



UNITED NEW YORK Early Intervention Providers and Parents As Partners (UNYEIP)

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Testimony to the New York State Legislature's Joint Budget Committee on Health *in the matter of Early Intervention* Wednesday, February 8, 2012

Chairman Hannon, Chairman Gottfried and distinguished members of the Senate and the Assembly, thank you for the opportunity to testify today on Governor Cuomo's 2012/2013 Executive Budget Proposal in the area of Early Intervention. My name is Leslie Grubler. I am a Speech-Language Pathologist for Early Intervention in the great state of New York. I also teach Speech-Language Pathology to incoming majors at Queens College. I have a background in Labor Relations and Employee Relations as well as nearly 25 years in the field of Staff Development and Training. As Founding Director of UNYEIP, the *United New York Early Intervention Providers and Parents as Partners Organization* which formed in April of 2010, I represent the interests of over 2500 current and former parents of children in NYS Early Intervention, as well as providers of service inclusive of: independent contractors, subcontractors, and small agencies, composed of allied health professionals and educators. Our memberships spans from the tip of Long Island to Buffalo and both east and west. Our underlying mission is to be the voice of the children -- who have no voice or vote -- and their parents who have not yet found their voice. Among others, our relevant goals include:

- *To Ensure that children, ALL children, from ALL religious, cultural, and socio-economic groups, of NYS Early Intervention are **PRIORITIZED***
- *To Advocate for and Educate on the Removal of ANY barriers to access or barriers to care*
- *To Ensure that the children of NYS Early Intervention receive not only individualized services but frequency and duration of services that are meaningful in relation to their delay or disability*
- *To Ensure that ONLY those children who are ELIGIBLE to receive services are those that do receive services*
- *To Preserve and Protect NYS Early Intervention so that it is maintained as the Premier State in NYS Early Intervention*

We do not rely on lobbyists. We do not bend or fold to special interests. We do not charge any dues or membership fees of any kind to our members. Simply, we are the stakeholders, the real deal.

The quote, "**Babies are such a nice way to start people....**" reminds me of how foundational Early Intervention truly is. A newborn's brain at birth weighs on the average 400g; yet, at three years of age, it triples in mass to 1200g. It is not a coincidence that this occurs during the period 0-3, precisely during the time that Early Intervention is provided through IDEA Part C -- when a child's brain is most malleable. **Early is Everything**. Since its inception in 1993 in NYS, a program initiated by another Governor Cuomo, it has given NYS the distinction in yet another category as the Premier State -- this time in Early Intervention. Since 2010 however, the

program from all clinical perspectives has lost its luster. As providers and parents, we need this luster restored for the benefit of our most vulnerable and for the future financial health of New York State, which will in the end benefit all.

Governor Cuomo's Executive Budget Proposals are courageous. This should not be news to you. We recognize that his Health Proposals are a bold Work/Vision in Progress, the product of significant consultations with stakeholders from all walks of life including the insurance industry. It is both an effort in transparency as well as an effort to increase productivity and yield meaningful reform. How?

- a. In his statement, "there will be no cuts in services to Early Intervention," Governor Cuomo communicated to his constituents that he is **prioritizing** our children with special needs;
- b. In referencing an Early Intervention agency whose Executive salary is said to be in excess of 2 million dollars, he is communicating to us that Early Intervention is important to him, and that he is readying a system that will track NYS dollars and ensure that a meaningful percentage of them will go to direct care...and, make no mistake, we know the meaning of direct care, *the provision of services to a patient that requires interaction between the patient and the provider* -- our voice will be heard when these words require a formal definition.
- c. Governor Cuomo's efforts at mandate relief inclusive of the development of a fiscal entity to reduce costs that municipalities in the past have borne, and by seeking other forms of funding -- the use of state regulated insurance, communicates that he wants the counties and Early Intervention to maintain viability simultaneously.

This is not an effort to dismantle early intervention. This is an effort to reform Early Intervention and unlike the Testimony provided by the NYS Business Council earlier this week, this is an effort to address and reshape the program into something more meaningful.

Change is difficult. Reforming healthcare is understatedly complex. We anticipate that this undertaking will ramble like square wheels, thump, thump, thump, until the corners are smoothed, all parties are working together like a well-oiled machine, and it rolls. UNYEIP will be there, not voiceless, to ensure that it rolls every step of the way, on behalf of our most vulnerable children, their families and extended families, and our providers -- the stakeholders.

But we need assurances from you. We need you to legislate tweaks to this plan that will protect the stakeholders. We need you to advocate as strongly as you did last year during this time to protect the integrity of the program and NOT to throw this program to the wolves, ie. irresponsible insurers who drag, who place inordinate demands on the therapeutic process, and in so doing, do not comply with IDEA Part C and do NOT act in the best interests of our state's most vulnerable children. Do not allow insurer involvement to be a barrier to care.

It is time, the right time to invite Insurers into Early Intervention. It is time that NYS receives assistance from Insurers in this regard. Governor Cuomo is fortunate to have a fearless visionary in Deputy Secretary of Health and Chairperson of the MRT Health Redesign, James Introne at his side, one who is unafraid to step out of the bureaucratic box and seek new better ways. One who recognizes the importance of Early Intervention and the savings this program affords the state in future expenditure. Heckman provides us with a wealth of data here -- investments in early intervention save the state \$7 for every 1 dollar spent. UNYEIP has worked with the Secretary 4X in the last 5 months. He IS a visionary and along with Governor Cuomo, both of these men can change the complexities of health care and essentially turn "what was," into "no more."

Many meet change with resistance, resulting in change occurring very slowly. As Providers Of Service in Early Intervention, we are trained to expect change even when change may appear distant to the lay person. We keep an open mind and we expect nothing less than change for the good.

While UNYEIP is hopeful, these are our concerns:

1. Early Intervention is a unique **home-based** service which insurance companies **MUST** cover. The word "home-based" does not appear in the wording of the Executive Budget Proposals. We essentially make 'house-calls' however, in relationship. What is the value of home-based treatment for children in EI?

- a. There are presently no barriers to care but convenient access to care.
- b. Therapeutic Assessment takes place in the most natural setting for the child so that the child adapts easily, opens readily, and that treatment can progress readily. Homeliness is therapeutic.
- c. The conditions we work in are not controlled by us, they are uncontrolled which means we work under good conditions if they exist or bad environmental conditions.
- d. We are constantly confronted with the truth of the child/parent's compliance
- e. As we visit a child's home, we make it possible for the provider to offer better care. Just looking around you know a lot of things that the office-based clinician cannot know.
- f. We observe how care-giving family members are handling their loved one's needs
- g. Home-based service rates are not equivalent to those in Centers, Hospitals. We see one child at a time. Never in groups. We travel great distances, home to home. The length and complexity of paperwork makes our work a 'life mission.'

2. Rates are to be **negotiated** with insurance companies by agencies/independent contractors. Because insurance companies do not typically negotiate rates, how will this be accomplished? Will the state, Can the state mandate and oversee these negotiations?

- a. The State Government and the State Insurers must commit to quality and price standards developed with the Early Intervention Home Care Community and in accordance with DOH Rates and incentives for providers. This will help guarantee a fair and accurate view of the quality of care delivered by individual providers, as well as providing consistent measures for quality.
- b. You must expect the state insurers to **EXPEDITE** the process of application and both the state and insurers **MUST** commit to streamlining all paperwork and reform paperwork redundancy and standardize requirements statewide.

3. It is incentives that produce change but the Early Intervention field has been de-incentified.

- a. EI has received one COLA in 18+ years of EI in NYC. Judges in NYS have been treated similarly. Our work could minimize their work.
- b. Seasoned Professionals in Early Intervention have left the field. Will "negotiated" rates force more out and further water down our profession.
- c. Rates have decreased 15 to 20+% in the last two years in addition due to budget reductions, implementation of the wage equalization factors (WEF) and the travel factor. Reductions in eligibility of services have decreased work. ALL providers in NYC recognize that "services are being authorized differently now." Children with developmental delays are receiving non-therapeutic mandates of 1X30 or 1X60 semi monthly or monthly. These mandates do not portend the development of therapeutic relationships. Progress is therefore slow or non-existent. This is a waste of the state's and city's money; yet NOONE is stepping up to address this issue. It is continuing and our reports indicate that this practice is inching its way throughout the state.
- d. For-profit agencies have had to reduce rates to subcontractors by 25 to 40% to cover their administrative costs.
- e. Small agencies have closed many of them women-owned. Will these current changes close more agencies?
- f. Are the incentive-based evaluations required in this budget going to be enough to lure professionals back into the field and keep those that have not left? These evaluations should include the demonstration of outcomes that portend reduced Special Educations costs for the future.
- g. I will step out on a limb and say that our providers, independent contractors, subcontractors, agencies, will function as ONE unit in these negotiations. How? By NOT accepting ANYTHING less than the DOH Rates that are currently in force.

4. *The Governor's Budget Proposals suggest a coordination of care between the child's medical issues and therapeutic needs. This can only make early intervention stronger*

Gratefully there are numerous other protections put into place in this legislation to reduce fraud, increase transparency, and reduce paperwork among others – but each **MUST BE MONITORED WITH CARE**, as a work in progress:

1. *The necessity for Arm's Length Relationships between the service coordinator, evaluator, and provider approved to provide services. This must be monitored with care.*
2. *Evaluations of Providers will be required -- We have offered to be part of the Evaluation Development and the offer has been accepted. We recognize that sometimes the bad apples spoil the whole bunch. Our industry like all others is NOT immune to this. WE will be critical to the development of this tool to maintain equity and protect both providers and parents.*
3. *COLA's with future increases based upon performance are reflected in the budget.*
4. *Newer agencies reflect the new 2010 regulations ie. Emphasizing Providers as Agency Owners and QA Staff. This can only make our work more meaningful and Early Intervention stronger.*
5. *Parents get to select the EVALUATOR.*
6. *IFSP Meetings will be conducted at a location preferred by the parent.*
7. *The parent can bring anyone to the initial IFSP (Individual Family Service Plan) meeting.*
8. *The IFSP should be reviewed at 6 months intervals or more frequently if parent requests. This suggests the possible elimination of 3 and 9 month progress notes – an effort in reduction of paperwork. Insurers must accept this as "paperwork in full" and NOT place additional demands.*
8. *Service Coordinators will coordinate a meeting with parents and the CPSE Chair to discuss transition of the child prior to CPSE evaluations*
9. *Parents will not be responsible for copay or deductibles on an eligible child's insurance coverage. .The provision of EI services will not impact annual or maximum benefits that the child/family is eligible for.*
10. *Financial responsibilities for EI by the counties will be significantly reduced – which will impact ALL NYS citizens.*
11. *Services provided by an insurance company to the child outside of NYS Early Intervention cannot be reduced or eliminated solely on the basis of the child receiving EI benefits. Additionally, no enrollee can be denied because the child is receiving EI benefits.*
11. *There must be sufficient providers in each geographical area to respond to the needs of EI..*

Essentially and critical to the UNYEIP Mission, EI Policies as it relates to these budget proposals should be dictated by **what is best for the children** as determined by those on the front lines -- parents, AND trained, experienced, and highly credentialed providers whose input is integrated by the DOH and Insurer stakeholders.

We need to put the children's interests before the special interests because Early is Everything.

In closing, Early Intervention is like "apple pie and ice cream" everyone wants to support it but finding ways to is complex. We extend our sincere gratitude for your support last year, and ongoing in this budget negotiation.

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