LENORE P. WOSSIDLO

2000 OCT 31 AMM: 48 PARENT OF A BEAUTIFUL CHILD WITH AUTISM

7457 MCCLURE AVENUE, PITTSBURGH, PA 15218-2338 412-241-4370, LWOSSIDLO@AOL.COM

October 22, 2000

Mr. Mel Knowlton Office of Mental Retardation P O Box 2675 Harrisburg, PA 17105

Governor Tom Ridge CC: Secretary Eugene Hickok

Dear Mr. Knowlton:

As the involved parent of a beautiful son with autism, I am deeply concerned about the proposed changes to Infants and Toddlers EI Regulations and would like to express my opinion to you.

When our pediatrician first suspected something was wrong, he referred us to Children's Hospital for a full evaluation. This was important because sometimes the characteristics of a problem don't come out in a screening, and the evaluator needs to be QUALIFIED. It is also important to let the public know about the early intervention program. So many times, parents don't know about programs and their children go without services. Let's inform the public, the taxpayers who are parents.

After my son was diagnosed with autism, we worked with a qualified team of professionals to provide him with the services he needed to work towards a productive life AND work with us as parents. These professionals need at least a bachelor's degree and preferrably a master's degree, but more importantly, THEY NEED FIELD WORK. Children also need to receive services promptly, with 10-14 days. They are changing every day, and every day that they do not have a service, they lose valuable education.

It is also important to make sure that services continue after the age of 3, that records are transferred from one agency to another so that everyone understands the child they are working with, and to continue services while disputes are worked out. Individuals with disabilities need continuity, not disruption. That is a small sacrifice to pay for helping these people become productive. And, please don't limit our choice of providers. Not all providers are appropriate for all kids. We have chosen our providers based on input from other parents and qualifications meeting needs.

My son is not a typical individual with autism. He is caring, loving, smart, active, and he will go far because of services he has been provided with. DON'T CHANGE THEM OR TAKE THEM AWAY FROM US. Individuals with disabilities WILL lead productive lives, but they need to be given the appropriate services to do so.

Helping Qur Community to Understand

Lenore P. Wossidlo, Involved Parent of a Beautiful Child with Autism

Original: 2122

To: Department of Public Welfare Mel Knowlton P.O. Box 2675

Harrisburg, PA 17105-2675

From: Katie Fry

Director of Children's Programs UCP of South Central PA 788 Cherry Tree Court Hanover, PA 17331 RECEIVED

2000 OCT 31 AMII: 47



United Cerebral Palsy

788 Cherry Tree Court Hanover, PA 17331 tel 717 632 5552 1 800 333 3873

fax 717 632 2315

Re: Comments on Early Intervention Regulations

Date: October 22, 2000

UCP of South Central PA is a provider of Early Intervention Services in York, Adams and Franklin Counties. In Fiscal Year 1999-2000, over 500 children and their families were served in the Birth – 3 programs. UCP of South Central PA have been providing early intervention services for the past 40 years. We have demonstrated a continuing commitment to the development of infants and toddlers with developmental delays. In reviewing the proposed regulations, there are a few areas of concern which we would like to make a comment on.

Early Interventionist - Clarification is needed on the position of the Early Interventionist. As this position is only one of two positions with responsibilities, requirements and qualifications listed, it appears that this position is of key importance in the provision of early intervention services. The qualifications for this position are listed (4226.56). However, certification and/or licensure are not listed. This is not consistent with the Infant and Toddler Medicaid Waiver Provider qualifications found in Appendix B-2. It is assumed by many that the early interventionist would provide special instruction. This would make sense as far as the provision of early intervention services. The families are already overwhelmed with the number of early intervention personnel with whom they come into contact. The early interventionist could perform the duties as outlined under the responsibilities in 4226.55 as well as provide special instruction.

However, the qualifications should be consistent with those in the Medicaid waiver. It would be beneficial for the continuation of services past the child's third birthday, if the early interventionist had a certification in early childhood, special education or a Certificate of Clinical Competency. Also, if these certifications are required, the requirements for professional development should also mirror those of the educational field. Six credit hours over a period of 5 years or a combination of professional education courses would be far more reasonable than 6 credit hours in one year. The requirement of 6 credit hours per year causes a few problems. First, it would be a financial burden to the agency employing the early interventionist or for the early interventionist. Also, 6 credit hours per year is also a fair commitment as far as time. Not everyone can make the time commitment to provide full-time early intervention



services and to take college level courses. Some of the personnel currently providing special instruction have a Master's degree. In some of the more rural areas of the state, there may not be a college or university close enough to attend on a part-time basis. Unlike, teachers in a school system, those personnel providing early intervention services do not have the summers off. Therefore, taking summer courses is out of the question.

Preservice and Annual Training - All early intervention personnel need continued training. However, the type of training that they need is what is in question. As services are provided in a child's natural environment with a caregiver present, it is unclear why personnel would need to be trained in fire safety and emergency evacuation. It is also uncertain that they would have to be trained in first aid and child cardiopulmonary resuscitation, as they are not the caregivers. The requirement for 24 hours per year for all personnel is not unreasonable. However, some of these requirements should be in the professional's field of expertise. Many of the contracted therapists work in other settings besides early intervention. They receive relevant training to their field and attend courses and seminars related to their profession or a relevant topic. For example, as more children are being diagnosed with autism spectrum disorders, there is more training available in that area. If the 24 hours of training requirements are to be in those areas listed in 4226.36 and 4226.37, the personnel may not have the time to take trainings in more relevant areas. Also, contracted therapists often provide early intervention services on a limited but needed basis. If the requirements become too stringent, the contractors may not be able to meet them. Therefore, they would no longer able to provide their services and we would be losing trained professionals from the field.

Natural Environments - There are currently proposed amendments to the Federal regulations governing Part C of the IDEA. Under section 303.341, there is a clearer interpretation of the justification of services provided in settings other than natural environments including center-based services. Please include this justification in the state regulations to make it easier rather than referring back to the federal regulations.

Please consider the above comments that I have provided. Thank you for the opportunity for making these comments.

Sincerely,

Katie Fry

Katie Frv

Director of Children's Programs



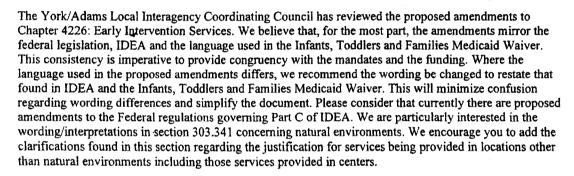
York • Adams Local Interagency Coordinating Council

October 20, 2000

Department of Public Welfare Mel Knowlton PO Box 2675 Harrisburg, PA 17105-2675

RE: Proposed Amendments to Chapter 4226: Early Intervention Services

Dear Mr. Knowlton:



Additionally we have three areas of concerns with the proposed amendments as drafted and have included our recommendations.

Section 4226.28: Recommendations to Parents (following initial screening).

We are concerned (referring to #4) that the family will not be informed of their option for an MDE. Wording should be changed to ensure that all families are provided with the option for an MDE as requested. Further, never would a child be determined ineligible for Early Intervention Services without an MDE.

Section 4226.36: Preservice Training

We recommend the requirements under number 9 be deleted. The training described in this paragraph (fire safety, emergency evacuation, first aid techniques and child cardiopulmonary resuscitation) are not necessary for professionals who provide services while caregivers are present. Early Intervention professionals are never alone with the child. It is the caregiver's responsibility to respond to these emergency situations should they arise in the home or community. Correspondingly, under section 4226.37 b. the need for recertifications is unnecessary.



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Section 4226.55: Early Interventionist

We are confused by the term early interventionist but assume this term refers to the early interventionist as found in the Infants, Toddlers and Families Medicaid Waiver and to services billed as special instruction services. We recommend that the requirements and qualifications for the early interventionist be amended to mirror those found in the waiver. See attachment. Additionally we recommend that the requirement for 6 credit hours of annual relevant continuing education be amended to include 6 hours of relevant training (deleting the word "credit" hours) per year.

Thank you for your attention to our recommendations regarding the Early Intervention proposed amendments. If you require additional clarification, please contact a member of the subcommittee as follows: Katie Fry at (717) 632-5552, Sharon Griffner at (800) 632-7568 or Robin Sterner at (717) 757-1227.

Sincerely,

Julie Monzi

Parent Co-chair York/Adams LICC

Nino Borremeo

Agency Co-Chair, York/Adams LICC

Nino Boueneo / pg

Katie Fry

Subcommittee Member, United Cerebral Palsy, South Central PA

Sharon Griffner

Subcommittee Member, York/Adams MHMR



York • Adams Local Interagency Coordinating Council

Robin Sterner

Subcommittee Member, Family-Child Resources, Inc.

cc: State Senator Mike Waugh

State Representative Stan Saylor

State Representative Todd Platts

State Representative Steven Nickol

State Representative Al Masland

State Representative Stephen Maitland

State Representative Ron Miller

State Representative Bruce Smith

State Representative Stephen Stetler

State Representative Dennis O'Brien

Rick Barbush, OMR

Jane Courten, OMR

Ginny Duncan, Parent Education Network

Liz Yarnell, Heath and Human Services Committee

Proposed regulations for Early Intervention Testimony from Richard Angeloni parent of 6 children, one Anthony whom is 6 years old and has a disability.

Anthony has a disability and is very happy, his parents are very happy to have the opportunity to be able to advocate for him. Their are a lot of stories I could tell regarding Anthony and your regulations, but the one I want to focus on is the regulation or lack of a regulation on self determination for children and families in early intervention. Really what I would like to see is a rule that says a family with a child with a disability can be self determined and that they can write a plan for their child and they can hire their own service coordinator and their own provider and they can recieve what they feel their child need's, because whom better to know what a child need's than his or her own parents. In our county (Philadelphia) you deal with a certin provider depending on where you live. At least in the begining when you are getting your child's evalution the area provider comes with your service coordinator. Who are these people you say to your self, and you need to build a real fast real cooperative relationship in about an hour. Is that what is best for a child and family with a disability. Or could I have a Early Intervention educator, someone that explains the rules to me and my chioces (conventional or Self Determined) and help educate me on the best practice's in early childhood and disability related issues come to me and talk to me about MA (Medical Assistance) ,BSU (base service unit), IFSP (Idividual Famialy service plan), Waivers, and therapies, stratigies and community and natural invironments . etc. And than I could study and read and interview and talk to other parents and make a good decision. MY SON WITH A DISABILITY WAS ONLY 0-3 ONCE. And so is every other kid, do we think we are doing the perfect thing for children. They are only that age once and if we miss we can't take it back. We should demand that it is PERFECT. Plenty of dollars are spent in Early Intervention for it not to be PERFECT.

When my son was 2 and a half he stopped eating so he had a feeding tube inserted. We had a feeding team locally see him once a week for a year with no luck, than we went to baltimore to the Kennedy Kreiger Institute for an evalution. They are internationally known for their feeding program. It took them 8 months for them to accept and admit him. When he was 5 Anthony and his mother spent 6 week's in Baltimore at the KKI for them to teach him how to eat. It was a great program but did not work in his favor, it was determined that if he would ever eat it could take years. When he was discharged we were given a feeding protocal and we were trained to keep up the training for him and that their was a chance he would respond.

This is where this story get's good!! We knew that we could not do the feeding with him because of his minipulative manner with his parents and his ODD (behavior) tendicies, so we started to interview for some one to come into our house to work

with him. During this time I was negoating with MA(keystone Mercy) to have them pay for this service, they advised me that they would after referals and perscriptions etc. and they directed me toward their home health care providers. After many phone calls to these providers it became aparent that they would be available for a minimum of 4 hours a day, but we only needed one or two hour's a day once at noon and the other at dinner. When we finally found the person to do this we were also told to try to get him employed by one of Keystone's providers so they could pay for it. Also the providers stated that they could not guarentee the same person would be available every time and that it could be a different person at noon and than at dinner. This was not going to work for Anthony or our family so we contacted his Pre school Early Intervention MAWA contractor and his EI pre school provider and had his feeding put on his IEP than we hired this person and paid him \$ 11 @ hour and sent the bill after paying him ourselfs and they reinbursed us. He would come to our house at dinner time and the pre school would do the feeding at 11 while he was in school. I paid this person \$66 a week. If I would have did this same thing through MA it would have been \$456.00 a week that is a 600% savings. It is now a year later and he is still getting his feeding at home he is no longer in EI so I am now going to have myself become a provider of service through MA so we can continue to save them 600% and be able to continue this service. AND BY THE WAY ANTHONY IS NOW EATING A JAR OF FOOD A WEEK. NOT MUCH BUT A JAR MORE THAN LAST YEAR ALL AT A SAVINGS OF \$20,000.00. Thank you Mr Angeloni

My next story has to do with him and his new school. Anthony is now in Kendergarden and is out of EI, he is going to one of these new charter schools. I know, you guy's have nothing to do with this stuff but you have to here it and it will conect to you. He as an IEP and it includes him having an aid during the day at school. Here we go again, I started to investigate who and how this get's acomplished, and figured that to do it right I would have to find this aid person my self. The school has no idea of what we are looking for in the way of and aid either his new charter school or the Philadelphia school district. I think they think they would get like somebody's mom who want's to hang aroud to do this for like \$ 6 an hour, well I figured he need's to get a TSS one on one, so I contacted CBH and they piont me toward their providers, who have a 8 week waiting list and that I investigated this somemore and figured it out that it would cost about \$51,000.00 a year to do the whole thing from evalution to service and that the person that would be doing the actual one on one would recieve about 65 % of that, and they would not have the degree that we feel would work. So I went looking for a person and found them, she has a Masters in Special Ed. and could do it for about \$31,000.00 a year. Well I am right now in the middle of going through this process and it will take me until January 2001 to get this done and finished. Waiver, Consolidated and or family centered, what are these things for ? My son

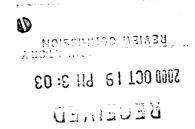
Anthony would be able to recieve these funds, but I seem to have a hard time figuring out how, or where to do this. I contacted my BSU and the person whom

would be my son's case manager has no idea how to do this waiver thing. And by the way my son is not a case he doesn't need to be managed. I think they have a hard time figuring this thing out for kid's. Also who figure's out what these thing's the waiver are covering, because if I was asked they would not cover anything they do cover and everything they don't cover. I called the county office and spoke to the person in charge regarding the waiver and explained my situation and she said she would get back to me that was three week's ago, and she has not got back to me maybe she think's my son has been cured !!!! I on the other hand accept my son for who he is and love him more and more each day and enjoy him so. Now my problem. This person at the county office whom is going to call me back and this person at ma and the providersc of service are in this business for themselves not for me or my son, they should be and they should have to answer to me. I should not have to answer to them and I should not have to be trying to get them to call me back. They should handle it and they should be viving for my business but they don't have to because this system tells them to do what, when, where, and how, for my kid so the providers and the sysetm are in bed together and taking care of themselves . I THINK YOU SHOULD GIVE ME THE MONEY AND LET ME DO WHAT I THINK IS BEST FOR MY SON I KNOW HIM BETTER THAN YOU.

Instead what you do is tell me everything I am to do and coddle me and take care of me and make me rely on your system and than when my son is 21 or so and out on his own he will be in need of you and I will be to old to do all this stuff. GUESS WHAT PEOPLE WITH DISABILITIES WHO ARE ABLE TO GET A JOB AND WHO WANT TO WORK ARE UNEMPLOYED AT A RATE OF 80%. Is this right or is this working for people with disabilities or is it working for people who work in the disability related business? You want to pay for what you want but is it what is needed not just in EI but in the whole system.

In your regulations you should add a self determination choice for families who want that choice. And get some families help you write how it will work not the system people. I will help just ask me.

Richard Angeloni 4232 Longshore ve. Phila., Pa. 19135



101

Original: 2122



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Early Intervention Providers Association

Department of Public Welfare Proposed Rulemaking for Early Intervention Services October 18, 2000

On behalf of the Early Intervention Providers Association I would like to thank you for this additional opportunity to provide written feedback on the proposed state early intervention regulations for children 0-3. The following represents points of concerns that are important, but were not included in our initial oral testimony. As stated in our previous that testimony, the following represents the association's views as a whole, not the views or opinions of a single persons or agency.

GENERAL PROVISIONS

Definitions 4226.5

(i) "Highest Requirements" - There is some confusion with this language. In our experience you generally set the minimum requirements and encourage the use of higher requirements.

GENERAL REQUIREMENTS

4226.3 Waiver Eligibility

We recommend changing the form that parent's sign related to the level of care statement. This will promote a clearer understanding on the part parents and their role and participation in the waiver.

4226.32 Contacting Families

(a) (b) Following with the spirit of IDEA contacting families within the tracking system should be individualized, not preset. A clearer statement about what the expectations of the tracking system are should be added, as well as, the parent's related rights.

4226.36 Pre-service Training

(9) Are recommendation is for the state to re-evaluate the appropriateness of the required training. The location of the services should be a primary consideration when determining what training to require of early intervention personnel.

IFSP's

4226.72 Procedures for IFSP Development, Review and Evaluation

It is our recommendation that a timeframe as to when services should start following the completion of the IFSP be added to the regulations.

4226.73 Participants in IFSP Meetings and Periodic Reviews

There should be a statement that supports and services are based on a team recommendation with someone present who has the authority to commit county resources.

4226.74 Content of IFSP

(4)(iii)(A) It is the feeling of the Association that the proposed state regulation regarding the frequency and intensity of IFSP's is written too restrictively. If the current format remains as it is, then the Association recommends a statement clarifying that the maximum number of times per month may not be delivered every month. There needs to be some understanding that services may be cancelled in order to permit staff to attend annual training (4226.37), vacations, holidays, staff illnesses, etc.

In conclusion we like to make a statement that officially supports the testimony presented in Harrisburg on July 24, 2000, by the Pennsylvania ChildCare Association by Terry Casey, Executive Director.

Respectfully Submitted,

Michele Myers-Cepicka, President

Kelli O. Thompson, Vice-President

Early Intervention Providers Association 1971 Baker road Anheim, PA 17545 (717) 665-4993

RECEIVED

2000 OCT 24 AMII: 22

REVIEW CONSISSION

To:

Mel Knowlton

PA Dept. of Public Welfare

From: Susan Vandervort

Transition Coordinator/Supervisor

ARC Allegheny, 711 Bingham St. Pitsburgh, PA 15203

Date: October 13, 2000

Re: Early Intervention Proposed Regulations

Thank you for extending the comment period for the proposed regulations for Early Intervention services. I am currently the Transition Coordinator/Social Work Supervisor for the Early Intervention Program at ARC Allegheny. While reviewing the proposed regulations, I realized the great deal of time and effort that the Department devoted to the development of the regulations. There are several areas on which I would like to comment.

The first area refers to the requirements and qualifications of a service coordinator. The proposed regulations state that a service coordinator could have an Associates Degree or Bachelors Degree in <u>any</u> subject area along with three years work or volunteer experience. There is no requirement that a service coordinator have experience in child development or that they have <u>any</u> experience in working with families. In a Family-Centered Model, the service coordinator's role is extremely important. The service coordinator is the family's first exposure to the Early Intervention system. Therefore, it is critical that during the first meeting with the service coordinator, the family feels comfortable in sharing information and confident in their service coordinator's skills and knowledge. The expectations the Department places on the service coordinator do not correspond with the qualifications in the regulations. At the very least, the qualifications should require a Bachelors Degree in a field related to Early Intervention, including experience in working with

families. In addition, the regulations should include a caseload maximum of 35 families to allow the service coordinator to perform their varied and complex responsibilities.

The second area I would like to comment on is in reference to the Preservice Training that is listed in the proposed regulations. The following topics should also be included in the training for service coordinators: Typical and atypical infant development, the nature of disabilities and their impact on the family, cultural and social diversity, effective listening, and identifying family strengths and needs. From my own personal experience as a social worker in Early Intervention over the past eighteen years, I have found that by utilizing family strengths in addition to helping families deal with their limitations, a greater affect on the development of a young child can be achieved.

The last area on which I would like to comment is in regards to Pendency. In Pennsylvania, when a child turns three, the responsibility for providing and funding the Early Intervention services switches from the Dept. of Public Welfare to the Dept. of Education. In order to prevent disruptions in service when a disagreement occurs between the family and the receiving agency, pendency must be in place, so that services can continue at the same level until the issues are resolved. Pendency is necessary to that families will not be forced to accept programs and services they feel are inadequate to meet their child's needs.

Thank you for considering my comments on the proposed regulations.

TO:

Mel Knowlton

PA Department of Public Welfare

RECHIVED

2000 OCT 24 AIIII: 23

FROM: Karol Scanlon, Early Intervention Manager

COMPRO of ARC Allegheny

DATE:

October 13, 2000

RE:

Early Intervention Draft Regulations

I am the Early Intervention Manager at COMPRO of ARC Allegheny, a position I have held for the last four years. Prior to that, I provided speech and developmental services to families for nine years at COMPRO. Thank you for this opportunity to comment on the proposed regulations for Early Intervention Services. I am aware of the effort that has been made in writing this document in a clear, concise manner, however, I disagree with some areas and have concerns that other areas need much more clarification. I appreciate your consideration of my following commments:

During my thirteen years in the field of Early Intervention, I have had many conversations with families about their expectations and satisfaction with EI services. Families have often shared with me how critical their first contact with Early Intervention personnel is in developing trust in the entire Early Intervention system. Therefore I have concerns with the qualifications of the service coordinator as stated in this draft. Considering the scope of duties required of the service coordinator, qualifications should minimally be :a bachelor's degree in a field related to EI (such as Special Education, Social Work or Early Childhood Education) and at least two years experience working with children and

families with special needs in an EI program. Families need and deserve that their first critical contact be someone who has knowledge of special needs children and is competent in assisting families in navigating the EI system. The current qualifications as stated in this draft minimizes the importance of the service coordinator's skills.

Families have also mentioned how important continuity is and that it should be maintained whenever possible. Therefore, I disagree with the requirement for initial evaluations to be completed by personnel independent of service provision. To my knowledge, there was no evidence found by the 1996 LBFC committee study of EI that proved services to families were compromised by evaluations done by providers in the past. Moreover, I found in my nine years experience as an EI speech and developmental therapist, the opportunity to complete the initial evaluation on a child and to actually be a member of the initial IFSP team, to be invaluable. Participating in those initial evaluations helped me serve children and family needs with a clearer vision, understanding and sensitivity of where they started and how far they had come at the time of the Annual evaluation. I often feel now, as a manager and coordinator of EI services, that therapists and families are missing out on that critical early connection and therefore compromising continuity. I also feel the term "personnel independent of service provision" needs clarification. A definition of "independent" is needed to make a distinction between services to a particular child, any child in the same agency or any child in another agency. Also, clarifying the term "service provision" would be helpful since an

evaluation is an early intervention service.

Finally I have a concern with identifying children receiving EI services as "mentally disabled". As an Early Intervention manager, I coordinate speech services provided by our speech therapists. Most of the children receiving these speech services are not mentally disabled and would never be referred as such. I believe this term is inadequate and may offend many families. Please consider changing this term to "children with disabilities", a term I feel would be less likely in deterring families from seeking early intervention services.

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DICTIVED.

Linda Radvak

Developmental Specialist

October 13, 2000

2009 COT 24 AM II: 22

Good Morning! My name is Linda Radvak. I am a Developmental Specialist with COMPRO. I have a teaching certificate in Early Childhood Education and I am a student at the University of Pittsburgh. The reason I am here is to give you an overview of what I do and to introduce you to the families I serve.

I will graduate in December with my masters in Early Intervention, Special Education birth through 5 years of age. The funding for my schooling at the University of Pittsburgh is from the federal government. It is a Federal Personal Preparation Grant funded under IDEA. The grant is used to provide tuition support for Early Intervention. The new grant this year is funded under IDEA-97. The new grant is a service obligation grant. Along with full tuition, the participants will continue in early intervention for 2 years working with children in an educational role.

Included is a copy of the classes I have taken for you to view. As you can see the course of study is intense. It includes practicums, curriculum, assessments, instruction in all domains, inclusion, partnerships with families, and community resources. This curriculum was designed to fulfill IDEA regulations.

The schooling has prepared me to be a much better developmental specialist. I am more knowledgeable about children with special needs and their development. I am committed to the families, working with them to meet their outcomes. I am able to guide the children and families through milestones with special designed strategies just for the child and family. We work together. We are a team.

The federal government says they want to increase teachers' salaries and have them further their education.

Masters in Early Intervention, Special Education

Title of Course	Credits
Introduction to Special Education	3
Inclusion Early Childhood	2
•	3
Medical, Physical Aspects of Disab.	
Early Ed. Children with Disabilities	3
Assessment Young Children with Disab.	
Programming in Early Intervention	3
Practicum Infant and Toddlers	1
Practicum Infant and Toddlers	1
Practicum Preschoolers	1
Practicum Preschoolers	1
Advanced Seminar	3
Community Resources	2
Family and Professional Partnership	3
Special Education Autism	1
Special Education Physical Therapy	1
Special Education Occupational Therapy	7 1
Special Education Communication	1
Special Education Language	1
Special Education Vision Therapy	1
Education and Society	3
Psychology of Education	3
Teaching Infants and Toddlers	2
Teaching Preschoolers	3
Introduction Research Methodology	3

The Education Law Center states that the federal government requires that the state's personnel standards for early intervention be based on the, "highest requirements of the state applicable to a specific profession of discipline." 20 U.S.C. Section 1435(a)(9)(B). A developmental specialist is a teacher. A teacher to the child and family. The parents are the child's first and most important teacher. My job is to help the parents be their child's best first teacher.

Speaking of families, I would like you to meet them. My families were not able to be here today in person. So, many of them decided to write you letters and send pictures. Along with the letters and pictures are some thank-you notes I have received.

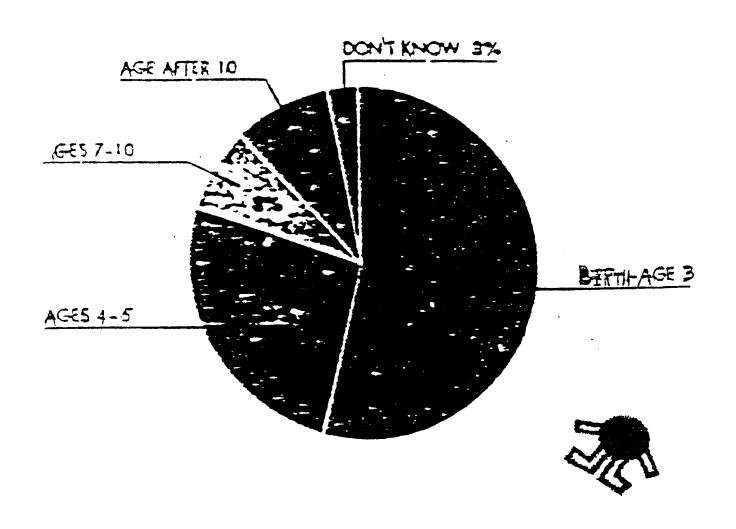
By age 3, the child's brain is 80% of the adult size. Birth through age 2, is the most critical and important time in a child's life. During this time million of synapses are being formed. A synapse is the result of axons and dendrites firing the when they meet. The highest density of synapses is reached around two years of age. The synapse will create the pathways for speech, thinking, problem solving, emotions, behavior, and motor skills.

Working as a Developmental Specialist is hard work and long hours. It takes a vast amount of knowledge and dedication. Every day there are new challenges and new success stories. Let's keep the success stories coming!

Thank you Linda Radvak



Many Parents Unaware Greatest Amount of Brain Development Occurs During Child's Early Years



Developmental Services has helper my son so much. When Jinda first started working with my son he was super shy and extremely sensitives. all lit took sometimes was a touch and help Through patience and perserverence Junda found ways to work with Ryan That worked for him as well as me He has recently started a preschool program and is doing great. He transitioned smoothly and amazes me everyday! If you could have seen where we started and where we've ended up you'd be amazed too &

> Bonne Dell Cot. 11, 2000



10/4/00

To Whom It May Concern:

We are writing this letter to stress how important we feel Early Intervention has helped out our daughter Madison who is 2-1/2 years old. We started receiving services for Madison when she was 2 months old. We felt that the sooner service started the better off she would be. We feel that this has helped her stay on track and not be far behind in her learning ability. Early Intervention has helped us as a family in seeing her potential and in setting goals for her to meet. Which she has. We are very thankful for the services that we have and all the people that have put forth a lot of teaching, and a lot of caring for Madison and ourselves.

Sincere Thanks,

The Orendi's

Dave, Lori, Kayla, and Madi

To Whom It May Concern;

My family and I are quite pleased with the developmental services. Linda Radvack has been instrumental in Alyssa's development. I recently had Alyssa evaluated at the Children's Institute for speech and fine motor skills. They were very impressed with Alyssa and I contribute most of that to her early developmental sessions with Linda. I would encourage any family that has a child with a delay to seek out these services.

Thank you,

Patricia M. Smith and family

Early Intervention has helped our
family in many different ways. Our
Son anthony has learned many things
toget without our therapide we would
have never achieved bothony progresses
ilvery day & ochieve his milestones
Dlawly but surely. We are so greatful
for the services provided to our family.
as first time periots with anchony
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Thank you for your assistance in making Kristin a happy, energetic and thriving child. The Early Intervention program has been nothing less than a positive and rewarding experience for us.

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Sincere Thanks,

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Thank you,

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Jane Pilditch
Testimony on early intervention
Proposed regulations
October 13, 2000

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Good morning. My name is Jane Pilditch, and like so many people in this room, I wear many hats. I am the Parent Advisor at The Alliance for Infants & Toddlers, the service coordination unit for Allegheny County's birth-three program. I co-chair the Western PA Coalition of Early Intervention Advocates & Friends, an organization of advocates from western PA who meet regularly to discuss ei issues. I am also serving as a co-chair for the Pittsburgh Allegheny County LICC, and I sit on the Board of Directors of the Center for Creative Play, and the Board of Trustees for The Watson Institute.

But my favorite hat, and the one I never take off, is that of a mother. I have two sons. Colin is 9 and Michael is 7. I'd like to tell you a little bit about Michael. I have some pictures that I'd like to share with you while I speak, because I think they can tell you, better than any words, why early intervention is so important to me.

Shortly after Michael's birth, he became very ill with a series of ailments and rare complications that left him very fragile medically and subsequently, experiencing developmental delays. The first year and a half of Michael's life was spent in and out of the hospital, as my husband and I struggled to manage his complex needs and seek out a diagnosis and cure. Finally, when Michael was 16 months old, a specialist at Children's Hospital of Philadelphia told us our son was dying, and that in a few short weeks he would become very ill and have to be hospitalized for the last time.

At the same time this was all happening, Michael was enrolled in early intervention. He received services in Allegheny County through The Alliance for Infants & Toddlers, Inc. During the course of the birth – three program, he received, at various times, pt, ot, speech, special instruction, and social work. Therapists came into our home, and at age two, we attended group therapy.

I have to tell you, I really thought many of the therapists were idealistic dogooders. I intended to be realistic. My son was dying. He was never going to walk, or talk, play with other children, or transition into a preschool. I felt that the therapists and my service coordinator were, to some extent, wasting their time.

I remember a conversation I had with Michael's physical therapist – a wonderful person who came into our home every week for three years – about how long and hard she would continue to work with a child who was never going to walk. She very kindly ignored my naivete' and told me that no child had a diagnosis, or a delay, that excluded them from receiving early intervention services and that every child had their own abilities and the right to achieve their full potential.

Well, to make a long story short, the doctors were wrong and the therapists were right. The doctors who couldn't figure out why Michael was sick can't figure out why he got better. Today he is a healthy, rambunctious little boy who walks, talks, plays with other children and goes to school. In fact, today he is spending part of his morning in a typical kindergarten class for the first time. Yes, he still has delays, but he has made incredible progress which continues every day.

That's why early intervention is so important to me and why I want to ensure that this valuable program stays intact and true to the philosophy and intent of IDEA.

Jane Pilditch Oct. 13 Testimony Page Two

I submitted written testimony this summer which goes through the state proposal line by line discussing specific issues, so I will not repeat that again. In closing, I would just like to make two points.

First, I would like to thank the department for listening to families and advocates who asked for an extended comment period and additional hearings. We appreciate your willingness to give us the time to disseminate information about the proposed regs to families.

Secondly, I would like to apologize ahead of time for rushing out of here. I have to leave immediately after I testify. I would like to stay and listen to all of the testimony, but I have to go pick my son up from kindergarten.

Jane Pilditch

400 Legendary Lane

Jane Pildutch

Mars, PA 16046 (724) 776-8083

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To:

Mel Knowlton

PA Department of Public Welfare

2000 OCT 24 AMII: 22

From:

Kimberly Palmer, Lead Developmental Therapist

Compro of ARC Allegheny REVIEW COMMISSION

711 Bingham St.

Pittsburgh, PA 15101

Date:

10/13/00

Re:

Early Intervention Draft Regulations

Good morning and thank you for this opportunity to speak on the proposed regulations for Early Intervention. I am currently the developmental therapy supervisor at Compro of ARC Allegheny as well as a developmental therapist. This has been my first opportunity ever to review regulations as well as to comment on them, and I commend the dept. of public welfare for drafting regulations which hit upon many issues in a clear, concise manner. However, there are a few areas in which more clarity is needed and a few areas in which I disagree altogether.

The field of Early Intervention, which I have been privileged to be in for almost six years, has changed my life, in ways that I view people with developmental delays and/or disabilities and their families. I have worked with families who just needed a small amount of information and guidance to work on their child's development, and have worked with families who were facing insurmountable odds with their child's prognosis and even their own, due to their health and/or their environment. As developmental therapists, we work in many strenuous and stressful situations which require the knowledge and education of how to communicate effectively with families of all backgrounds and how to work with infants and toddlers of all abilities. This brings me to my first contention with the regulations, which states that a service

coordinator have either a bachelor's or an associate's degree along with volunteer work depending on which degree is held. These qualifications are not sufficient for the importance or the scope of working with children with developmental delays and their families. Service coordinators are the first people the families meet. They must establish a trusting relationship quickly and must have the knowledge to know what services would benefit each child and their family. At the minimum, service coordinators should possess a bachelor's degree in a field related to Early Intervention and one year of experience working with children with special needs, not counting volunteer work.

Another issue which I am unclear about and disagree with is the Early Interventionist position. The clarity falls short with the job description. I do not see the difference of an early interventionist compared to a service coordinator, therapist, or program supervisor. This position appears redundant and wasteful when the service coordinators, therapists, and supervisors already carry out these responsibilities. And since these qualifications duplicate the qualifications of service coordinators, the early interventionists qualifications fall short.

As a therapist I am fortunate enough to meet and even befriend many parents.

Parents of children in our program never cease to amaze me with their tireless efforts and abundant energy for their children. Unfortunately, some children are not so lucky and have to be removed from their biological parents to a safer environment with foster parents. The definition of "parent" excludes foster parents, who should be included in that definition in these certain circumstances: 1) when the biological

parents' authority to make decisions has been terminated under state law; 2) when the foster parent has an ongoing, long term parental relationship with the child; 3) when the foster parent is willing to take on these responsibilities; 4) when there is no conflict of interest. Since these "circumstances" occur on a regular basis, foster parents need to be acknowledged as parents in the regulations. They are just as committed to the welfare of these children we serve as biologically tied parents, and want to see these children live up to their potential just as much. They carry over our ideas and activities and participate in our therapy sessions. Many of them try to adopt the foster children in their care because they see themselves as the "parents." Please include them in the definition of "parent."

The final issue with which I disagree is the content of the County MH/MR program definition. At Compro of ARC Allegheny, we serve over 800 children all with a 25% delay in one or more area. Not all 800 children are mentally disabled. Many have a physical impairment, sensory impairment, or a speech delay brought on by environmental factors or oral motor defects such as a cleft palate. This definition is inaccurate and does not include many children and families who would qualify. Please expand on that definition so as not to deter these families from services that would benefit their children and them.

Again, thank you for providing this opportunity to speak on the new regulations of Early Intervention. These services have helped countless children and families, and if we could just fine tune the regulations a bit, we could provide services to families even more effectively.

Michele Myers-Cepicka Testimony on Proposed Rule Making October 13, 2000

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Good morning. My name is Michele Myers-Cepicka. I am Executive Director of The Alliance for Infants & Toddlers, Inc., the service coordination unit for birth-3 early intervention services in Allegheny County. I also serve as president of the Early Intervention Providers Association, a statewide organization of early intervention service providers.

To begin, I would like to commend the department for being so responsive to families, advocates and early intervention professionals by extending the comment period and sponsoring two additional public hearings. I believe this additional time is critical in getting the word out about the proposed regulations, and allowing families and local communities, through organizations such as the LICCs, to offer their vital input.

I was able to testify at the public hearing in Pittsburgh this past July, and since my comments at that time were targeted to specific line-by-line items, which are a part of the public record, I will not restate those recommendations. I would, however, like to take a few moments today to state some comments about the process in general given the recent release of new proposed federal regulations.

I am encouraged by the department's plans to move forward with the state regulations. I know that some individuals are recommending that it would make more sense to hold off until the federal regulations are in place. I'm afraid, however, that if we wait for the federal government to finish its process; it may be months, even years before the state is able to implement our own. By that time, who knows what other changes will have occurred in early intervention? Also, OSEP has been urging the state to adopt regulations. We can always go back to fine-tune and make changes at a later time. (This is inevitable under any circumstances.) For these reasons, I agree and wholeheartedly support the department's plans to proceed.

I would, however, urge the department to take a close look at the recommendations the federal government is making as we finalize our own program's regulations. Within the federal proposal is some very strong language regarding issues states have struggled with, including natural environment, how the decision making process for services and supports should be handled and the use of a family's private insurance for services. It would only make sense to scrutinize these areas of policy closely so that the regulations we implement are not in glaring opposition to the federal proposal. Not doing so would only lead to a huge burden, financially and otherwise, on the department. Worse yet, it could force interpretation of issues to be hammered out in the courts. (A situation that would be unpleasant for the families involved and the department.)

For the benefit of the House and Senate committees who must receive all the comments on the proposed regulations, and the Independent Regulatory Review commission, I would now like to speak to you about what I believe is the heart of early intervention. A few of the over 1200 children and their families our county serves

annually, have spoken with me or sent letters about early intervention's benefit to their child and family, here is what some of them have said.

"When I first started with the Alliance, I was quite skeptical of dealing with an agency that was funded and run by the county government. Now I must say that I am quite impressed. My service coordinator was an excellent resource and I also found her to be extremely knowledgeable and professional. Anytime I asked for anything or had a question; it was answered or handled usually within the same day. She showed up on time for appointments, helped me with anything I asked, and was always polite and eager to help. My speech therapist was also excellent. Your organization is one of the best I've dealt with – in terms of both professionalism and quality of care."

Our service coordinator helped us coordinate so much and made us feel so informed that any decisions that we will need to make on our son's behalf in the future will be done in confidence that we are doing our best."

"We want to thank you for recognizing that our son had special needs to be addressed. Our pediatrician, friends and family were not supportive of our decision to take your advice and pursue further analysis. We are grateful to you for your expertise and your diplomatic and caring handling of the situation."

"Our family would like to recognize our service coordinator, who did a great job under some difficult circumstances. She was consistent with information and appropriate practices for infants and toddlers. I know this due to my participation with the LICC. I always set high standards and she came through. She made IFSP meetings fun and productive; and helped me to learn how to run my own IEP meetings. Now that we have transitioned I feel confident that I can lead my daughter's IEP meetings. The knowledge and confidence to do this was a direct result of the work with my service coordinator."

"I feel like our service coordinator has become a true friend of our family and I don't know what we would do without her to guide us through this confusing time. It is so nice to feel like someone is on your side when going through such a trying time."

"The information that both our therapists have provided has been very beneficial to our family. The trauma of having our grandson lose his hearing from a bout with meningitis left all of us searching for answers. Talking to doctors, checking the Internet, reading books - - all left a lot of unanswered questions about the future and where to turn. I also had a comfortable feeling that my grandson is in good hands...our service coordinators were also caring and able to answer questions and communicate in an informed manner."

"Had early intervention and our service coordinator not gotten involved with our son, he would never be receiving the services that he is getting today. I would still be floundering trying to figure out what is available and where I could go to get him appropriate services."

In summary I would like to read a poem given to me by a parent that sums up what early intervention should be like for parents.

Growing Together

Once upon a time there was a little grape stem. She was so glad to be alive. She drank water and minerals from the soil and grew and grew. She was young and strong and could manage quite well...

All By Herself.

But the wind was cruel, the rain was harsh, and the snow was not one bit understanding. The little grape stem experienced pain. She drooped, weak and suffering. "It would be so easy to stop trying to grow, to stop trying to live," thought the little stem. She felt poorly. The winter was long, and she was weary. But then the little stem heard a voice. It was another grape stem calling out to her...

"Here, reach out, hang on to me." But the little stem hesitated.

What would this mean? She wondered. For you see the little

Stem had always managed quite well...

All By Herself.

Then ever so cautiously, she reached out toward the other grape stem. "See, I can help you," it said. "Just wind your tendrils about me, and I will help you lift your head."

And the little stem trusted. Suddenly, she could stand straight again. The wind came... and the rain... and the snow, But when it came, the little stem was clinging to many other stems. And although the stems were swayed by the wind... and frozen by the snow, they stood strongly united to each other. And in their quiet strength, they could smile and grow.

One day, the little stem said, "here, hang on... I will help you."

And another stem reached up to the little grape stem.

And together, all the stems grew.

Leaves budded... flowers bloomed... and finally

The grapes formed.

And the grapes fed many.

-Anonymous-

Respectfully Submitted,

Michele Myers-Cepicka

The Alliance for Infants Toddlers

Birmingham Towers, Suite 705

2100 Wharton Street.

Pittsburgh, PA 15203

(412) 431-1905, extension 133

Original: 2122

Lisa Maloney
Testimony on Early Intervention
Proposed regulations
October 13, 2000

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Good morning. My name is Lisa Maloney and I am speaking on behalf of the Pittsburgh/Allegheny County LICC. I am also the mother of four children, two of whom received early intervention services in Allegheny County.

The Pittsburgh/Allegheny County LICC is pleased that the Department agreed to extend the comment period for the proposed regulations, and hold additional hearings. Because our LICC does not meet during the summer months, it was difficult for us to get the information out about the state's proposal without the extension. Many families were away on vacations, or busy with their children's summer activities. In addition to involving as many families as possible, the LICC wanted time to review the information and advise our members as to how the proposal might affect their agencies. By extending the comment period, we were able to dedicate part of our September meeting to a presentation on the regulations.

The Pittsburgh/Allegheny County has a committee dedicated to issues and public policies, and we would like to know that there is a direct line of communication between the Department and our organization. We would like to be partners with the Department and are ready to collaborate as we proceed with the regulatory process at the state level, and also as the Department reviews and prepares a response to the recent amendments proposed by the federal government.

We would ask that as this process continues, the Department keep us informed by sending us any announcements and information related to the progress of the state and federal proposals on a timely basis, and by actively seeking out the advise and consent of the LICC's to the greatest extent possible.

Thank you.

Lisa Maloney

Pittsburgh/Allegheny County LICC

Low Malmy

c/o The Alliance for Infants & Toddlers, Inc.

2100 Wharton St., Suite 705

Pittsburgh, PA 15203

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Children's Center of Mercer County 900 North Hermitage Rd. Hermitage, PA 16148

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THOUSATORY EARLY INTERVENTION REGULATIONS - TESTIMONY 10/13/00 1/15 STON By: Thomas R. Hawkins Ph. D., Executive Director

Proposed regulations for PA's program for infants and toddlers (birth to age three) were published on June 2, 2000. These are the written comments and testimony filed within the period specified and by October 31, 2000, to the Department of Department of Welfare

Specific to the area of Pre-school are the following concerns:

In the first instance, and prior to the newer regulations, just specified, we are concerned that the 0 to 3 population is, with some certainly, being under serviced within the specified 'natural environment' regulations. The number of children are not in evidence today, as they were prior to this specific 'natural environment' requirement. There should be a demographic study of clients, numbers being served, before, and after, the changed regulations. A cost analysis, should be undertaken, reflecting the financial impact upon the 3 to 5 year old cohort, and the financial impact on the public schools, K-12, in the future, if children do not get the services they need during the 0-3 cohort.

In the proposed regulations we find the following concerns:

The definition of developmental delay is not age specific; the definition of special education services is now applied to preschool children, making it unclear as to whether an eligible child could receive services such as PT/OT/Speech therapy if they have a delay in only one developmental area; a change in specific timelines; lack of direction to MAWA agencies when parents make a verbal request for an evaluation; reevaluations every two years, which is problematic because of the age and learning rate of pre-school children. Specifically, at age two, a variety of options should be available to ascertain the best venue for service in such a transitional time period for child development.

MORE:

Children's Center Testimony 10/13/00, Page 2.

In addition, in a further review of the proposed regulations, parents and professionals have reported the following additional concerns:

A proposed screening process that would prevent some children from receiving a full evaluation; insufficient requirements & qualifications for service coordinators; a new position called an "early interventionist", who can be hired with less than a bachelor's degree and whose role is unclear; lack of clarity about who is required to be on the evaluation and IFSP teams; lack of requirement for a written evaluation report; no mention of the authority of IFSP teams to make decisions about appropriate services and environments; no timelines for program implementation after an IFSP is written; and a confusing conflict resolution & mediation system.

Thank You

Thomas R. Hawkins Ph. D. Executive Director Children's Center of Mercer County Pennsylvania

To:

Mel Knowlton

PA Department of Public Welfare

From:

Elisabeth D. Gottus, M.Ed. PT/OT Coordinator for COMPRO of Arc Allegheny 7/1 Bunghom St. Pak. Pa 15303

Date:

October 13, 2000

Re:

Proposed Early Intervention Draft Regulations

Good Morning. First, I would like convey my appreciation for the opportunity to comment on the proposed regulations for Early Intervention services in Pennsylvania. As a twenty-year veteran in the field of Early Intervention, I have worked directly and indirectly with the families who have benefited from our services. Through the years, I have seen many changes transpire and as a result, I truly understand the need for all of us to have clear, defined regulations in Early Intervention.

At the risk of sounding redundant, there are many positive changes that are addressed in the current draft that I fully support. However, in order to ensure quality services for families and children, there need to be changes and clarifications made to the proposed draft.

The following issues are the ones that I feel most strongly about: Number one . . . The requirements and qualifications for Service Coordinators needs to be revisited because of the complexity of this position. A service coordinator must be multi-faceted and requires a wide range of expertise in order to do a competent job. As the first contact, it is imperative that the service coordinator make an impact in terms of providing professional support and guidance to the family. From my past experience in working with families, this is a time when parents may feel overwhelmed and have many questions regarding the system, child development, and future concerns. The requirements and qualifications for service coordinators need to reflect the complexity and diversity of the families we serve.

Secondly, what exactly is an early interventionist and how does this person's role differs from service coordinators, therapists and supervisors? The qualifications listed for this position are broad and do not meet the criteria for what families want in a therapist or special educator Either we clarify or eliminate this position.

Third, the document needs to reflect early intervention language and not Refer only to the "mentally disabled. We provide services to infants and Toddlers who have only physical, sensory delays or speech delays.

Fourth, please reconsider the role foster parents have in early intervention

and the children they agree to take care of. They participate in the child's therapy and carry over the suggestions and recommendations. They need to be included in the definition of "Parent" when they are involved in early intervention.

Please consider our comments and suggestions . . . Your time and efforts are greatly appreciated.

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REVIEW COMMSSION

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