by trained professionals, not substitute for them.

We are concerned by calls we have received from parents stating that the New York City Early Intervention Program has used embedded coaching as a justification

for reducing services provided by professional therapists. For example, we heard from the parent of a young child who had severe delays in his communication, cognitive, fine motor, and gross motor skills. The child had started receiving Early Intervention services in New York City prior to the implementation of embedded coaching. His family moved out of New York City temporarily and then returned a few months later. The child's new Early Intervention evaluations showed that he continued to have the same significant delays he had when he left. Therefore, his parent was confused when Early Intervention drastically reduced his services.

Contrary to the recommendations of the child's evaluators and doctors, the Early Intervention Program decreased his occupational therapy from three thirty-minute sessions per week to two sixty-minute sessions per month. The Early Intervention Program decreased his physical therapy from two thirty-minute sessions per week to *one* sixty-minute session *per month*. In total, his services were reduced by thirteen hours per month.

What had changed? The Early Intervention Official Designee explained to the parent that there was a new policy whereby EI would provide fewer services and parents would fill in the gaps. This parent was concerned that she had no training in special education or in speech, occupational, or physical therapy, but was expected overnight to be able to provide all of these services to her child. She was eager to learn techniques for working with her child, but did not understand how one physical

therapy session per month could prepare her to provide physical therapy to her child for the other 29 days. Given how young her child was, his physical therapy needs would likely change over the course of the month, but she would have no interaction with the therapist. Furthermore, her son could not tolerate an hour-long therapy session at such a young age. We have also heard concerns around cultural sensitivity, as well as parents' work schedules.

While the implementation of embedded coaching may be well intentioned, it has emerged at a time when the state has slashed the Early Intervention budget. State funding for Early Intervention decreased by nearly 30 percent from Fiscal Year 2010-2011. With such a focus on cost containment, it is no surprise that Early Intervention officials would use embedded coaching as a justification for reducing services.

The City Council should continue to monitor the implementation of embedded coaching as this is a model that we support when implemented correctly. We also urge the City Council to ensure that there is adequate funding to provide appropriate Early Intervention services. By providing services at a time when children's brains have the most elasticity, Early Intervention services provide the best opportunity to address developmental delays, saving taxpayers money in the long run.

Thank you for the opportunity to speak with you today. I would be happy to answer any questions you may have.

Dear members of the Council.

My name is Paola Jordan, I am a parent of twins (boy and a girl) who received EI services since an early age and that right now are in CPSE. I am also a member of the SEICC, however, today I am presenting my testimony as a parent who experience firsthand all the benefits of EI for over 3 years.

When I received the email from Ms. Queen about this public hearing, it calls my attention the way it was written, specifically the following paragraph:

*Under the older **service model**, therapists provided an array of services in the home during a certain number of visits per week*

My kids stopped receiving EI services on august 2012 and I wasn't informed that there was a "new service model" called "embedded coaching" that was schedule to begin on july 1, 2011.

I looked for the Official Early Intervention Program Definitions and I got the following:

69-4.10 Service model options.

(a) The Department of Health, state early intervention service agencies, and early intervention officials shall make reasonable efforts to ensure the full range of early intervention service options are available to eligible children and their families.

(1) The following models of early intervention service delivery shall be available:

(i) **Home and community based individual/collateral visits**: the provision by appropriate qualified personnel of early intervention services to the child and/or parent or other designated caregiver at the child's home or any other natural environment in which children under three years of age are typically found (including day care centers and family day care homes).

(ii) **Facility-based individual/collateral visits**: the provision by appropriate qualified personnel of early intervention services to the child and/or parent or other designated caregiver at an approved early intervention provider's site.

(iii) **Parent-child groups:** a group comprised of parents or caregivers, children, and a minimum of one appropriate qualified provider of early intervention services at an early intervention provider's site or a community- based site (e.g. day care center, family day care, or other community settings).

(iv) **Group developmental intervention**: the provision of early intervention services by appropriate qualified personnel to a group of eligible children at an approved early intervention provider's site or in a community-based setting where children under three years of age are typically found (this group may also include children without disabilities).

(v) **Family/caregiver support group**: the provision of early intervention services to a group of parents, caregivers (foster parents, day care staff, etc.) and/or siblings of eligible children for the purposes of:

For the Record

(a) enhancing their capacity to care for and/or enhance the development of the eligible child:

(b) providing support, education, and guidance to such individuals relative to the child's unique developmental needs.

Base on the previous definitions, I see that "Embedded coaching" is not a "service model". I can think of this rather to be an "approach" that can be an appropriate one for some families and children but not all of them. It is not a one-size fit all approach. Also, I think is appropriate to indicate what is the research done that supports this "approach".

I believe the definition of embedded coaching that is being used ...*the embedded coaching model has therapists* ***train parents to provide services*** *so that they are incorporated in the child's day throughout the entire week...* promotes a compliance role for parents and suggest that the service system can save money if parents learn how to be service providers, which the majority of us are not, we are just parents trying to deal with the reality of having a child with special needs that need all the help and emotional support that we can offer as parents with the support of a group of professional that can provide them with the services that they need to reach their potential.

I strongly believe that families needs to have the right to address their priorities for their child´s development by learning ways to incorporate strategies and activities into our daily routines that will foster our child´s development without adding additional stress/burden to the family. My family achieved this through a monthly team meeting and co-visits (for OT and PT) that did not took away precious therapy time from my kids.

Now, I want to ask you how embedded coaching will help kids that are in a preschool/child care setting, foster homes, shelters? The kids with just one parent in the home that need to work all day to provide for the family?

As I said earlier, "embedded Coaching" is not a one-size fit all approach and needs to be discuss in more detail, supported by scientific evidence that it works.

Thank you,

Paola Jordan

My name is Nellie Velez and I'm the Consumer Vice President of the Bronx DD Council and a parent.

I think Embedded Coaching can produce great results if implemented correctly. I applaud the NYC Bureau of Early Intervention for wanting to introduce best practices that will yield better outcomes for children and families. However, the implementation can be improved by paying attention to the following issues:

- **Preparation for Embedded Coaching**: Families should be better prepared from the start of Early Intervention about family participation in the services. Embedded Coaching entails coaching the family to work with their child. This is still, sometimes, unclear to families when interventionists start services. A large campaign should be introduced in NYC to educate families regarding the change in philosophy. For years, parents have learned to expect that when the "professional" arrives at the home, they would work with the child in order to make the child "better". Some families question the interventionists that don't separate the child but instead ask the family to participate in the session.

- **Not all interventionists have been trained**: Only some interventionists have been trained on Embedded Coaching and there is not a clear timeline for when all NYC interventionists will be trained. Some interventionists that are practicing embedded coaching have been asked to be taken off cases because families are still seeing therapists working with the child in isolation. Interventionists should work on all Functional Outcomes. Many interventionists are still resistant to this since they may never have gone through a formal training on Embedded Coaching. The parents, also, need to be trained in this new philosophy. The children remain in Early Intervention through their 3rd birthday and families need to understand that they make the biggest impact on their children's lives. This method of delivering services for families needs to be explained to the family so they understand that they will be a participant in this new philosophy. The family needs to understand that they will be a participant and be "hands on" with the therapist.

- **IFSPs sometimes do not reflect Embedded Coaching**: IFSPs should focus on family priorities. They should include daily routines, and goals should be compatible with the goals, values, and beliefs of the families in order to successfully implement Embedded Coaching techniques. The service authorization model needs to better align with Embedded Coaching. NYC is now approving less units of service per child since the expectation is that parents will teach their children during everyday family routines and activities. I agree with that. However, in order for an interventionist to coach a parent and participate in family activities (such as meal times) trust and rapport must be established. It is now normal for NYC to approve services "2 times a month". It is unrealistic to expect a family to trust a stranger that they see so infrequently! NYC should explore ways to approve services in a way that will foster collaboration between family members and interventionists. Perhaps services can be approved with a higher level of frequency in the beginning and decreasing the frequency at the six month review depending on the strides that have been made with the family and the child.

- **Co-treatment**: There is no option in NYC EI to conduct co-treatment sessions. In order for Embedded Coaching to succeed, the family should dictate the mode of service delivery. If a parent of an Autistic child wants help during the child's birthday party for example, this is not possible right now since billing rules prohibit more than one interventionist in the home at a time. NYC should create more flexibility in the service delivery system by approving more "co-treatment" sessions. This will give not just the therapists teaching the parent but it gives the therapists an opportunity to present as a cohesive front when interacting with the family. The family will feel that the therapists have the best interest of the child and lend an opportunity for families to work better with them.

- **Continuity from beginning to end**: It's important for a family to have consistency from evaluation to age out. In other states where embedded coaching is done well (look at CT which has a great program) utilizing a clinical team for evaluation, service coordination, and act as an EIOD to assist in the creation of a cohesive plan for the family is the norm. NY is moving further away from this model. NYS wants to prohibit the evaluating agency from also being an option for the family to choose as a service provider. Although many families choose services from the agency that evaluated the child, they do so not because they are coerced. They do so because they form a bond with the evaluation team. If the family has a positive experience with the evaluation team, it is only normal for families to want to, also, receive services from that same agency. Let's not forget that most families in the Early Intervention system are still dealing with all the issues associated with finding out "your child is not perfect." Asking families to develop a new bond with a different agency will only add to their sense of being overwhelmed. As a parent of children with disabilities, I ask the City Council to petition Governor Cuomo to move away from this non- cost saving measure. Government changes should be adapted to help families in need, **not** to add to their stress levels. Let the families make their own choice and don't take that away from them. The City Council needs to stand up for NYC families and hold Albany accountable. While NYC is being a trail blazer by introducing Embedded Coaching, the NYS Bureau of Early Intervention will undo all that by creating chaos in the system and eliminating family choice!! As a parent, a Service Coordinator and proud advocate, I ask this Council to request a moratorium on this issue. Beginning in January providers will not have contracts with individual counties in NYS. All contract and payment responsibilities will lie in Albany. This is not the time to introduce a change to the system which will not save money but will have devastating effects on the service delivery system. The NYC Council should request that the Governor's office create a task force to explore the creation of a coordinated statewide Early Intervention Program. I would be more than happy to sit on a council for the betterment of the families. As elected officials, it is your duty to safeguard the rights of vulnerable citizens. I think parents of infants and toddlers with disabilities are in a very vulnerable stage in their lives. Please be a voice for the children and families of NYC and stop Albany from disrupting this very essential program.

In section 303.700(b)- (State Monitoring and Enforcement) of Part C Regulations 2011, the primary focus of the state's monitoring activities must be on

1. Improving early intervention results and functional outcomes for all infants and toddlers with disabilities, and
2. Ensuring that EIS programs meet the program requirements under Part C of the Act, with a particular emphasis on those requirements that are most closely related to improving early intervention result for infants and toddlers with disabilities.

"Embedded Coaching addresses child development outcomes through a shift from direct, hands-on "treatment" to supporting families through collaboration and consultation."

From the frontline of ongoing service provision, the feedback relating to the implementation of Embedded Coaching has elicited overwhelming outcry of indignance by most parents and providers. The majority of parents on my caseload have expressed anger with confusion as to the purpose of forcing them to work with their child while (the therapist) sits down and watches: apparently only getting help for their child through suggestions and once in a while incidental demonstrations by the therapist of what is expected. Parents have seen noticeable improvement in their child when specialized techniques were successfully applied by the therapist and wondered how they could be expected to promote the same progressive results for their child.

Parents expressed satisfaction and improved determination to further challenge their child more often after collaborative intervention where the child struggled less and tolerated graded difficulty using routine tasks. Parents showed increased eagerness to volunteer updates on how they have changed their child's performance patterns in between sessions, as their understanding of and ability to implement effective motor responses strengthened through collaborative therapist-caregiver efforts.

A parent has an integral role of providing first hand details of their child's performance patterns and their concerns with skill deficits as their child shows frustration, task avoidance or limited responses and predictable preferences during routine activities. Parents readily voiced that they are happy to collaborate but not substitute or replace a highly skilled, specially trained and experienced therapist. Working together, the parent and therapist can use independent observations of the child's responses through the trained eye of a therapist and parent respectively, to most effectively formulate functional short and long term objectives to address the underlying triggers causing the developmental delay in function.

Therapists utilize evidenced-based practice, in-depth knowledge of developmental milestones and strong, balanced clinical reasoning to analyze the performance and patterns of routine functional task engagement of the infant or toddler in their natural environment. Throughout the therapeutic process the therapist is mindful of

any cultural relevance's while exposing the child to the mainstream culture of this educational system. Body function and structures encompassing neuromuscular, sensory, visual, perceptual, cognitive and mental functions; along with cardiovascular, digestive and integumentary systems are critically assessed for level of impact on child's ability to successfully traverse age appropriate tasks encountered.

Working directly with an infant or toddler through hands-on approach allows the therapist to most accurately identify internal and/or external factors limiting functional performance and impacting the development of age appropriate skills. Direct one-on-one service provision is essential ,for example, to ascertain abnormal high or low muscle tone, active and passive range of motion in all extremities, spasms, tender to touch muscle tissue, subtle compensatory positioning of proximal or distal joints, changes in respiration, variations in body temperature(during therapeutic handling), any new bumps especially to head, presence or absence of reflexes, teeth grinding, laxity in joints ,sensory defensive issues and soft tissue contractures. Identification of any or a combination of these restricting movement and exploration in the child's natural setting is critical in applying function enhancing therapeutic interventions.

Analyses with subsequent advancement of functional outcomes through direct method of therapeutic intervention, provides hope to the most important stakeholder in the child's life...the parent... of embedded life enhancing abilities possible for the infant or toddler. Parents can use facilatory techniques observed and educated on, along with their self initiated strategies, to always raise the bar for their child's ultimate goal of participation in mainstream education with their peers.

Anne Bridgelall, OTR/L
NYC Regional Coordinator, UNYEIP
(917) 696-4536

My name is Lynn Decker, and I have two sons with Autism Spectrum Disorder. Evan is now 16 and Justin is 14. One or both of my sons were receiving Early Intervention services from late spring 1998 when Evan was diagnosed through August 2001 when Justin began preschool. They have subsequently had a long journey through NYC special education placements and OPWDD funded programs.

So my Early Intervention experience is in some respects old news, but since around 2000 I have coordinated a parent support group with a focus on Children with Autism Spectrum. In 2005 I created an e-mail 'listserv' to complement that group, and today only the listserv is active, but it has more than 300 subscribers. This list is a valued resource for perspective, resource finding, and a chance to know others who are traveling a similar road. Through this list, I've been able to stay in touch with the issues families of young children similar to my own are encountering in the EI service system.

Parents and guardians of children with ASD who live in the NY Metro area can become members of the group, which is called
SpectrumParentNYC@yahoogroups.com

New York City launched of EI services in 1993, which was mandated by the IDEA amendments of 1986, though I understand there had previously been a city program called Infant Enrichment. By the time my household came on the EI scene, New York City was offering intensive behavioral therapies to children with Autism and related disorders under a consent decree. ~~So~~ I learned early in my career as a special needs parent to appreciate that that access to things my family needed were the result of a fight by families who came before us. So I am here today to advocate that the robust intervention program provided to my children exists for a young child diagnosed today.

therefore

I have testified elsewhere on the profound impact EI services had on our family, and though my children were not among those who responded most robustly to this type of therapy and have moved on to less restrictive settings and study at grade level, I believe that early intensive instruction made a huge difference in their ongoing engagement with the world, and in my capacity to believe that something effective could be done to help them learn skills and be in the community without stigma.

And around the time Justin was aging out of EI, NY State issued practice guidelines for young children with autism that carried forward some of the key elements of that consent decree and favored some types, specifically ABA, over others such as Floortime, RDI, & play based therapies. Those practice guidelines are scheduled to be revisited and revised next year, and that's proper, as the evidence base has grown considerably over a decade. EC doesn't seem to be as agressively for this group.

My overarching concern about embedded coaching, the approach that is under discussion today, is one that I've had many times in many venues – will it be

executed in New York City in a fashion that is faithful to the design, in this case crafted by a national expert, such that any reasonable person would see the connection to evidence based practice. Or, as is so often and so tragically the case, will this new way of conducting business merely be a cover for achieving fiscal targets.

I also am concerned that this sort of approach with a focus on generalization and natural contexts, will be offered essentially as a substitute for, rather than an adjunct to, previous practice. And I'm aware that the extreme fiscal demand resulting from improved screening and awareness of Autism is a key driver of increasing service volumes and costs. But I understand that the state practice guidelines are treated as though they have the force of regulation.

Suggestion to the committee that in carrying out its oversight they ask the department to present data on total service volumes before and after the introduction of embedded coaching.

In closing, I want the committee to consider that Early Intervention is expensive, and growing in expense, because there is a growing need for such services, and to look to the growing national evidence base that early services reduce intensity of service needs down the road in the school and community as children mature.

In more soft form, I would applaud embedded coaching if it provides endorsement from what I experienced as a best practice in my household, though we were conscious that what we did was not to regulation. Embedded coaching happened before However, I'm worried that this method will provide cover for an overall lowering of expectations

Testimony for the New York City Council
Committee on Mental Health, Mental Retardation, Alcoholism,
Drug Abuse and Disability Services
Hearing on Early Intervention

Wednesday October 3, 2012

My name is Nina Lublin, and I am representing Resources for Children with Special Needs, Inc. (RCSN), a federally funded PTI (Parent Training and Information) Center where I have worked as the Early Childhood Specialist since 1993.

In 1993, in New York State, 4,000 or so families of infants and toddlers with disabilities and special needs were expected to start the new Early Intervention program, but over 20,000 did. Since that time, I have served on state and local committees, helped develop training curriculum and conducted trainings for NYC parents, caregivers and professionals both through the state's EI training initiative and on behalf of RCSN.

I was also a member of the NYC LEICC for about 10 years. Within that capacity, I was part of the group that provided input and feedback on the pre-"embedded coaching" approach, Families as Partners, and subsequently became an outspoken critic of key aspects of its implementation. I am concerned today about the continued roll out of the current embedded coaching approach to more and more families. We are here to advocate for further consideration of the research and outcome data to date, and remind the NYC EI program that differentiating individual service authorizations based on true child need and ability are essential.

New York City's parents and caregivers have many different points of entry, skills, and abilities to "become their child's therapist". Infants and toddlers have a very wide range of disability. For some babies, "more is better", and the current approach seems to start with the assertion that "less is better" or "less is more". Families must participate in IFSP meetings with a full understanding of the intent of embedding coaching, and have the opportunity to access more intensive services when they are needed. Families must have a complete explanation and orientation when services begin so they will feel confident about their role and engagement in the process. The age of the child and probable duration of EI services should be considered before beginning this methodology.

There is, after some 40 years of research, great consensus that "early intervention works"! We are at a unique point where there are so many infants and toddlers in need of services at the same time as the newest research- and evidence-based approaches are in demand and are required. Each eligible child's IFSP must be better tailored to their individual abilities and needs, with the authorized services, therapies and methodologies as well as frequency and duration appropriate to their specific disability.

If a child requires a particular intervention 3 or 4 times a week for 60 minutes to start – provide it. If the family needs a particular type of coaching or methodology 3 or 4 times a week – authorize it. For so many of our families, starting with more and eventually requiring less should be automatic – and not a challenge -- at the first IFSP meeting. An infant who is medically fragile with developmentally disabilities and an overwhelmed mom will require more services

initially, while a 2-year old with significant behavioral and communication disorders whose parent is at an Early Head Start program will require fewer and different services.

The most rigorous, recent analysis of Early Intervention research by Harvard University's Center on the Developing Child, led by Dr. Jack Shonkoff, reinforces the fact that "intervention is likely to be more effective and less costly when it is provided earlier in life rather than later". The correct investments and more appropriate services now, at this very early age, can decrease the need for special education and other services when the child is three and later when the child is five-years old. It should continue to be the city's priority – "the earlier the better".

Thank you for your consideration of these remarks.

Celebrating 125 Years
Innovation for a Lifetime

10/3/2012

Thank you for the opportunity to address the Council regarding Early Intervention. I am the Director of Family and Clinical Services at University Settlement and have been a part of Early Intervention in NY since its inception , first as a social worker, and then as a Director of Programs. I am also a sibling of a developmentally disabled adult who is employed in the private sector and lives in a supportive apartment program. I am currently enrolled in a NYC training to be a practice mentor to therapists practicing embedded coaching.

We have always known that Early Intervention works best with families who are engaged and involved, and when therapists use their skills to assist families in their daily routines by suggesting strategies and solving problems. We know that children learn best when they are engaged in pleasurable activities that are meaningful to them, and that mastery of skills which promote independence is our mission.

The reality is that Early Intervention includes children with surmountable delays who will eventually be discharged as well as children with significant or profound delays including paralysis, brain damage, and genetic syndromes. All of them will benefit from the embedded coaching model, but some also need a more intensive, skilled, hands-on therapy program. Parents vary in their ability to learn and practice, and their availability to attend sessions and learn. Many children are in daycare, and while embedded coaching should and can be done with caregivers, the staffing patterns really don't support this.

Early Intervention is a program that has large and small agencies, experienced and new therapists. Embedded coaching is a paradigm shift, and is an ambitious attempt. It requires training, coaching and monitoring. It requires case conferencing, and individualization. Regulation changes alone will not accomplish the desired result, and if poorly implemented, embedded coaching will resemble a reduction in services wrapped in rhetoric.

Early Intervention is a meaningful, effective program and should embrace new ideas and evolve. There needs to be adequate funding to ensure that the actual practice lives up to the promise. Parents and children deserve our best. We can only do our best with a well trained and supervised workforce. The current model does not go far enough in providing this support. In a time when we are all asked to do more with less, this is an overly ambitious shift with potentially dire consequences. In a more perfect universe, we would more adequately fund early childhood programs to ensure that parents, teachers , caregivers and therapists were prepared to implement well what we already know works.

Bonnie Cohen,LCSW

For more information contact:
Bonnie Cohen, LCSW, Director of Family and Clinical Services
University Settlement ■ 184 Eldridge Street ■ New York, NY 10002
Phone: 212-453-4510 ■ Email: bonnie@universitysettlement.org

My name is Leslie Ann Caraballo. My son currently receives services through Early Intervention and will do so until December. I am here today for the next generation of EI parents and children, because while there is a need to reform EI to some extent, the proposed plan of substituting direct therapeutic services with only parent training is NOT the answer, and will cost the city more in the long run than perhaps the DoH and this council realize.

My son was diagnosed at 2 ½, what is considered "late," in the context of Early Intervention. Although it was recommended that my son receive an immediate battery of therapy—ABA (Applied Behavioral Analysis), Speech, Occupational, and Physical therapies—it took four months to get all of those services, and only after I spent a great deal of time advocating for them. From Feb-June, I was on the phone, requesting further evaluations, following up with my coordinator, and personally seeking an OT, because there is a shortage of OTs in my area.

As a parent, I was in a good situation, having a job that paid me well, and offered a flexible schedule. And even with those resources, advocating and treating my son was and is overwhelming. It took all of my time, every minute of every day. I attended as many therapy sessions as I could, read almost every possible book to learn how to work with my child. And in all that time, I often thought of other mothers, like my mom who worked for the city for 30 years, who did not have resources I had. A master's level education and a lot of flexible time to do the things I needed to do for my son. What about the mom working 9-5, or longer? The parent with multiple children, I only have one. Elderly grandparents that watch over children during the day, but who would have great difficulty getting down on the floor with their grandchildren to administer, much less learn, new therapies. Or who hold cultural beliefs that go against the very idea of intervention.

Most therapists are highly educated professionals. They hold Masters degrees. It boggles my mind that the DoH thinks that effective therapy will come from therapists imparting several years of training to a varied population of parents at different educational levels and with different employment situations, in a few hours at a time. Speech, OTs and PTs are required to take Anatomy, Physiology, Neuroscience, Psychiatry, and Neuromuscular studies among others. These are 2-3 year MA and doctoral programs. Most ABA's are special education teachers, holding Mastres degrees in addition to their prescribed ABA training.

Family training is a very important part of effective EI therapy, in fact I do believe it should be given more emphasis, but it is a component, a piece of a whole. Not the whole. No parent ever wants to be in this position. To need outside help so that their children may become functional members of society. The silver-lining of this situation is that better outcomes can be had with effective, early, professional intervention.

Eliminating direct therapy service would be detrimental to the children, their families, the therapists, and to the city. The children that do not receive effective therapy at the earliest years will only continue to be a burden on this city—on the educational system

that will struggle to accommodate children that are not ready for the classroom, on the mental health system that will have to deal these teens and adults whose diagnosis worsen instead improve—the years between birth and 3 are vital in mental development and it becomes increasingly difficult to help a delayed child after the age of five, and finally on city residents and the criminal justice system as studies show that children with unchecked behavioral problems become adults with behavioral problems that lead to crime and incarceration.

To end direct therapeutic services would be at best, irresponsible and at worst, criminal.

Thank you.

Leslie C.
Mother, Early Intervention
maileslie@yahoo.com

THINGS THAT EARLY INTERVENTION **REALLY** NEEDS

1.) TRANSPARENCY. Accessible information. Early Intervention is an opaque agency that does not volunteer information, but hides vital information on obscure web pages and information packets. EI needs it's own website, with clear information, including an expanded section on mediation and impartial hearings.

2.) FUNDING. Further avenues of finance need to be explored so that the EIOD can stop treating parents like stick-up thieves when inquiring about services for their children. This can include outside fundraising from the private sector, more responsibility from Insurers, and a last resort—sliding scale contribution from parents that can afford to pay towards services. EI should stay available to those who need it at no cost.

3.) PARENTAL SURVEYS/AGENCY OVERSIGHT. Parents should be offered the opportunity to review their experiences with therapeutic agencies, and even individual therapists. Exceptional therapists should be recognized and lauded so that others are encouraged to excel in their service delivery to families.

4.) ABA OVERSIGHT/ACCREDITATION. There should be a set standard of ABA delivery. As it stands, ABA therapists seem to come from a varied background of training so delivery of essential ABA therapy varies from therapist to therapist.

5.) STANDARDS FOR PARENTAL TRAINING. There should be a bulleted, or stated list of family training goals, especially for ABA.

6.) EDUCATIONAL CAMPAIGNS. There should be a poster outreach campaign to pediatric offices so that parents are thinking about development, and are aware of Early Intervention. Infant development workshops or info sheets so that parents know what milestones to look for and encourages the vital engagement that toddlers need. Further, the DoH should reach out to high schools and universities promoting jobs in the therapeutic fields, for example, Occupational Therapy, where there are a number of communities that are under-served because of the lack of therapists.

THE COUNCIL
THE CITY OF NEW YORK

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I represent: Self

Address:

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I represent: myself

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Address: 45 Tremont Ave

I represent: Herself/Department

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Name: Linda Kass

Address: 2166 Broadway 7FE NY NY 10024

I represent: All families

Address: _____

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Name: Bo Young Cho

Address: 216 W. 100th St @1224

I represent: Columbia University TC

Address: _____

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Name: LESLIE CALABRESE

Address: NYC 10040

I represent: PARENTS, CHILDREN, THERAPISTS

Address: _____

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Name: NINA LUBLIN

Address: _____

I represent: Resources for Children w/ Special Needs, Inc

Address: 116 East 16th Street 5th Fl. NY, NY 10003

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Name: Bonnie Cohen

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Name: Randi Levine

Address:

I represent: Advocates for Children of New York

Address: 151 West 30th St, 5th Fl, New York, NY 10001

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Name: Dr. Marie Casalino, Assistant Commissioner

Address: 42-09 28th St. LIC

I represent: Health Department

Address:

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Name: Anthony Fasciano, Senior Director of Revenue

Address: 42-09 28th St. LIC

I represent: Health Dept.

Address:

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Name: Nelida Velez

Address: 1881 O'Brien Ave Bx 10473

I represent: myself & Bx DD Council

Address:

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Address: 86-55 110th STREET, Richmond Hill, NY 11418

I represent: UNYEIP

Address: Queens, NY

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Name: Leslie Grubler

Address: 53-42 203rd Bayside, NY

I represent: UNYEIP

Address: Bayside, Queens, NYC

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