Quality & Fairness in Pennsylvania's Public Schools
EDUCATION LAW CENTER

July 11, 2000

Mr. Mel Knowlton
PA Department of Public Welfare
P.O. Box 2675
Harrisburg, PA 17105-2675

RE: Proposed Infants and Toddlers Regulations

Dear Mel:

Enclosed you will find the comments of the Education Law Center – PA regarding the above. I'd be happy to discuss any of these matters with you further if you would find that helpful. Thanks for this opportunity for input.

DEFINITIONS

4226.5: The state definitions are drawn, virtually verbatim, from the federal regulations, and are generally fine. I have problems/suggestions with regard to the following:

- County MH/MR program (legal entity) is defined as an entity that "provides a continuum of care for the *mentally disabled*." Given that the I&T population also includes children who are physically impaired and have sensory impairments, that description is inadequate and may confuse or deter some families from asking for services. I would suggest "persons with disabilities."

- The definition of "early intervention services" should include the phase, "including, but not limited to, the following:

- In the definition of "parent," the Department should make clear that no employee of a public *or private* foster care agency can be considered a parent. (This does not include foster parents, who are not, "employees of an agency"; see below for argument that use of foster parents should be maximized).

  Moreover, this definition should make clear that, in certain circumstances, a foster parent is considered to be a "parent" (not just a person who is eligible to be appointed as a surrogate parent). A foster parent is considered to be a parent when: the natural parents' authority to make decisions has been extinguished under

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state law (the regulation should make clear that this means that parental rights have been terminated, or other clear state court action has taken place); the foster parent has an ongoing, long-term parental relationship with the child; the foster parent is willing to undertake these responsibilities; and there is no conflict of interest. 34 C.F.R. Section 303.19(b).

- The Department should also add a definition of "tracking," partly drawn from the 1997 regulations: "A systematic process to monitor the development of infants or toddlers who are at risk for a delay or disability to determine whether they have become eligible for early intervention services."

FINANCIAL MANAGEMENT

4226.12 (Waiver funds): A County does not completely control whether Waiver funds can be expended; that depends on whether there are enough eligible services and eligible children whose parents have agreed to participate. Therefore, the following phrase should be added at the end of the paragraph: "to the extent that eligible services and eligible children can be identified, and the children's parents consent to participate in the Waiver."

4226.13 (Nonsubstitution of Funds). It is appropriate and important to encourage counties to use private and public revenues to the extent possible, consistent with protecting families' rights. However, counties can't be held accountable for not using funds which are not accessible because the parents will not consent to their use. This section should be rewritten as follows:

> (a) Early intervention State funds may not be used to satisfy a financial commitment for services which could have been paid for from other public and private funding sources, so long as the use of those funds is without cost to the families, and the families have consented. A legal entity is responsible for providing all of the early intervention services in the child's IFSP whether or not those services are eligible under the Medicaid program.
>
> (b) Parents cannot be required to apply for Medicaid in order to receive early intervention services. Parents who have private insurance are not required to use their insurance. After being informed of their right to refuse consent, the parents may volunteer to use their insurance only if they will not suffer financial losses, which include, but are not limited to, one or more of the following:
>
> (1) A deductible, or a decrease in available yearly or lifetime coverage, or any other benefit under an insurance policy.

4226.15 (Documentation of other funding sources). For similar reasons, section (a) should be rewritten as follows:

Written documentation that all other private and public sources available to the child and family that can be used without financial loss to the child and family, and to which the parents have consented, have been accessed and exhausted shall be kept with the child and family's permanent legal entity's file. In no case shall a child's early intervention services be delayed in order to secure public or private sources, nor should services included in a child's IFSP be adjusted to reflect available funding sources .

GENERAL REQUIREMENTS

4226.23 (Waiver eligibility). To accurately reflect the Waiver process, I would recommend the following changes in subsection (a): "The legal entity shall ensure that if infants and toddlers until the age of 3 are eligible..., and with the parents' consent, as follows:

4226.24 (Comprehensive child find system): The regulations do not include any reference to the federal requirements that there be a "public awareness program," in addition to a child find system. 34 C.F.R. Section 303.320 requires the system to inform the public about the early intervention program. Moreover, with respect to "child find" itself, the regulations simply pass on to the County the responsibility for these functions, including coordination with and avoidance of duplication among child serving agencies. Clearly, there is an important role for the county, but the state has to create the infrastructure through, *e.g.*, memoranda of understanding. The regulation should state that the legal entity will perform these functions, "with the assistance of the State."

4226.24(f) (timelines): The section is very confusing. It does not make clear that, for a child determined to be eligible for services, the IFSP must be developed within 45 days of referral. [34 C.F.R. Section 303.342(a)]. Under this language, the timeline is satisfied if the child is only evaluated within the 45 day period. And it suggests, at 4226.24(f)(2)(iii), that the multi-disciplinary evaluation (MDE) could be bypassed altogether in favor of a plan for further assessment and tracking, which is also inconsistent with the federal requirements. [See, e.g., 34 C.F.R. Section 303.322(a)(1)].

4226.25 through 4226.29 (Screening): I believe this screening process is inconsistent with the federal regulations. Those regulations state that, within 45 days of the date the "public agency" (here the county) receives a referral, the public agency shall, "[c]omplete the evaluation and assessment activities...." [34 C.F.R. Section 303.321(e)]. This screening process does not comply with these requirements, but can still result recommendations that can only be made after a full MDE. These provisions should be removed.

However, it is entirely acceptable (and in the case of evaluations secured by the family mandatory) for the MDE team, with the family's consent, to consider the results of prior evaluations. Nothing in these comments should be construed as disfavoring such an approach – so long as the entire MDE complies with federal and state requirements, and only the MDE team

makes recommendations that are committed exclusively to its authority and expertise.

4226.35 (Preservice training): The Department should add to this list training in community resources and family centered planning and service delivery.

PERSONNEL

4226.54 (Requirements and qualifications [of service coordinators]: This is one of the most important issues in the proposed regulations – the level of expertise that the service coordinator must have to do this job competently. From the first draft (and these credentials are at a lower level than in either of the 2 earlier drafts), we and others have expressed our concern that these qualifications are inadequate. For example, a service coordinator could have an associate's degree *in any subject area*, and three years' work or volunteer experience in management or supervision, and qualify. There is no requirement that the service coordinator bring to this task training or even experience in child development, the needs of children and families with disabilities and so forth. We attach to these comments the proposal that we submitted to the Department in 1998, which was based on input from professionals in the field. We believe that the qualifications should reflect the competencies required, a position that we believe the Department embraces. This 'competency based' approach was used with respect to service coordinators when the Department contracted with Dr. Phillipa Campbell in (approximately) 1997.

We also think that the regulations should include a caseload maximum for service coordinators, so that we can be certain that they can perform their complex responsibilities adequately. In the early years of this program, the state informally used 35 children with active IFSPs as a guideline. Some think even this is too high.

4226.55-.56 (Early interventionist, requirements and qualifications): This is also a hugely important issue. Through these regulations, the Department has created a new type of early intervention service and provider, described here in only the most general terms. It is unclear how this service differs from that provided by the service coordinator and the special educator. What does it mean to, "implement the child's IFSP directly or by supervising the implementation of services provided by other early intervention personnel?" If the person is delivering special instruction, he is a less qualified person usurping the role of the special educator. And, how can such a person "supervise" other qualified and licensed early intervention personnel? If the person is simply coordinating the services in the child's IFSP, he is usurping the role of the service coordinator.

These questions become more urgent when one reviews the relatively minimal requirements for such a staff person. Again, the person could have an associate degree *in any subject matter* and three years volunteer work with children (say at a camp for children with disabilities), and qualify as an early interventionist. Again, we submitted an alternate proposal to the Department in 1998, to which we never received a substantive response.

I believe that the creation of this position, and in particular the setting of qualifications for this position that are less than those of a special educator, are a violation of, among other things, the federal requirement 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). In August, 1999, I sent a letter to the Department in which I detailed my legal objections. I have received no substantive response to this letter either.

4226.57 (Effective date of personnel qualifications): This provision grandfathers in indefinitely service coordinators and early interventionists **with even fewer credentials than are required by these regulations.** While it is reasonable to give personnel some time to come into compliance, the regulations should require all such staff to meet applicable standards within a four year period. (In fact, I believe that such a requirement is mandated by federal law. See, *e.g.*, 34 C.F.R. Section 303.361(c) and (e), which require a state that does not have sufficient qualified personnel to include in its Application timelines for the retraining or hiring of personnel that meet appropriate professional requirements; and that in case of shortage permit a state to use "the most qualified individuals who are making satisfactory progress toward completing applicable course work....").

EVALUATION AND ASSESSMENT

4226.62(a)(2)(MDE): This provision requires an evaluation by someone other than the provider in all cases. It is, in general, a good idea for the evaluation to be done by personnel independent of the provider who will deliver the services – it reduces the likelihood that the child will be determined to need only those services that the provider has available. On the other hand, there needs to be some "exception" process for those situations where a particular type of evaluator is needed in a region of the state where no comparably skilled independent evaluator is available. Perhaps the regional office could play a role in this.

Moreover, the language is ambiguous and will lead to confusion in the field. It states that the person performing the MDE must be, "independent of service provision." Does that mean that they will not be providing services to the child who is the subject of the evaluation; that they cannot in the future provide services to that child; or that they are not providing early intervention services to any child? I understand that counties are currently implementing this requirement in a variety of ways because of this confusing language in Department directives.

Some additional issues regarding the MDE process are:

- The regulation should require that a written MDE report be shared with the family before the IFSP is developed. Otherwise, families are without the information they need to participate effectively in the IFSP meeting. (This is required for students covered by Part B of the IDEA);

- The regulation should require that parents be given advance written notice that they can ask that other persons participate in the MDE or the IFSP meeting, and

that they can bring whomever they wish to these meetings.

4226.62(d): This provision should make clear that the 45 day period runs from the date of referral, and that, for children determined eligible, the initial IFSP meeting must also be held within this time period. 34 C.F.R. Section 303.342(a).

IFSPs

4226.72(b)(Procedures for IFSP development, review and evaluation): The federal regulation states that IFSPs shall be reviewed at 6 month intervals, or more often, "if the family requests such a review." 34 C.F.R. Section 303.342(b)(1). This phrase should be added to this provision.

4226.73 (Participants in IFSP meetings and periodic reviews): This is the list of personnel required by the federal regulations. However, this provision should also state that the service coordinator must have the authority to commit the County's resources, or someone with that authority must attend. The IFSP team (and not the County) has the responsibility, and therefore must have the authority, to make decisions as to what a child needs – and therefore what must be listed on the IFSP. We have received complaints that teams have reached tentative decisions, but that the ultimate decision has been referred to the County. Such a process violates the law, and would be avoided with the above addition.

4226.74 (Content of IFSP): The IFSP must include the "location" (this term defined, but it does not state that the location must be listed in the Plan).

4226.74(7)(i) (Dates, duration of services): This provision includes the phrase from the federal regulations, namely, that the services must start, "as soon as possible after the IFSP meetings." Timely implementation of IFSPs is key to the success of the whole system – and has been problematic in many counties (see, for example, the situation in Philadelphia which led to litigation; and in Montgomery County where the Regional Office had to order corrective action). The only way to make sure that families are clear on their rights, and that counties are clear on their duties, is to set a deadline – and we suggest 14 days, the timeline suggested by DPW in one of the earliest drafts of the regulations. I consider this one of the most important issues in these regulations; without this kind of clarity, many children will be denied needed services.

4226.74(9)(transition): First of all, this section should include the transition components in 34 C.F.R.303.344(h), which spell out the extent to which the IFSP must provide for training and discussions with parents; require steps to help the child adjust to the new setting; and clarify whether records can be transmitted. Given that the state regulations will replace the federal regulations as guidance to the field, it's important that these requirements be explicitly listed. In addition, the state has agreed, and has put in its Bulletin, that "pendency" applies between these systems, and that children cannot be dropped from the service in the IFSPs at 3 because their parents do not agree with the services offered by the MAWA. This requirement should be

regulatory.

We also recommend that this provision contain the language in the current (and proposed) Bulletin/BEC on transition, that the child's program and placement remain the same during the transition year, unless there are programmatic (rather than administrative or funding) reasons for the change.

PROCEDURAL SAFEGUARDS

4226.91 (General responsibility of legal entity for procedural safeguards): These regulations make no mention of the complaint management system required by 34 C.F.R. Sections 303.510-.512. In fact, contrary to the federal requirements, Section 4226.97 (prior notice) does not state that the written notice must describe, "[t]he State complaint procedures..., including a description of how to file a complaint and the timelines under those procedures." Parents simply do not know that this system exists and how to use it, despite the State's obligation under the federal regulations of, "widely disseminating to parents and other interested individuals, including parent training centers, protection and advocacy agencies, independent living centers, and other appropriate entities, the State's [complaint management] procedures...." 34 C.F.R. Section 303.510(a)(2). Since the State has chosen to include the federal language on all other requirements, it should also include this requirement, with appropriate modification to reflect the PA procedure.

4226.96 (Opportunity to examine records): This section should include the applicable federal procedures, and should also state (this is a PA option) that families can have access to copies of their records without cost.

4226.97 (Prior notice; native language). In addition to the point made above, the regulation deletes the phrase in the federal regulations that notice must be, "written in language understandable to the public." This is an important protection. 34 C.F.R. Section 303.403(c)(1).

4226.101(b)(1)(Parent rights in administrative proceedings): Parents often cannot afford to retain an attorney, and the regulation should make clear that the parents can utilize the services of whomever they wish to assist them at a hearing. We recommend the use of the language that applies to children covered by Part B of the IDEA: "Parents may be represented by any person, including legal counsel." 22 Pa. Code Section 14.64(h).

4226.102 (Impartial hearing officer): This section includes the federal language on impartiality, but not the language on qualifications and duties (which were, by the way, the subject of litigation in *Jill D. v. DPW*, when DPW was using hearing officers from the Fair Hearing System who were not knowledgeable about these children or these laws). 34 C.F.R. Section 303.421 states that hearing officers must, "have knowledge about the [early intervention law] and the needs of, and services available for, eligible children and their families." It also lists the hearing officers' "duties."

4226.103 (Convenience of proceedings; timelines): The section does not, in fact, contain the timeline for resolving hearing requests, which is 30 days. 34 C.F.R. Section 303.423(b).

4226.105(f) (Surrogate parents): This section confuses the federal criteria for when a foster parent is considered to be a parent, with the criteria for when a foster parent is eligible to serve as a surrogate parent. The result is that this regulation would significantly limit foster parents' ability to serve as surrogate parents for children in their care. See 34 C.F.R. 303.19(b) and discussion above under definition of "parent."

Limitations on foster parents serving as surrogate parents are extremely ill-advised, since foster parents are the ones with physical access to, and the daily responsibility of care for, these children – and are most often the best (and sometimes the only) adults able to perform this function. Very rarely do counties (or local educational agencies for children of school-age) maintain a pool of surrogate parents, and many delays (and sometimes gaps in program) occur because no one is legally competent to give consent or to authorize services. I recommend restoring the language from the 1997 draft, which stated: "A foster parent is eligible to serve as a surrogate if all requirements for surrogate ... are met." Section 4225.196(d). [See 34 C.F.R. Section 303.406 for applicable criteria for surrogate parents].

We also strongly urge the Department to restore Section 4225.194(b) of the 1997 draft (which authorized the County program to appoint a surrogate parent at the request of the parent under certain circumstances), and Section 4225.201 (which protects surrogate parents from liability if they perform their duties in good faith). The Education Law Center has surveyed all of the counties regarding the problems they encounter in providing services to children in foster care. It is clear that there are many problems. Making the surrogate process easier and more effective will be a big help.

IMPORTANT OMISSIONS

A key criticism of this draft is that it omits some progressive and essential requirements from earlier drafts. Just before the 2 year review of the 1998 draft began, as a follow-up to the last stakeholder meeting, I sent to DPW a list of the provisions whose elimination would most hurt kids and families. In addition to those already included above, I would add the following:

1997 Draft on Health Component of MDE (Section 4225.126), which gives clear direction to counties in an area that is unfamiliar, and will go far towards insuring that service coordinators meet their obligations to coordinate, "the provision of early intervention and other services (such as medical services...) that the child needs or is being provided." 34 C.F.R. Section 303.22(23)(ii).

1997 Draft on Independent Evaluations (Section 4225.72). Although the old version wasn't perfect, it made clear that families could request one independent evaluation per year, at the expense of the County program. The settlement in the *Jill D.* lawsuit, and the current Bulletin

resulting from that lawsuit, in fact required that an evaluation at public expense be provided whenever a parent requests a hearing. This should be added to the 1997 draft language.

Many parents do not have the resources to secure independent information about what their child needs. Often, this information will confirm the County's offer, and will leave all parties with confidence that the IFSP is correct. But, in the context of a hearing, such evaluations are crucial if the family is to have a meaningful chance to present its case to the hearing officer, and this information should not be available only to families with resources.

Thanks for this opportunity for input.

Very truly yours,

Janet E. Stotland
Co-Director

Public Comment #25

SPIN, Inc.
Special People In Northeast, Inc.

Original: 2122

July 21, 2000

Mr. Mel Knowlton
Department of Public Welfare
P.O. Box 2675
Harrisburg, PA 17105-2675

Dear Mr. Knowlton:

Attached please find comments and recommendations related to the proposed Early Intervention Services regulations published in the Pennsylvania Bulletin on June 3, 2000. We've been working toward this since 1994, and I was concerned that I would retire before seeing it to completion. Thank you for the open and professional way you have worked with stakeholders over the years. I appreciate the opportunity to participate in this process.

Sincerely,

Trina Losinno

Trina Losinno
Executive Director

xc: Robert Nyce, IRRC
Representative Dennis O'Brien
Senator Harold Mowery
Elizabeth Yarnell

Early Intervention Services Regulations
55 PA.CODE CHS.4225 and 4226

Comments and Recommendations on Proposed Rulemaking

Preface Section

#4226.35-.37 (relating to training; preservice training; and annual training)

Concern: *The Department will determine how many hours of training early Intervention staff will receive on an annual basis.*

Issue: In order to plan and budget for training, providers need to have a firm number of hours of training that staff are required to take each year.

Recommendation: Staff will be required to take 24 hours of training annually which includes topics in early childhood development areas, health concerns of children and renewal of required certifications such as first aid, fire safety, CPR, etc.

Summary of Fiscal Note

Concern: *It has been determined that the requirements of these regulations are cost neutral.*

Issue: When the study was done by the department to determine appropriate rates, the impact of PART C of the IDEA, the Infants, Toddlers and Families Waiver, documentation and monitoring protocols and, as introduced in the proposed regulations, the requirement for staff training were not factors. As these elements have developed, providers have had only COLA increases. No adjustments have been made to the rate for additional requirements which are not billable units of service.

Recommendation: Authorize a rate adjustment.

#4226.23 Waiver Eligibility

Concern: (a)(1)(ii) *Performance that is slightly higher than two standard deviations. . .*

Issue: The interpretation of slightly will differ across the state and would arbitrarily cause some children to be eligible and others to be ineligible.

Recommendation: Clearly define the criteria.

#4226.24 Comprehensive child find system.

Concern: (f)(2)(iii) *Develop a plan for further assessment and tracking.*

Issue: IDEA, Part C requires the IFSP to be developed within the 45-day timeframe. A plan for assessment and tracking is not an IFSP.

Recommendation: Delete (f)(2)(iii) as an option.

#4226.26 Purpose of Initial Screening

Concern: *The purpose of the initial screening shall be to determine the need for referral for an MDE to determine eligibility for early intervention services or tracking.*

Issue: The screening process should not be used to determine eligibility which is what it does if a child is refused an MDE based on the results of the screening. This is of great concern in light of the haphazard "screening" process that occurs across the state.

Recommendation:

1. More clearly define "screening."
2. Develop a universal screening procedure to be implemented by all legal entities.
3. Add to the regulation at section 4226.28 (4a) that requires the parent to be informed of the screening results in writing and which states their right to an MDE in the event that they disagree with the screening results.

#4225.27 Content of Screening

Concern: *Entire section.*

Issue: The screening process is inadequate and subject to great variability across the state and even within each legal entity.

Recommendation: Require a screening process that is standardized, universal and implemented and interpreted by trained professionals.

#4226.35 Training

Concern: *Professional and paraprofessional personnel who serve on the interdisciplinary team or who provide direct care or service to a child shall be certified, licensed or registered, as approved by the Department of State, for the discipline that they are providing.*

Issue: What job category does this pertain to? I assume therapists but am not sure since paraprofessionals are included.

Recommendation: Include in the section job titles for whom the section applies.

#4226.36 Preservice Training

Concern: (a) *Training. . .(for all staff), as well as for the early interventionist and other personnel who work directly with the child. . .*

Issue: It is unclear what (for all staff) means when it seems to be explained by what follows.

Recommendation: Delete (for all staff).

#4226.37 Annual Training

Concern: (a) *relating to 24 hours of in-service training specific to early intervention services.* (b) *relating to training in certification areas that require annual recertifications.*

Issue: Requiring more than 24 hours of training annually is a burden to the employee as well as a financial burden to the provider. It also takes away time available to provide service to children and families.

Recommendation: Combine the elements of (a) and (b) to require 24 hours of training annually in the combined topics. See the recommendation at 4226.35-.37 for wording.

#4226.38 Criminal history records check

Concern: *The section details criminal history record checks.*
Issue: There is no requirement for child abuse clearance through the Department of Public Welfare under Act 33.

Recommendation: Require all staff who have direct child contact to comply with Act 33.

#4226.54 Requirements and Qualifications (relating to service coordination)

Concern: (a) *A minimum of one service coordinator intervention service shall be employed directly or through subcontract by the legal entity.*

Issue:
1. Lacks clarity.
2. A maximum caseload size should be added to safeguard ability of the service coordinator to provide appropriate services since this is a critical activity in early intervention.

Recommendation:
1. Delete the words "intervention service" from the sentence.
2. Set a maximum caseload size of 35 children per service coordinator.

Concern: (a) *A service coordinator shall have one of the following groups of qualification:*
(1),(2)

Issue: Qualifications are insufficient for the job responsibilities.

Recommendation: Delete (1) and (2). Add a new (1). A bachelor's degree in a field related to early childhood, special education, psychology, social work or family studies and one year of paid experience working directly with children and families.

Issue: Volunteer experience is not recognized in the State Civil Service Commission and is not a good indicator of the acquisition of needed skills since there is not usually a formal evaluation of a volunteer's work for a reference point when hiring.

Recommendation: Delete volunteer experience.

Issue: Qualifications should incorporate the tenets of IDEA, Part C, Section 303.344(g):

Recommendation: Include in the qualifications: "Service coordinators must be persons who have demonstrated knowledge and understanding about:

1. Infants and toddlers who are eligible under this part;
2. Part C of the Act and the regulations under this part; and
3. The nature and scope of services available under the State's early intervention program; the systems of payment for services in the state, and other pertinent information.

#4226.55 Early Interventionist

Concern: *The title.*

Issue: Is this a general term for all staff who provide direct service to the child and family, excluding the service coordinator? Or is it the person who provides special instruction?

Recommendation: Define early interventionist as the person who provides special instruction. Consider adding a section to define other early intervention personnel, i.e. therapists, supervisors, aides, etc.

Concern: (2) *Implementing the Child's IFSP directly or by supervising the implementation of services provided by other early intervention personnel.*

Issue: If early interventionist means the person who provides special instruction, then it would be unacceptable for that position to be supervising others. If early interventionist includes supervisory and/or management personnel, then the entire responsibilities section becomes a problem.

Recommendation: delete from ". . .or by supervising" etc. to "other early interventionist personnel."

Concern: (3) *Working with the family to assure that the needs of the child and family are met.*

Issue: This is a service coordination responsibility.

Recommendation: Delete (3) from the section.

#4226.56 Requirements and Qualifications

Concern: (a) *An early interventionist shall have one of the following groups of qualifications: (1) and (2).*

Issue: The qualifications are inadequate to carry out the job responsibilities, particularly when these responsibilities are carried out in the home and community where there is only intermittent supervision available.

Recommendation: (1) A bachelor's degree in a field related to special education, early childhood education, psychology or other fields which relate directly to child development or child disability. Delete the requirement of experience; the field needs to compete with the education system for these people.

Issue: Need for specialized training for providers working with children having low incidence disabilities.

Recommendation: Add a section which states "All personnel who work with children who have low incidence disabilities must be specifically trained to meet the needs of the children with these disabilities."

Issue: Volunteer experience.

Recommendation: Volunteer experience is a poor indicator of the acquisition of needed skills since there is not usually a formal evaluation of a volunteer's work for reference point when hiring.

Concern: (b) *An early interventionist shall obtain six credit hours annually. . .*

Issue: This is an undue hardship on employees who are underpaid, are already required to do at least 24 hours of in-service training and who already have degrees in these areas. It is also unreasonable to expect this requirement to be a condition of employment forever. This requirement also has cost implications for the provider. According to information from the U.S. Department of Labor, this would be considered "involuntary attendance" and would be considered hours worked. The provider would have to pay for all hours in the classroom. Also, the Portal-to-Portal Act would require that time and travel expense would have to be paid if the employee had to leave work and go directly to class and/or had to return to work from class. It is unclear, at this time, whether the employer would have to pay tuition in all cases; however, due to this provider's union contract, we would be required to do so.

Recommendation: Delete this requirement.

#4226.62 MDE

Concern: (2) *The initial MDE is conducted by personnel independent of service provision.*

Issue: Precludes anyone who does even one MDE from ever providing early intervention services. Also, there may be appropriate exceptions to independent MDE provision. One may be in geographic areas where appropriate professionals who could do MDE's are also the only one who can provide the needed service. another would be in the case of parental request to have the evaluation and the service be provided by the same professional.

Recommendation: Add the word future before service provision. Add a paragraph allowing for exceptions to this regulation that would permit the legal entity the ability to provide the MDE and the needed service in the manner most appropriate for the child and

family.

Concern: (2) *The annual MDE will be composed of the family, service coordinator, anyone whom the parent would like to invite and at least one other professional.*

Issue: This does not constitute a multidisciplinary team due to the fact that only <u>one</u> professional discipline is required to be represented. Service coordination is a service, not a discipline. The federal definition of multidisciplinary (Part C, Sec. 303.17) "...means involvement of two or more disciplines or professionals. . ."

Recommendation: Expand the MDE team to include two disciplines or professionals.

<u>#4226.72</u> Procedures for IFSP development, review and evaluation.

Concern: (b) *The IFSP shall be evaluated once a year and the family shall be provided a review of the plans at six month intervals, or more often based on infant or toddler and family needs.*

Issue: The "or more often. . ." is too subtle.

Recommedation: Please add to the end of the sentence ". . .and/or as requested by the family or other team member."

<u>#4225.73</u> Participants in IFSP meetings and periodic reviews.

Concern: (4)*The service coordinator. . .responsible for implementation of the IFSP.*

Issue: The service coordinator or designee of the legal entity who has the authority to commit the resources of the legal entity to carry out the IFSP should be at the IFSP meetings and reviews.

Recommendation: Add to the end of the sentence "and who has the authority to commit the resources of the legal entity to carry out the IFSP.

Concern: (6) *Persons who will be providing services to the child or family, as appropriate.*

Issue: Presence of providers of service must be required to be present or represented.

Recommendation: Delete the words as appropriate.

#4225.74 Content of IFSP

Concern: (a) *"Frequency" and "intensity"*. . .
(b) *"Method"*. . .
[iv) *"Location"*. . .

Issue: In the past, it has been known that team decisions around these three areas have not always been honored by the legal entity. The IFSP then becomes driven by cost factors or other agendas.

Recommendation: In the regulations a statement needs to be made that indicates respect and commitment to the teams' decisions by the legal entity. Authority for this comes from a letter from OSEP to Mr. John Heskett (5/26/99), "In all instances, individual determinations must be made by the participants on the Individual Family Service Plan (IFSP) team, which includes the parent(s), regarding the services to be provided to an infant or toddler. . ."

#4226.74

Concern: (5) *Natural environments.*
Issue: Statement needs strengthening.

Recommendation: Add to the paragraph, "If it is the decision of the IFSP team that it is appropriate for all or some of the services to be provided in settings other than the natural environment, justification shall be made in writing in the IFSP during the initial and/or annual IFSP meeting. Funding for the services provided in settings other than natural environments will not be unreasonably withheld by the legal entity.

#4226.74

Concern: (7) *Dates; duration of services. The IFSP shall include the following:*
(i) The projected dates for initiation of services. . .

Issue: There are no number of days specified for implementation of the IFSP. "As soon as possible" is too subjective.

Recommendation: Delete (i) as it is and replace it with: The IFSP must be implemented within 21 days of the IFSP meeting unless otherwise requested by the parent(s).

#4226.75

Concern: (8) *Service coordinator. The identification of the service coordinator from the profession most immediately relevant to the infant's or family's needs...*

Issue: While this is the way service coordination should take place on a truly transdisciplinary team, it is not the current reality. There is an existing independent service coordination system in place in each of the legal entities. If a family believes that the best team member to coordinate services for their child is the physical therapist and not the service coordinator, it raises the issue of independence of service provision and service coordination, and due to the rate structure, the PT's hours doing service coordination would not be billable.

Recommendation: Delete (8).

#4226.72 (9) Transition for early intervention services.
Concern: (B) *Review the child's program options for the period from the child's 23rd birthday through the remainder of the school year.*

Issue: 23rd birthday must be an error.

Recommendation: Change to 3rd birthday.

Concern: [c](iii) *This section does not exist currently.*

Issue: Pendency is not addressed here.

Recommendation: Please consider discussing pendency in this section as well as in 4226.104.

#4226.101

Concern: (1) *To be accompanied and advised by counsel and by individuals with special knowledge or training. . .*

Issue: Many families do not have the means to hire legal counsel.

Recommendation: Change to: To be accompanied and advised by counsel and/or by individuals. . .

#4226.102 Impartial hearing officer

Concern: *There is not a section which states the qualifications or the duties of the hearing officer.*

Issue: Needed for clarity and consistency.

Recommendation: Add qualifications and duties of the hearing officer to the section.

#4226.103 Convenience of proceedings; timelines

Concern: *A proceeding for implementing the administrative resolution process shall be carried out at a time and place that is reasonably convenient to the parents.*

Issue: Does not meet standard of IDEA, PART C, Section 303.423(b).

Recommendation: Add "and within 30 days" to the end of the sentence.

Public Comment 17

Original: 2122

TO: Department of Public Welfare
Mel Knowlton
P.O. Box 2675
Harrisburg, PA 17105-2675

FROM: Elaine Moore, PhD
Director of Preschool and Parent Infant Programs
Western PA School for the Deaf

RE: TITLE 55. Chapter 4226. Early Intervention Services

DATE: July 20, 2000

Please note the following comments:

• First, in definitions, 4226.5, under the definition for *Early Intervention Services, (vi) provided by qualified personnel...(A) Special educator.*

This section would assure better service to parents and children if it read "special educator with specific expertise to address the child's needs, including cognitive, physical and/or sensory (deafness or blindness) related needs"

This same language change would be appropriate at 4226.74 regarding the IFSP and specifically under 4226.74 (4) (ii) (M) Special educator.

When providing services for children with deafness, it is critical that the special educator who interacts with the child and parents is knowledgeable about the communication needs of a deaf child and how those needs impact the language development, future education, and life of a child. The child's educational and lifelong success will be greatly dependent on early and efficient access to a communication system. This will include extensive assistance to the parents both to gain the information they need to effectively parent the child and to develop skills in interacting with a child who is dependent upon visual communication. Too often, professionals with little expertise in sign language development, social interaction, and communication needs of deaf infants and young children are those selected to offer support and information to families. At a time when parents are called upon to make critical decisions regarding their child's development and education, they need to have regular and expert information regarding their child's educational options and potential. Given the current wording in the new regulations, responsible agencies could appoint any "special educator" to provide in home services. Although the regulations acknowledge the need for speech therapists to provide speech services for some children and for audiologists to provide clinical evaluation of hearing, there is no consideration of specific knowledge and expertise being required of the "special

educator" who will address the needs of families as they raise their deaf infants and toddlers.

• Second, in 4226.30, At-risk children, there is no mention of children with a family history of hearing loss. An item could be added:

(_) Children who have a family history of a genetically related condition such as deafness or hearing loss.

Language development begins at birth, and language is the basis for all communication and future learning. A child born with a significant hearing loss is at great disadvantage if his parents are hearing and have no visual communication system. Many children with genetically linked deafness have hearing parents who will not attend to the possibility of their child's being deaf except through early diagnosis and intervention.

Thank you for this opportunity to offer comment on these regulations.

Elaine Moore

Original: 2122

Public Comment #33

Children's Seashore House *of* The Children's Hospital *of* Philadelphia

3405 Civic Center Boulevard
Philadelphia, Pa. 19104-4388
215-590-1000

Attention Deficit Disorders Clinic
Child Evaluation Clinic
Medical Specialty Clinics
Neonatal Follow-up
Neurodevelopmental Evaluation
Nutritional Counseling
Occupational Therapy
Physical Therapy
Psychological Services
Social Work
Speech/Language Therapy

2000 AUG -1 PM 2:34

REVIEW COMMISSION

July 21, 2000

Mel Knowlton
Pennsylvania Department of Public Welfare
P.O. Box 2675
Harrisburg, PA 17105

Dear Mr. Knowlton:

I have enclosed my comments regarding the proposed changes in Pennsylvania's regulations regarding early intervention services for infants and toddlers. Thank you for the opportunity to address the Department and express my opinions.

Sincerely,

Judith A. Silver, Ph.D.

Judith A. Silver, Ph.D.
Director, Starting Young Program
Department of Pediatric Psychology
The Children's Hospital of Philadelphia;
Clinical Assistant Professor of Pediatrics,
Associate Director, Leadership Education
In Neurodevelopmental Disabilities Program,
Division of Child Development and Rehabilitation
University of Pennsylvania School of Medicine

Date: July 21, 2000

To: The Pennsylvania Department of Public Welfare

From: Judith A. Silver, Ph.D.
Clinical Assistant Professor of Pediatrics,
Associate Director
Leadership Education in Neurodevelopmental Disabilities Program
Division of Child Development and Rehabilitation
University of Pennsylvania School of Medicine;
Director, Starting Young Program
Department of Pediatric Psychology
The Children's Hospital of Philadelphia

Re: Proposed Changes in the State Infants and Toddlers Regulations

I would like to comment on the recently proposed modifications to the Pennsylvania regulations regarding early intervention services for infants and toddlers. My remarks are based on over 15 years of clinical experience in the developmental evaluation and follow-up of infants and toddlers who have been discharged from neonatal intensive care units. In addition, for the past 8 years, I have directed the Starting Young Program, a developmental follow-up program infants and toddlers in foster care, and served as its psychologist. I am also writing from the perspective of the training director of federally-funded fellowship program for professionals in pediatric and allied health fields, which promotes leadership training in the interdisciplinary care of children with developmental disabilities and related disorders.

Foster Parents as Surrogate Parents

Specifically, I wish to express concern that the proposed changes limit the ability of foster parents to be appointed as surrogate parents in the service of overseeing their foster children's IFSPs and early intervention programming. There is a fairly extensive body of research in the pediatric professional literature that consistently reports that children in foster care have elevated rates of chronic medical problems, developmental delays and learning problems[1]. Among children under 3 years of age, several independent studies report that 50% or more qualify for early intervention services[2]. These findings have been replicated by my own data, which includes multidisciplinary developmental evaluations of over 300 children under 31 months of age who are involved with the Philadelphia Department of Human Services[3]. The fact that half of the infants and toddlers in foster care have significant developmental delays is an extraordinary prevalence rate, and is approximately 4 times the expected rate among children in the general population[4].

There is an imperative that early intervention services should be family-centered. Consequently, it is preferable for a foster parent to serve as the surrogate parent regarding foster children's early intervention programming than for the foster care worker or legal advocate to serve in this role. It is the foster parent who likely will implement many interventions recommended by the child's early intervention therapists or educators. It is

the foster parent who observes the child daily and around the clock, who can advise the IFSP team regarding the child's needs, progress and preferences. In many cases it is the foster parent 's home in which the early intervention services are provided.

In addition, coordinating services for children in foster care is a complex and unwieldy process.[5] When it comes to implementing early intervention services, precious time can be lost in trying to recruit a surrogate parent outside of the foster family household. Foster care case workers and the child's legal advocate are unlikely to have sufficient time to attend IFSP meetings routinely, considering their heavy and demanding case loads. I am not alone in making the recommendation that foster parents should be considered to serve as surrogate parents. The Pennsylvania Children's Health Coalition 's Subcommittee for Children in Substitute Care recently published health policy recommendations,[6] which also support this recommendation. This subcommittee is composed of pediatricians and other health care professionals, child welfare professionals from the public and private sector, public health administrators and legal advocates who convened specifically to improve foster children's access to health care and early intervention services. To date the report's recommendations, including the appointment of foster parents as surrogate parents for the purposes of early intervention services, has been endorsed by a significant number of private child welfare agencies, legal advocacy agencies, and professionals who work with children in foster care.

After 8 years of working with over 400 infants and toddlers who were involved with the child welfare system, I can attest to the positive impact of early intervention services for those children who qualified. These interventions directly help the children and often provide important supports to the foster families caring for them. Consequently, early intervention services can be a positive influence in maintaining a child with special needs in a stable placement. In the absence of intervention the demands of the child's care or behavior can result in a failed placement which, in turn, will subject the baby to a change in foster homes and disruption in developmental progress. For all of these reasons I strongly recommend that the Pennsylvania Department of Public Welfare restore language from the 1997 draft which clearly indicates foster parents' eligibility to serve as surrogate parents [Section 4225.196(d)]. I also recommend the restoration of section 4225.201, which protects surrogate parents from liability if they perform their duties in good faith.

Personnel

I make the following remarks based on my experiences in the academic and clinical training of health care and allied health professionals over the course of 20 years. In the past year this experience has intensified as I assumed the position of Director of Training for a post-graduate fellowship program at the Children's Hospital of Philadelphia, the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program, which is funded by the federal Maternal Child Health Bureau. This program provides a comprehensive, demanding curriculum for professionals in many of the fields that are represented in the provision of MDEs and early intervention services: physicians, nurses, occupational therapists, physical therapists, speech/language pathologists, psychologists,

and social workers. Its mandate is to instill leadership in the interdisciplinary care of children with developmental disabilities and delays, with the overarching goal of decreasing the prevalence and morbidity of these conditions among children.

The proposed changes in Pennsylvania's Infant and Toddler regulations present a misguided effort to water down the qualifications of personnel who will be coordinating and treating infants and toddlers with developmental delays and disabilities. Specifically, in 4226.54-.56 it diminishes the eligibility requirements and qualifications for Service Coordinators and creates a position of Early Interventionist. In both of these positions the qualifications can be as little as an associate degree in *any* subject matter, in conjunction with volunteer experiences. It is troubling that eligibility for each of these positions does not require ANY academic preparation or credential in early child development, developmental disabilities or in a field related to the interventions provided to infants and toddlers with developmental delays and disabilities. Including the broad, vague category of "volunteer experience" with children provides no guarantee that the individual received any meaningful supervision, nor that supervision was from a qualified professional.

These proposed changes fail to ensure fundamental professional preparation for personnel entrusted with the coordination of services and care for children with complex needs and their families. Families relying on early intervention services expect that knowledgeable professionals will be serving and advising them in their efforts to improve their children's functioning and developmental progress. By requiring such minimal qualifications of members of the early intervention team, the state misleads families and fails to meet the federal requirement that the state's personnel standards for early intervention should be based on the "highest requirements of the state applicable to a specific profession or discipline." (20 U.S.C. Section 1435 (a) (9) (B). On these same grounds I also find 4226.57 objectionable and unproductive, in that it grandfathers in indefinitely service coordinators and early interventionists with even fewer credentials than those required in 4226.54-.55!

By diminishing the qualifications and credentials required for positions involved with early intervention services, the quality of services will be diminished, families' trust in the state and the early intervention program will be breached, and most significantly, the children's outcomes will be attenuated. The adage "Penny-wise and pound-foolish" comes to mind. I strongly urge the state to: revise the regulations for infants and toddlers and change the service coordinators' qualifications to higher standards; to clarify or dispose of the proposed early interventionist position; and to require a specific, relatively brief time period for individuals who are "grandfathered in" to achieve appropriate credentials.

References:

[1] Chernoff, R., et al., (1994). Assessing the health status of children entering foster care. *Pediatrics, 93*, 594-601. Halfon, et al., (1995). Health status of children in foster care. *Archives of Pediatric and Adolescent Medicine, 149*, 386-392.Hochstadt, et al. (1987).

The medical and psychosocial needs of children entering foster care. *Child Abuse & Neglect, 11*, 53-62. Simms (1989).The foster care clinic: A community program to identify treatment needs of children in foster care. *Developmental and Behavioral Pediatrics, 10*, 121-128. Swire & Kavaler (1977). The health status of foster children. *Child Welfare, 56*, 635-653.Takayama, et al. (1998). Relationship between reason for placement and medical findings among children in foster care. *Pediatrics, 101*, 201-207.

[2]Halfon, *op. cit.*, Hochstadt, *op. cit.*, Klee, et al.(1997). Foster care's youngest: A preliminary report. *American Journal of Orthopsychiatry, 67*, 290-299., Simms, *op. cit.*

[3]Silver, et al., (1999). Starting young: Improving the health and developmental outcomes of infants and toddlers in the child welfare system. *Child Welfare, 78*, 148-165.

[4]Baker (1989). *Education indicators*. (National Center for Education Statistics. U.S.Department of Education.) Washington, DC: U.S. Government Printing Office.

[5]Pennsylvania Children's Health Coalition Subcommittee for Children in Substitute Care (1999). *Health policy recommendations for children in substitute care in Philadelphia.* Author.

Cc: Independent Regulatory Review Committee

Public Comment 6
#14-452

EARLY INTERVENTION TESTIMONY

July 17, 2000

Good morning, I am pleased to have this opportunity to offer comment regarding the proposed Early Intervention regulations on behalf of the Dr. Gertrude A. Barber Center's Early Intervention Team of professionals who collectively possess over 225 years of experience in working with young children with disabilities. Our comments are provided sequentially in the order in which the topics appear in proposed Chapter 4226 of PA's Title 55.

1. Sections 4226.11-15 describing fiscal management requirements, primarily the language related to the role of parents' private insurance in payment of Early Intervention is not clear. The language of this section appears to imply that insurance will be billed, and Early Intervention funds will only be used in the interim until such billing begins. We are sure this is not the department's intent and suggest that a straight-forward list of funding sources and the order in which they may be accessed be written into these sections.

2. Section 4226.24 The language in this proposed section outlines general requirements, but should be revised to provide clear, specific strategies to structure and improve child find and address funding for child find. The current unit-funded mentality for all Early Intervention services does not allow a county or its providers to draw funding for required activity not directly tied to an individual child. Prior to unit-funding many provides worked in collaboration with county offices, LICC's and Service Coordinators to promote Early Intervention, to publicize the need and importance of Early Intervention, and to find children. Child specific unit-funding prevents thorough and collaborative child find. Proposed regulations should be revised to allow state Early Intervention funds to be used categorically, to fund personnel expenses related to County approved child find. Child find activity cannot be solely assumed and implemented by volunteer LICC's. If the time required to implement a thorough and successful child find system is not financially supported by the Department, the results will depend on the efforts of other systems and volunteers.

3. Sections 4226.25 through 29 related to screening. 4226.26 states that the purpose of initial screening is "to determine the need for referral for an MDE to determine eligibility for early intervention services or tracking." We are very concerned that children could be "screened out" of Early Intervention without an MDE on the basis of a Service Coordinator's interview, observation and single screening instrument. A single certified professional, should not be making this decision. Federal law entitles families to an MDE, so there should be no "screened out" or "screened and placed in tracking". These must come or recommendations of an MDT after an MDE.

4. Sections 4226.36 and 37 address preservice and annual training requirements. We applaud the Department for strengthening the professional development requirements of all staff in Early Intervention. We strongly believe that quality Early Intervention hinges on the quality educated and experienced staff. We are concerned that as a provider we would have to absorb the added financial impact of having staff available for further training as opposed to service delivery. We strongly believe that the Early Intervention regulations must include the allowance for each County to program fund providers for the time that staff are engaged in professional development activities. While training dollars are available to pay actual training costs, how will the providers recover the income lost when staff are not available to deliver "units of billable time"?

5. 4226.54 through 56 present regulations governing the requirements and qualifications of personnel. In section 54(a) allows for an individual without a college degree to deliver Early Intervention service. The success of Early Intervention for each child and family hinges on the provision of supports and services delivered by qualified, well-trained personnel. Would you entrust your child's long-term health to someone with "an associate degree or 60 credit hours"? Why, then, should parents entrust their child's development to anyone other than a certified and/or licensed professional. In asking parents if they would feel confident in a non-degreed person delivering Early Intervention, most parents responded "maybe if they had 20 years of experience in Early Intervention". The proposed regulations of this subsection do not meet IDEA Part C requirement of appropriately certified staff. Paraprofessional, individuals without degrees, working in any human service must be working directly under the supervision of certified professional, in implementing programs. This subsection of the chapter should be omitted. If not omitted, it must be expanded to significantly limit the scope of practice of an "early interventionist" or the service coordinator who does not have a four year degree.

6. 4226.61 through 63 describes the purpose, process and timelines of the MDE. Specifically, an evaluation independent of providers of service is required. This portion of the regulations provide no further guidelines than are currently in existence which have proven difficult to consistently implement across the state. In areas of the commonwealth where there was a smoothly working system that provided choice to parents in quality evaluation, the parents now have no choice for provider of initial evaluation - the "Independent Team" is it.

   The service coordinator, as representatives of the County and working for the family, should be the voice at any MDT meeting to raise questions - particularly if there is a concern about type and/or level service. If this is done, an "Independent Evaluation Team" isn't necessary.

   We believe that while the Independent Evaluation process can be run smoothly, putting the providers back in touch with the family and child from the start will lead to a more meaningful intervention plan from the outset. Participating first hand in an evaluation is much more meaningful that reading a report and interpreting the language.

I appreciate the opportunity to provide comment and wish to express our concern that publication of draft regulations during the summer will dramatically limit the number of professionals and parents available to review and comment. A longer comment period, or more public hearings, are necessary. The Early Intervention community has waited years for regulations - an additional month or two seem appropriate if it will assure more opportunity for input.

On behalf of the Dr. Gertrude A. Barber Center Early Intervention faculty, thank you.

Sincerely,

Kathleen M Bastow

Kathleen Bastow, M.Ed.
Early Childhood Coordinator
Special Education Supervisor

Public Comment 11
#14-452

Original: 2122

July 17, 2000

Department of Public Welfare
Mel Knowlton
P.O. Box 2675
Harrisburg, PA 1705-2675

UCP

United Cerebral Palsy of Beaver, Butler and Lawrence Counties, Inc.

101 Hindman Lane
Butler, PA 16001

724-482-4765 Voice/TTY
724-482-2250 Fax
ucpbbl@nauticom.net

Adult Services Program

Attendant Care Program

Children's Recreation Program

Community Home Program

Home Service Nurse Program

Homemaker Chore Program

Infant Stimulation Program
(724) 482-9215 Voice/TTY

Instructional Homemaker Program

Supportive Adult Day Services
(724) 482-4444 Voice/TTY

A United Way Agency

Dear Mr. Knowlton,

On behalf of the Board of Directors of United Cerebral Palsy of Beaver, Butler, and Lawrence Counties, Inc., I would like to offer the following comments on the proposed regulations for the infant/toddler early intervention program:

General Provisions

4226.6 Definitions

Parent. The language of this definition should also include foster parent when the parental rights of the natural parents have been terminated or interrupted due to legal action and when the foster parent has an on-going parental relationship with the child and is willing to participate in an early intervention program with the child.

General Requirements

4226.24 **Comprehensive Child Find System**

The proposed regulations do not include a requirement that a public awareness program about early intervention services be developed and implemented in addition to a child find system. This is a requirement under 34 C.F.R. Section 303.320. UCP recommends the department develop and implement a state-wide multi-media public awareness campaign which local counties can use in addition to their own local efforts.

4226.24 (f) **Timeliness**

This section of the proposal is confusing. It implies that timeliness (45 days from referral) is met as long as the child has been evaluated. As required in 34 C.F.R. Section 303.342, a child must be evaluated and an IFSP developed within 45 days of referral. The language in this section should clearly state this requirement.

Personnel
4226.54-55-56 Requirements and qualifications of service coordinators and early interventionists

Through its twenty-five years of intervention services to infants and toddlers, UCP has learned that staff do not always need to have a teaching certificate or a degree in social welfare to provide exceptional service to children and their families. What they do need, however, is a competency in child development and experience working with young children with disabilities and their families.

To that end UCP recommends that the qualifications for both service coordinators and early interventionists include competency in child development as gained through education and, if possible, experience and competency in working with young children with disabilities as gained through volunteer or employment experience of at least two years.

Thank you for the opportunity to provide input on these regulations. Please feel free to contact me at (724) 482-4765 if I can further clarify this response.

Sincerely

Pat Brennen

Pat Brennen
Executive Director

Public Comment 21

Original: 2122

July 18, 2000

To Whom It May Concern;

I have recently reviewed the Proposed Rulemaking for Early Intervention Services document. This document outlined amendments, which, if adopted, would be implemented statewide. This proposal was distributed at the OSEP Monitoring Meeting at the Early Intervention Conference, June,2000.

The concern I have and which I would like to submit for consideration relates to the current process of initial eligibility evaluations. I refer to **4226.62 MDE section(b) subsection (C).** It is proposed that the independent evaluators assess the needs of the child and determine the appropriate services to meet those needs, at the time of the evaluation. This proposal is in direct contradiction with the IFSP team process of identifying the priorities of the family, needs, strengths, and resources of the child, discussion of outcomes and strategies,followed by a **collaborative** decision process of how those needs should be met, and who should facilitate them.

Since the inception of independent evaluators, the degree of clinical/direct therapy recommendations has been dramatically increased. Providers are not part of initial evaluations for the obvious reason that services are yet to be determined. The difficulty occurs when those evaluators are unaware of the capacity of some providers to furnish both educators and therapists with transdisciplinary skill levels. We, as an agency are more than capable, in many instances, of providing language stimulation through educators, and cognitive development ideas through our motor therapists. Independent evaluators have no way of knowing the dynamics within provider agencies. It is very frustrating to think that the educational model of early intervention is no longer deemed as pertinent to a family focused IFSP, as is a therapeutic model. Funding sources are being diminished sooner with a current shifting to a more medically modeled approach to service recommendations. I fully understand the philosophy of the avoidance of a conflict of interest in the determination of eligibility. Nonetheless, it is very difficult for families to understand that more is not always better and that therapies alone will not "fix" what is broken if the state is not in obvious support of family training, education and follow-through. Furthermore, one might look upon the independent evaluator as promoting his or her discipline as the only means to providing needed supports, if one were so inclined.

The point is that it is vital to the programming of the child and to the collaborative aspects of a team approach to have a provider more directly involved with the planning phase of eligible children who are recommended for services. If the evaluation process continues in its current format, please consider having a designated provider present for the initial IFSP. If time were allotted for a provider to read the MDE report, prior to participating in the IFSP meeting, I feel that the family would experience fewer anxieties over the intervention process. The current process of evaluation and IFSP immediately following is overwhelming for all involved.

Thank you for your consideration of this issue.

Sincerely,

Denise P. Braun

Denise P. Braun
Program Supervisor
0-3 Homebased Services BARC

July 18, 2000

To Whom It May Concern:

I am responding to the Proposed Rulemaking document that outlines amendments to be implemented statewide if adopted. I need clarification on the following definitions:

Special Educator vs Early Interventionist
Mobility Specialist vs Physical Therapist -- Are these interchangeable titles for similar services?

Also, please expand on the provision of transportation and the acceptance of costs to enable a child and family to receive other services, as being a billable service. Is this provided under Service Coordination, or is it a provider responsibility?

Sincerely,
Denise P. Braun
0-3 Program Supervisor
GARC

July 18, 2000

To Whom It May Concern:

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Special Educator vs Early Interventionist
Mobility Specialist vs Physical Therapist -- Are these interchangeable titles for similar services?

Also, please expand on the provision of transportation and the acceptance of costs to enable a child and family to receive other services, as being a billable service. Is this provided under Service Coordination, or is it a provider responsibility?

Sincerely,
Denise Braun
0-3 Program Supervisor
GARC

Public Comment 12
#14-452

Original: 2122

July 20, 2000

TO: The Department of Public Welfare
Mel Knowlton
PO Box 2675
Harrisburg PA 17105-2375
717-783-5764
717-787-6583 FAX

FROM: Pennsylvania Parents of Deaf and Hard of Hearing Children
PO Box 10232
Erie PA 16514-0232

Submitted by: Diana Dougan
5045 Cider Mill Road
Erie PA 16509

PAGES: 11 including cover sheet

RE: Written comments, suggestions and objections regarding the proposed amendments regarding **Part C of the Individuals with Disabilities Education Act (IDEA) of 1997, Early Intervention Services.**

Before the
Pennsylvania Department of Public Welfare
Mel Knowlton
PO Box 2675
Harrisburg PA 17105-2675
717-783-5764
717-787-6583 fax

In the Matter of
Notice of Proposed Rulemaking
Regarding Part C of the
Individuals with Disabilities Education Act (IDEA) of 1997

Early Intervention Services
(55 PA. Code Chapter 4226)

Comments of the
Pennsylvania Parents of Deaf and Hard of Hearing Children
(PPDHHC)

Submitted by:
Diana Dougan
5045 Cider Mill Road
Erie PA 16509-3918
814-825-4872 v/tty
814-825-7261 fax

July 13, 2000

Pennsylvania Parents of Deaf and Hard of Hearing Children
PPDHHC
PO Box 10232
Erie PA 16514-0232

In the Matter of
Notice of Proposed Rulemaking
Regarding Part C of the
Individuals with Disabilities Education Act. (IDEA)
Amendments of 1997

Early Intervention Services
(55 PA. Code Chapters 4226)

Comments of the
Pennsylvania Parents of Deaf and Hard of Hearing Children

INTRODUCTION

Established in 1997, PPDHHC is a parent run organization which serves as a link between parents with experience to parents seeking answers. PPDHHC provides information, referral, and support through printed resources, a quarterly newsletter and we publish home phone numbers, home email addresses and home fax numbers of the Board Members.

PPDHHC is pleased to submit these comments to the Department of Public Welfare on the Notice of Proposed Rulemaking, Part C of the Individuals with Disabilities Education Act (IDEA) of 1997, Early Interventions Services.

We thank the Department of Public Welfare for the opportunity to comment on this important NPRM.

OVERVIEW OF ISSUES

1. The "Comprehensive Child Find System" must begin to include all deaf and hard of hearing infants and toddlers.

2. Personnel responsible for coordination, screening, evaluation, assessment and delivery of service programs must be "special educators" who are specifically trained in parent-infant education *and who are specifically trained in their area of expertise.*

3. Resulting from low incidence; screening, evaluation, assessment persons or agencies *MAY* be used for the delivery of services for deaf or hard of hearing infants and toddlers.

4. Specific disability definitions must be added or modified in these regulations to meet the unique needs of deaf and hard of hearing infants and toddlers.

ISSUES

General Provisions
4226.5 (6) Definitions.

Appropriate professional requirements
(i) Modify to read as, "Are based on the highest requirements in the profession or discipline in which a person is providing early intervention services, *specific to their area of expertise*, to enable the individual to obtain licensure, certification or registration in the profession.'

(ii) Modify to read as, "Establish suitable qualifications for personnel, *specifically trained in their area of expertise*, providing early intervention services under this part to eligible children and their families who are served by public and private agencies.

Deaf and hard of hearing infants and toddlers have specific needs. Coordination, screening, evaluation, assessment and services must be provided by people who are specially trained in this low incidence, specific disability.

Assistive technology service
(v) Training or technical assistance for a child with disabilities or, if appropriate, that child's family.
ADD: *A As in the case of deaf and hard of hearing infants, toddlers, their parents and their families, training may include instruction in a visual language such as American Sign Language.*

Communication
Definitions should include a definition for "Communication" that clarifies that communication *may* include sign language, for example, *"As used in this part, communication may include sign language."*

Sign language may be the primary mode of communication of many deaf and hard of hearing infants and toddlers. It is an important and specific need of a deaf or hard of hearing infant and toddler. This must be included in the definitions.

Early intervention program
(vi) Provided by qualified personnel, including at a minimum, the following:
ADD: *(N) Sign language instructors*

Family training, counseling and home visits
Modify to read as, "Services provided by social workers, psychologists, *special educators* and other qualified personnel to assist the family of a child eligible under this chapter in understanding the special needs of the child and enhancing the child's development."

ADD: *(i) Special educators are specifically trained in parent-infant education and who are specially trained in their area of expertise, such as a teacher of the deaf or a teacher of multiply disabled children.*

Families should receive, where appropriate, visits from special educators to help them address the *specific needs* of their child. For example, families of deaf children should receive home visits from teachers of the deaf who assist them in communicating and interacting with the child during his or her every day activities.

ADD: *(ii) Family training means assisting parents in understanding the special needs of their child and providing parents with information about child development and with training that parents need in order to address their child's special needs, such training may include, for example, training in sign language or other forms of communication."*

ADD: *(iii) Families should receive information about resources available to them on learning about how to communicate with their children. This training may include information about assistive technology, augmentative communication, sign language or other forms of communication. Families should be provided with the opportunity to meet other parents and to participate in community activities, parent support groups and training classes which will benefit the family as a whole.*

It is not enough to provide parents only with assistance in understanding special needs and with information about child development. The needs of children served under IDEA are varied and can be intensive. Often parents need specialized, "hands on" training in order to address these needs. Including this addition in the regulations will help ensure parents receive this training. Information and opportunities to participate in activities will enhance parent's ability to meet the needs of their children.

Native language
This should be clarified as the "*Parent's native language*," or the "*Child's native language*."

In the case of a deaf child born to hearing parents, the languages may be different. The parent's language may be verbal and English and their child's *may* be visual and American Sign Language.
A clear definition of both must be included in these regulations.

Natural environment
Settings that are natural or normal for the child's age peers who have no disabilities.

ADD: *(i) For deaf or hard of hearing infants and toddlers, the natural environment may be a school or program for the deaf or any other environment where the child's language or mode of communication is used as the primary language or mode of communication.*

The infant and toddler years are the most critical ones for language development. Many deaf children are most successful at acquiring language in an environment where they interact with individuals who are already fluent in a visual language. Many deaf children require a specialized setting, which also functions as a natural environment for these children. The infant's home may not provide access to communication. In many instances, the parents do not communicate with their infants and toddlers, at an appropriate level, through a "language".
This must be made clear in the current regulations.

Sign Language Instructor
ADD: Definitions should include, *"Sign Language Instructor" is a person with certification from National Association of the Deaf (NAD) Level 3 (Average performance) and above or certification from Registry of Interpreters for the Deaf (RID) Levels -Certificate of Interpretation, Certificate of Transliteration, Comprehensive Skill Certificate, or Certified Deaf Interpreter.*

Currently there are no regulations governing sign language and sign language instructors in the Commonwealth, except for government agencies(see the Governor's Management Directive), therefore the quality of the language and the ability of the instructors vary. Deaf and hard of hearing infants and toddlers, their parents and families must be taught, in least with an "average" quality of communication and language to meet the needs of these children and their families.

Special Instruction
ADD: *(v) For children who do or may experience delays in spoken language, delivery of information may be through other forms of communication, such as sign language.*

Many deaf and hard of hearing children have difficulty acquiring speech and require access to a visual language. Further, some hearing children, such as some children with autism or mental retardation, benefit from exposure to sign language. Regulations should clarify that this is one type of special instruction that should be available to these children.

Financial Management

4226.14 Documentation of other funding source
(a) Modified to read as," Written documentation that all other private and public funding source available to the child and family, *with their knowledge, consent and the implications of using such funding sources,* have been accessed and exhausted shall be kept with the child and family's permanent legal entity's file.

General Requirements

4226.24 Comprehensive child find system
Add: (7) Newborn & Infant Hearing Screening Act.
Pennsylvania must accept responsibility for their "Comprehensive child find system." Pennsylvania must pass legislation that will find all deaf and hard of hearing infants and toddlers. Pennsylvania must follow the federal government's lead, that passed the "Newborn Infant Hearing Screening and Interventions Act of 1999," the Walsh bill. It is time for our Commonwealth to do the same.

The average age that children with hearing loss are identified in the U.S. is 2.5 years old. Yet, hearing loss is the most common congenital disorder in newborns; 20 times more prevalent than phenlyketonuria (PKU), a condition for which all newborns are currently screened.

A majority of hospitals only test infants considered "at risk for hearing loss," who have conditions such as low birth weight, a family history of hearing problems or other specific medical conditions. However, research indicates that testing only those babies considered "at risk" results in the identification of only 40 -50% of infants and toddlers with hearing loss.

Infants identified with hearing loss can be fit with amplification by an audiologist as young as 4 weeks of age. With appropriate early intervention, language, cognitive, and social development for these infants is very likely to develop on par with hearing peers. Those infants identified and given appropriate intervention before six months of age have significantly better language skills than those identified after six months of age. Eighty percent (80%) of a child's ability to learn speech, language and related cognitive skills is established by the time the child is thirty-six months of age, and hearing is vitally important to the healthy development of such language skills. Infants with appropriate intervention during infancy followed with appropriate intervention, minimizes the need for rehabilitation during the school years.

Personnel

4226.53 Activities (Service Coordinator)
This section should clarify that the Part C system may use early intervention funds to assist families to understand and access systems of financing early intervention and other health and social services needed by the family. Further, to facilitate family access to multiple sources of funding for early intervention and other health and social services related to the needs of the families. Access also should include informed consent on the implications of using such funding sources.

It is crucial for families to receive knowledge of how to finance early intervention and other health and social services needed.

4226.54 Requirements and qualifications (Service Coordinator)
(c) Modified to read as, "A Service coordinator, *specifically trained in their area of expertise*, shall have one of the following groups of qualifications:

Deaf and hard of hearing infants, toddlers, their parents and their families need to have knowledgeable recommendations for evaluations, assessments and services made by professionals with specific knowledge about deafness and hard of hearing.

DELETE: (3) Certification by the Civil Service Commission as meeting the qualifications of a Caseworker 2 or 3 classification.

This level of training is not an acceptable level for personnel who have so much responsibility to make the system work.

4226.56 Requirements and qualifications (Early Interventionist)
(a) Modified to read as, " An early interventionist, *specifically trained in their area of expertise*, shall have one of the following groups of qualifications:

Deaf and hard of hearing infants, toddlers, their parents and their families need to have knowledgeable recommendations for evaluations and assessments and services made by professionals with specific knowledge about deafness and hard of hearing.

4226.58
ADD: 4226.58. Good faith effort
The early intervention lead agency should have a policy which requires that early intervention provider agencies have established, implemented, and maintained outreach and recruitment measures to broaden candidate pools to include external geographical areas and personnel who meet the personnel standards and has documented the recruitment methods use.

Evaluation and Assessment

4226.62 Multidisciplinary evaluation (MDE)
(2) Modified to read as, "The initial MDE is conducted by personnel, *advising in their area of expertise*, who are independent of service provision.

ADD: *(i) In the case of an infant or toddler who is deaf or hard of hearing, the MDE may be conducted by personnel, advising in their area of expertise, who may also provide service.*

The low incidence rate of deafness and hard of hearing causes the availability of professional personnel or agencies, knowledgeable in the area of deafness and hard of hearing, to be limited. These professional personnel or agencies, *may provide both*, the most appropriate evaluations and assessments *and* the most appropriate services.

This exception *must* be included and clarified in the regulations.

4226.63 Nondiscriminatory procedures
(1) Modify to read as "Tests and other evaluation materials and procedures are administered in the native language of the parents *or the child or other mode of communication of the child*, unless it is clearly not feasible to do so."

For many deaf and hard of hearing children, American Sign language or another mode of communication is their native language or their mode of communication. This is true even though the native language or mode of communication of the parents may be different, such as the case of deaf or hard of hearing children with hearing parents. Regulations must clarify that these children should be tested and evaluated in the *child's* native language or mode of communication.

IFSPs

4226.74 Content of IFSPs
(4)(ii) A - N
ADD: *O Sign Language Instructors.*

4226.74 Content of IFSPs
(5) Natural environments.
Shall include the definition earlier stated in my comments, in 4226.6 Definitions, (i).
This section should clarify that, when considering the environments in which early intervention services are to be provided, the multidisciplinary team shall document and consider the preference of the parent.

The parent brings to the discussion knowledge of the child that no other IFSP participant possesses. Parental knowledge and information are important in determining appropriate placement. Parental consent for services would be rendered meaningless if parent preference were not considered on the important issue of placement.

Further, a Note should be added specifying that "Determination of the environment in which early intervention services are to be delivered is made through agreement by the IFSP team based on outcomes to be achieved." This lends support for the multidisciplinary team to determine placement based on the objective consideration of outcomes, not a subjective view point.

4226.74 Content of IFSP
Section of "Special factors" should be included.

*ADD: **(10) Special Factors.***
(i) In the case of an infant or toddler whose behavior impeded his or her development, consider, when appropriate, strategies, including positive behavioral interventions, strategies and supports to address that behavior.
(ii) In the case of an infant or toddler of a family with limited English proficiency, consider the language needs of the child and family as such needs relate to the child's IFSP.
(iii) In the case of a child who is blind or visually impaired, provide for instruction in Braille unless the IFSP team determines that instruction is Braille is not appropriate.
(iv) In the case of an infant or toddler who is deaf or hard of hearing, consider the communication needs of the child and opportunities for direct communication with peers, professional personnel and deaf adults in the child's language and communication mode, developmental level and full range of needs related to the child's language and communication mode.
(v) Consider whether the infant or toddler requires assistive technology devices and services.

"Special factors" considerations are critical to determining the child's educational needs. For example, deaf and hard of hearing children's unique communication and language needs cannot be appropriately addressed with out the assessment of the child's communication level, developmental level and other needs related to the child's language and communication mode.

CONCLUSION

We urge the Department to include the above clarifications, additions and modifications.

We sincerely thank the Department for the opportunity to comment and for all that it has done on behalf of deaf and hard of hearing infant and toddlers.

Public Comment 13
#14-452

Original: 2122

Quality & Fairness in Pennsylvania's Public Schools
EDUCATION LAW CENTER

RECEIVED
2000 JUL 25 PM 3:39
REVIEW COMMISSION

July 11, 2000

Mr. Mel Knowlton
PA Department of Public Welfare
P.O. Box 2675
Harrisburg, PA 17105-2675

RE: Proposed Infants and Toddlers Regulations

Dear Mel:

Enclosed you will find the comments of the Education Law Center – PA regarding the above. I'd be happy to discuss any of these matters with you further if you would find that helpful. Thanks for this opportunity for input.

DEFINITIONS

4226.5: The state definitions are drawn, virtually verbatim, from the federal regulations, and are generally fine. I have problems/suggestions with regard to the following:

- County MH/MR program (legal entity) is defined as an entity that "provides a continuum of care for the *mentally disabled*." Given that the I&T population also includes children who are physically impaired and have sensory impairments, that description is inadequate and may confuse or deter some families from asking for services. I would suggest "persons with disabilities."

- The definition of "early intervention services" should include the phase, "including, but not limited to, the following:

- In the definition of "parent," the Department should make clear that no employee of a public *or private* foster care agency can be considered a parent. (This does not include foster parents, who are not, "employees of an agency"; see below for argument that use of foster parents should be maximized).

  Moreover, this definition should make clear that, in certain circumstances, a foster parent is considered to be a "parent" (not just a person who is eligible to be appointed as a surrogate parent). A foster parent is considered to be a parent when: the natural parents' authority to make decisions has been extinguished under

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state law (the regulation should make clear that this means that parental rights have been terminated, or other clear state court action has taken place); the foster parent has an ongoing, long-term parental relationship with the child; the foster parent is willing to undertake these responsibilities; and there is no conflict of interest. 34 C.F.R. Section 303.19(b).

- The Department should also add a definition of "tracking," partly drawn from the 1997 regulations: "A systematic process to monitor the development of infants or toddlers who are at risk for a delay or disability to determine whether they have become eligible for early intervention services."

FINANCIAL MANAGEMENT

4226.12 (Waiver funds): A County does not completely control whether Waiver funds can be expended; that depends on whether there are enough eligible services and eligible children whose parents have agreed to participate. Therefore, the following phrase should be added at the end of the paragraph: "to the extent that eligible services and eligible children can be identified, and the children's parents consent to participate in the Waiver."

4226.13 (Nonsubstitution of Funds). It is appropriate and important to encourage counties to use private and public revenues to the extent possible, consistent with protecting families' rights. However, counties can't be held accountable for not using funds which are not accessible because the parents will not consent to their use. This section should be rewritten as follows:

> (a) Early intervention State funds may not be used to satisfy a financial commitment for services which could have been paid for from other public and private funding sources, so long as the use of those funds is without cost to the families, and the families have consented. A legal entity is responsible for providing all of the early intervention services in the child's IFSP whether or not those services are eligible under the Medicaid program.
>
> (b) Parents cannot be required to apply for Medicaid in order to receive early intervention services. Parents who have private insurance are not required to use their insurance. After being informed of their right to refuse consent, the parents may volunteer to use their insurance only if they will not suffer financial losses, which include, but are not limited to, one or more of the following:
>
> (1) A deductible, or a decrease in available yearly or lifetime coverage, or any other benefit under an insurance policy.

4226.15 (Documentation of other funding sources). For similar reasons, section (a) should be rewritten as follows:

Written documentation that all other private and public sources available to the child and family that can be used without financial loss to the child and family, and to which the parents have consented, have been accessed and exhausted shall be kept with the child and family's permanent legal entity's file. In no case shall a child's early intervention services be delayed in order to secure public or private sources, nor should services included in a child's IFSP be adjusted to reflect available funding sources .

GENERAL REQUIREMENTS

4226.23 (Waiver eligibility). To accurately reflect the Waiver process, I would recommend the following changes in subsection (a): "The legal entity shall ensure that if infants and toddlers until the age of 3 are eligible..., and with the parents' consent, as follows:

4226.24 (Comprehensive child find system): The regulations do not include any reference to the federal requirements that there be a "public awareness program," in addition to a child find system. 34 C.F.R. Section 303.320 requires the system to inform the public about the early intervention program. Moreover, with respect to "child find" itself, the regulations simply pass on to the County the responsibility for these functions, including coordination with and avoidance of duplication among child serving agencies. Clearly, there is an important role for the county, but the state has to create the infrastructure through, *e.g.*, memoranda of understanding. The regulation should state that the legal entity will perform these functions, "with the assistance of the State."

4226.24(f) (timelines): The section is very confusing. It does not make clear that, for a child determined to be eligible for services, the IFSP must be developed within 45 days of referral. [34 C.F.R. Section 303.342(a)]. Under this language, the timeline is satisfied if the child is only evaluated within the 45 day period. And it suggests, at 4226.24(f)(2)(iii), that the multi-disciplinary evaluation (MDE) could be bypassed altogether in favor of a plan for further assessment and tracking, which is also inconsistent with the federal requirements. [See, e.g., 34 C.F.R. Section 303.322(a)(1)].

4226.25 through 4226.29 (Screening): I believe this screening process is inconsistent with the federal regulations. Those regulations state that, within 45 days of the date the "public agency" (here the county) receives a referral, the public agency shall, "[c]omplete the evaluation and assessment activities...." [34 C.F.R. Section 303.321(e)]. This screening process does not comply with these requirements, but can still result recommendations that can only be made after a full MDE. These provisions should be removed.

However, it is entirely acceptable (and in the case of evaluations secured by the family mandatory) for the MDE team, with the family's consent, to consider the results of prior evaluations. Nothing in these comments should be construed as disfavoring such an approach – so long as the entire MDE complies with federal and state requirements, and only the MDE team

makes recommendations that are committed exclusively to its authority and expertise.

4226.35 (Preservice training): The Department should add to this list training in community resources and family centered planning and service delivery.

PERSONNEL

4226.54 (Requirements and qualifications [of service coordinators]: This is one of the most important issues in the proposed regulations – the level of expertise that the service coordinator must have to do this job competently. From the first draft (and these credentials are at a lower level than in either of the 2 earlier drafts), we and others have expressed our concern that these qualifications are inadequate. For example, a service coordinator could have an associate's degree *in any subject area*, and three years' work or volunteer experience in management or supervision, and qualify. There is no requirement that the service coordinator bring to this task training or even experience in child development, the needs of children and families with disabilities and so forth. We attach to these comments the proposal that we submitted to the Department in 1998, which was based on input from professionals in the field. We believe that the qualifications should reflect the competencies required, a position that we believe the Department embraces. This 'competency based' approach was used with respect to service coordinators when the Department contracted with Dr. Phillipa Campbell in (approximately) 1997.

We also think that the regulations should include a caseload maximum for service coordinators, so that we can be certain that they can perform their complex responsibilities adequately. In the early years of this program, the state informally used 35 children with active IFSPs as a guideline. Some think even this is too high.

4226.55-.56 (Early interventionist, requirements and qualifications): This is also a hugely important issue. Through these regulations, the Department has created a new type of early intervention service and provider, described here in only the most general terms. It is unclear how this service differs from that provided by the service coordinator and the special educator. What does it mean to, "implement the child's IFSP directly or by supervising the implementation of services provided by other early intervention personnel?" If the person is delivering special instruction, he is a less qualified person usurping the role of the special educator. And, how can such a person "supervise" other qualified and licensed early intervention personnel? If the person is simply coordinating the services in the child's IFSP, he is usurping the role of the service coordinator.

These questions become more urgent when one reviews the relatively minimal requirements for such a staff person. Again, the person could have an associate degree *in any subject matter* and three years volunteer work with children (say at a camp for children with disabilities), and qualify as an early interventionist. Again, we submitted an alternate proposal to the Department in 1998, to which we never received a substantive response.

I believe that the creation of this position, and in particular the setting of qualifications for this position that are less than those of a special educator, are a violation of, among other things, the federal requirement 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). In August, 1999, I sent a letter to the Department in which I detailed my legal objections. I have received no substantive response to this letter either.

4226.57 (Effective date of personnel qualifications): This provision grandfathers in indefinitely service coordinators and early interventionists **with even fewer credentials than are required by these regulations.** While it is reasonable to give personnel some time to come into compliance, the regulations should require all such staff to meet applicable standards within a four year period. (In fact, I believe that such a requirement is mandated by federal law. See, *e.g.*, 34 C.F.R. Section 303.361(c) and (e), which require a state that does not have sufficient qualified personnel to include in its Application timelines for the retraining or hiring of personnel that meet appropriate professional requirements; and that in case of shortage permit a state to use "the most qualified individuals who are making satisfactory progress toward completing applicable course work....").

EVALUATION AND ASSESSMENT

4226.62(a)(2)(MDE): This provision requires an evaluation by someone other than the provider in all cases. It is, in general, a good idea for the evaluation to be done by personnel independent of the provider who will deliver the services – it reduces the likelihood that the child will be determined to need only those services that the provider has available. On the other hand, there needs to be some "exception" process for those situations where a particular type of evaluator is needed in a region of the state where no comparably skilled independent evaluator is available. Perhaps the regional office could play a role in this.

Moreover, the language is ambiguous and will lead to confusion in the field. It states that the person performing the MDE must be, "independent of service provision." Does that mean that they will not be providing services to the child who is the subject of the evaluation; that they cannot in the future provide services to that child; or that they are not providing early intervention services to any child? I understand that counties are currently implementing this requirement in a variety of ways because of this confusing language in Department directives.

Some additional issues regarding the MDE process are:

- The regulation should require that a written MDE report be shared with the family before the IFSP is developed. Otherwise, families are without the information they need to participate effectively in the IFSP meeting. (This is required for students covered by Part B of the IDEA);

- The regulation should require that parents be given advance written notice that they can ask that other persons participate in the MDE or the IFSP meeting, and

that they can bring whomever they wish to these meetings.

4226.62(d): This provision should make clear that the 45 day period runs from the date of referral, and that, for children determined eligible, the initial IFSP meeting must also be held within this time period. 34 C.F.R. Section 303.342(a).

IFSPs

4226.72(b)(Procedures for IFSP development, review and evaluation): The federal regulation states that IFSPs shall be reviewed at 6 month intervals, or more often, "if the family requests such a review." 34 C.F.R. Section 303.342(b)(1). This phrase should be added to this provision.

4226.73 (Participants in IFSP meetings and periodic reviews): This is the list of personnel required by the federal regulations. However, this provision should also state that the service coordinator must have the authority to commit the County's resources, or someone with that authority must attend. The IFSP team (and not the County) has the responsibility, and therefore must have the authority, to make decisions as to what a child needs – and therefore what must be listed on the IFSP. We have received complaints that teams have reached tentative decisions, but that the ultimate decision has been referred to the County. Such a process violates the law, and would be avoided with the above addition.

4226.74 (Content of IFSP): The IFSP must include the "location" (this term defined, but it does not state that the location must be listed in the Plan).

4226.74(7)(i) (Dates, duration of services): This provision includes the phrase from the federal regulations, namely, that the services must start, "as soon as possible after the IFSP meetings." Timely implementation of IFSPs is key to the success of the whole system – and has been problematic in many counties (see, for example, the situation in Philadelphia which led to litigation; and in Montgomery County where the Regional Office had to order corrective action). The only way to make sure that families are clear on their rights, and that counties are clear on their duties, is to set a deadline – and we suggest 14 days, the timeline suggested by DPW in one of the earliest drafts of the regulations. I consider this one of the most important issues in these regulations; without this kind of clarity, many children will be denied needed services.

4226.74(9)(transition): First of all, this section should include the transition components in 34 C.F.R.303.344(h), which spell out the extent to which the IFSP must provide for training and discussions with parents; require steps to help the child adjust to the new setting; and clarify whether records can be transmitted. Given that the state regulations will replace the federal regulations as guidance to the field, it's important that these requirements be explicitly listed. In addition, the state has agreed, and has put in its Bulletin, that "pendency" applies between these systems, and that children cannot be dropped from the service in the IFSPs at 3 because their parents do not agree with the services offered by the MAWA. This requirement should be

regulatory.

We also recommend that this provision contain the language in the current (and proposed) Bulletin/BEC on transition, that the child's program and placement remain the same during the transition year, unless there are programmatic (rather than administrative or funding) reasons for the change.

PROCEDURAL SAFEGUARDS

4226.91 (General responsibility of legal entity for procedural safeguards): These regulations make no mention of the complaint management system required by 34 C.F.R. Sections 303.510-.512. In fact, contrary to the federal requirements, Section 4226.97 (prior notice) does not state that the written notice must describe, "[t]he State complaint procedures..., including a description of how to file a complaint and the timelines under those procedures." Parents simply do not know that this system exists and how to use it, despite the State's obligation under the federal regulations of, "widely disseminating to parents and other interested individuals, including parent training centers, protection and advocacy agencies, independent living centers, and other appropriate entities, the State's [complaint management] procedures...." 34 C.F.R. Section 303.510(a)(2). Since the State has chosen to include the federal language on all other requirements, it should also include this requirement, with appropriate modification to reflect the PA procedure.

4226.96 (Opportunity to examine records): This section should include the applicable federal procedures, and should also state (this is a PA option) that families can have access to copies of their records without cost.

4226.97 (Prior notice; native language). In addition to the point made above, the regulation deletes the phrase in the federal regulations that notice must be, "written in language understandable to the public." This is an important protection. 34 C.F.R. Section 303.403(c)(1).

4226.101(b)(1)(Parent rights in administrative proceedings): Parents often cannot afford to retain an attorney, and the regulation should make clear that the parents can utilize the services of whomever they wish to assist them at a hearing. We recommend the use of the language that applies to children covered by Part B of the IDEA: "Parents may be represented by any person, including legal counsel." 22 Pa. Code Section 14.64(h).

4226.102 (Impartial hearing officer): This section includes the federal language on impartiality, but not the language on qualifications and duties (which were, by the way, the subject of litigation in *Jill D. v. DPW*, when DPW was using hearing officers from the Fair Hearing System who were not knowledgeable about these children or these laws). 34 C.F.R. Section 303.421 states that hearing officers must, "have knowledge about the [early intervention law] and the needs of, and services available for, eligible children and their families." It also lists the hearing officers' "duties."

4226.103 (Convenience of proceedings; timelines): The section does not, in fact, contain the timeline for resolving hearing requests, which is 30 days. 34 C.F.R. Section 303.423(b).

4226.105(f) (Surrogate parents): This section confuses the federal criteria for when a foster parent is considered to be a parent, with the criteria for when a foster parent is eligible to serve as a surrogate parent. The result is that this regulation would significantly limit foster parents' ability to serve as surrogate parents for children in their care. See 34 C.F.R. 303.19(b) and discussion above under definition of "parent."

Limitations on foster parents serving as surrogate parents are extremely ill-advised, since foster parents are the ones with physical access to, and the daily responsibility of care for, these children – and are most often the best (and sometimes the only) adults able to perform this function. Very rarely do counties (or local educational agencies for children of school-age) maintain a pool of surrogate parents, and many delays (and sometimes gaps in program) occur because no one is legally competent to give consent or to authorize services. I recommend restoring the language from the 1997 draft, which stated: "A foster parent is eligible to serve as a surrogate if all requirements for surrogate ... are met." Section 4225.196(d). [See 34 C.F.R. Section 303.406 for applicable criteria for surrogate parents].

We also strongly urge the Department to restore Section 4225.194(b) of the 1997 draft (which authorized the County program to appoint a surrogate parent at the request of the parent under certain circumstances), and Section 4225.201 (which protects surrogate parents from liability if they perform their duties in good faith). The Education Law Center has surveyed all of the counties regarding the problems they encounter in providing services to children in foster care. It is clear that there are many problems. Making the surrogate process easier and more effective will be a big help.

IMPORTANT OMISSIONS

A key criticism of this draft is that it omits some progressive and essential requirements from earlier drafts. Just before the 2 year review of the 1998 draft began, as a follow-up to the last stakeholder meeting, I sent to DPW a list of the provisions whose elimination would most hurt kids and families. In addition to those already included above, I would add the following:

1997 Draft on Health Component of MDE (Section 4225.126), which gives clear direction to counties in an area that is unfamiliar, and will go far towards insuring that service coordinators meet their obligations to coordinate, "the provision of early intervention and other services (such as medical services...) that the child needs or is being provided." 34 C.F.R. Section 303.22(23)(ii).

1997 Draft on Independent Evaluations (Section 4225.72). Although the old version wasn't perfect, it made clear that families could request one independent evaluation per year, at the expense of the County program. The settlement in the *Jill D.* lawsuit, and the current Bulletin

resulting from that lawsuit, in fact required that an evaluation at public expense be provided whenever a parent requests a hearing. This should be added to the 1997 draft language.

Many parents do not have the resources to secure independent information about what their child needs. Often, this information will confirm the County's offer, and will leave all parties with confidence that the IFSP is correct. But, in the context of a hearing, such evaluations are crucial if the family is to have a meaningful chance to present its case to the hearing officer, and this information should not be available only to families with resources.

Thanks for this opportunity for input.

Very truly yours,

Janet F. Stotland
Co-Director

Public Comment 3

#14-452
7-12-00

Original: 2122

Mel Knowlton, DPW
P.O. Box 2675
Harrisburg, PA 17105-2678
FAX: 717-787-6583

July 12, 2000

CC: Senator Tim Murphy
FAX: 412-429-5092

CC: Independent Regulatory Review Committee
FAX: 717-783-2664

CC: Representative Dennis O'Brien
FAX: 717-787-1339

The following are comments on the recently published proposed regulations for early intervention for children under three in the state of Pennsylvania. My top priority concern is the incomplete list of personnel providing early intervention services. *Missing* from the list of services provided (4226.5 –Definitions. .A-L) are ***Hearing Sensitivity Services.*** An entire bulletin was devoted to the topic of Teachers of the Hearing-Impaired providing services and it is absent from the regulations. This professional service should be defined and included. It is not the same as Audiology.

Secondly, clarification as to who is an *early interventionist* and what purpose do they serve in early intervention, needs to be made (4226.55). The current responsibilities listed are generic as is the term early interventionist. The qualifications are very broad and do not meet the criteria for what families want in a therapist or special educator. This term needs to be clarified or eliminated.

The requirements and qualifications of service coordinators should include some training and experience in child development, training and experience in the needs of children with disabilities and their families as well as training in counseling. The responsibilities placed on individuals in this position do not match the requirements and qualifications in these regulations. Service Coordinators should be grandfathered in and given time to meet applicable professional requirements, not exempted from them.

And, finally, the provision of when services must start after the IFSP is completed needs to be clarified (4226.74). In earlier drafts of the regulations, the period of 14 calendar days was suggested. A specific timeline needs to be reinserted. Families need to know what is expected of their provider and explicit timelines are critical for that purpose.

These are some of my primary concerns. The document needs to reflect early intervention language throughout and not refer only to the mentally disabled. Early intervention services are provided to infants and toddlers with only physical or sensory delays. These children are not mentally disabled and probably never will be. The language should also promote services in natural environments. We don't do fire safety, emergency evacuation, first aid or CPR procedures in families' homes. Teaching some families about obtaining smoke detectors and how to call for help if there is an emergency may be a part of the family training. LICCs could sponsor training for family members in CPR, but essentially the entire Preservcie training (4226.36) piece needs to be reworked.

There is much more I would like to comment on and I hope the comment period will be extended. Many of the families we serve will be unable to attend the public hearing in Western Pennsylvania due to vacations, scheduled medical appointments and the many other distractions families have in the summer with other siblings home from school and the many demands on their time. Thank you for your consideration of the above points.

Sincerely,

Lynda J. Wright, PH.D.
Director of Early Intervention Services
Allegheny County-COMPRO of ARC Allegheny

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Lynda J. Wright, PH.D.
Director of Early Intervention Services
Allegheny County-COMPRO of ARC Allegheny

ARC Allegheny
711 Bingham Street
Pittsburgh, PA 15203

Fax Cover Sheet

DATE:	July 12, 2000	**TIME:**	3:26 PM
TO:	**Independent Regulatory Review Committee**	**FAX:**	**717-783-2664**
FROM:	Lynda J. Wright, Ph.D.	**PHONE:**	412-995-5000 x 420
	ARC Allegheny	**FAX:**	412-995-5001
RE:	Comments on proposed Early Intervention regulations		
CC:	Mel Knowlton, Senator Tim Murphy, Representative Dennis O'Brien, Nancy Hubley		

Number of pages including cover sheet: 2

Message

These are my comments to the proposed EI regulations.

Public Comment 4
#14-452

Original: 2122

The Alliance
for Infants & Toddlers, Inc.

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Department of Public Welfare Western Region
Proposed Rulemaking for Early Intervention Services
Public Hearing
July 17, 2000

Good afternoon. My name is Michele Myers-Cepicka, and I am the Executive Director of The Alliance for Infants & Toddlers, Inc. The Alliance is the service coordination unit for Allegheny County and, at present, serves 1200 children with IFSP-based and tracking services. I appreciate the opportunity to share my organization's input on the state's proposed early intervention regulations. Because testimony is limited to five minutes, I will be highlighting the major issues I see with the regulations and will also submit written testimony to further elaborate on the entirety of the proposal.

To begin with, I concur with the recommendation made by the SICC at its June meeting that the comment period for the proposed regulations be extended beyond 60 days. It is my understanding that the Department has the discretion to do this by announcing an extension of the public comment period in the Pennsylvania Bulletin, and I was pleased when Nancy Thaler said, at that SICC meeting, that she would be willing to pursue an extension. As you know, many families are away during the summer and might find it difficult to be able to participate in this process. Also, LICCs do not usually meet during the summer months, and it is vital to have their input and participation in this process, as they are charged to do in Act 212.

An extended comment period would also allow for wider dissemination of the proposed regulations. The early intervention community did not see a draft of the proposal before publication in the Bulletin, nor did we receive an announcement that the regs were being published. Although the department met with stakeholder groups in the original development of the regulations, that was over two years ago, and was before the release of the federal early intervention regulations. It's important that those professionals who actually implement the state's early intervention program have an opportunity to review and comment on these policies.

In following the order of the regulations, the first point I would like to address is Section 4226.22 3(b) which deals with the use of informed clinical opinion. I am concerned that the definition used in this section is more restrictive than the language in federal policy. Federal policy states that informed clinical opinion is important when standardized measures do not exist or are not appropriate, but does not restrict the use of clinical opinion to only those instances. I would advise that the language in this section be revised to more accurately reflect what I believe to be the intent of the federal regulations.

Next, Section 4226.24(f) 2, dealing with timelines is, I believe, inconsistent with IDEA. It states that "(2) Within 45 days after it receives a referral, the legal entity shall do one of the following: i) complete the evaluation activities in 4226.62, ii) hold an IFSP meeting in accordance with 4226.72, iii) develop a plan for further assessment and tracking. Federal law mandates that within 45 days the county complete evaluation and assessment activities (303.321 (e)) and hold an IFSP meeting. The way it is written now, the county would only have to complete an evaluation within 45 days and would not have to hold an IFSP meeting. I would advise removing the words "one of" so that it is clear that all three activities must be complete by the end of the 45 days. This point comes up again under MDEs, Section 4226.62 (d).

I would like to see Sections 4226.26 through 4226.28 regarding the purpose of the initial screening be revisited. 4226.26 is inaccurate because it is my understanding that it is not possible, under federal law, to determine by a screen alone (particularly one that might be done over the phone) that a child is ineligible for services, unless the parents agree not to pursue further evaluation. If the family requests an MDE, that is their right under IDEA. While a child can be deemed eligible for services by a screen alone, based on diagnosis or the presence of a condition indicative of a high probability of developmental delay, no child can be automatically deemed ineligible for services by a screen.

I would also advise that The Recommendations to Parents as outlined in Section 4226.28 be rewritten to mirror language in part (g) under Screening Procedures in the state bulletin, which more clearly state the purpose of an initial screen and possible outcomes. One last point having to do with screening involves Section 4226.32 Contacting Families which states that the legal entity shall contact families at least every four months after a child is referred to the tracking system. I would hesitate to put either a minimum or maximum on the number of contacts service coordinators make, as that should be individualized according to the family's needs.

As someone directly responsible for hiring service coordinators and other early intervention staff, I have some questions regarding the section on training and qualifications. First, Section 4226.36 (9) requires pre-service training in fire safety, emergency evacuation, first aid techniques and child CPR. Because most early intervention services are provided in the home, and oftentimes involve medically fragile children, I feel strongly that these requirements need to be clarified further. Issues such as Do-Not-Resuscitate (DNR) orders, liability of direct care staff, and the feasibility of fire and evacuation plans for every home visited need to be further reviewed before being required of providers.

With regard to the qualifications of a service coordinator, we make it a practice in Allegheny County to hire individuals with a Bachelors Degree, if not a Masters. However, while educational background is certainly an important criterion in hiring, I think demonstrating competencies in the field of early intervention and being qualified to work with families and children to be the most important qualifications an individual can bring to this position. It is important as an administrator to be able to use my discretion to hire people who have experience and expertise, but who may not necessarily have a particular degree.

Section 4226.55 is unclear to me. I am not sure who the early interventionist position is describing - a developmentalist, a service coordinator, or if this is a new position entirely. I would like to see this section clarified, along with the requirement that an early interventionist obtain a minimum of 6 credit hours annually. I question whether or not those early interventionists with Bachelors or Masters degrees will also be required to get these credits, and at whose cost?

Under the category IFSPs, Section 4226.74 (7)(I) includes the phrase from the federal regulations that services must start "as soon as possible" after the IFSP takes place. I recommend changing this provision to read that services must start "as soon as possible, but not to exceed 21 days, unless so requested by the family".

In closing, I would just comment that while I know the bulk of the state regulations incorporate the federal early intervention regulations, it would be helpful to include the federal citations where appropriate. It is difficult to crosswalk the two regulations in their current form.

Again, thank you for your time and consideration of my comments. I am willing to assist the department in any way that I can as we proceed with this process.

Respectfully Submitted,

Michele Myers-Cepicka, Executive Director
The Alliance for Infants & Toddlers, Inc.
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Public Comment 2
#14-452

Original: 2122

Before the
Pennsylvania Department of Public Welfare
PO Box 2675
Harrisburg PA 17105-2675
717-783-5764
717-787-6583 fax

In the Matter of
Notice of Proposed Rulemaking
Regarding Part C of the
Individuals with Disabilities Education Act (IDEA) of 1997

Early Intervention Services
(55 PA. Code Chapter 4226)

Submitted by:

Diana Dougan
5045 Cider Mill Road
Erie PA 16509-3918
814-825-4872 v/tty
814-825-7261 fax

June 28, 2000

In the Matter of
Notice of Proposed Rulemaking
Regarding Part C of the
Individuals with Disabilities Education Act. (IDEA)
Amendments of 1997

Early Intervention Services
(55 PA. Code Chapters 4226)

I am a parent of a young deaf adult and I belong to several deaf advocate organizations.

I am pleased to submit these comments to the Department of Public Welfare on the Notice of Proposed Rulemaking, Part C of the Individuals with Disabilities Education Act (IDEA) of 1997, Early Interventions Services.

According to the PennData Enrollment as of December 1,1997 deaf and hard of hearing children make up 1% of special education students served in Pennsylvania. Of the 1.8 million public school students, only 3,004 are deaf or hard of hearing. Deaf and hard of hearing children are a minority in special education, and special education is a minority in public education. Needless to say, the incidence of deafness and hard of hearing is very low.

The incidence is low and the needs are specific. Communication and language is a primary need of deaf and hard of hearing children. The needs of deaf and hard of hearing infants and toddlers served in the Early Intervention Services are also specific with the primary focus on communication and language.

For these infants and toddlers to have their needs met by the Commonwealth of Pennsylvania, specific conditions must be written into these regulations, which will be unique to deaf and hard of hearing infants and children.

I thank the Department of Public Welfare for the opportunity to comment on this important NPRM.

OVERVIEW OF ISSUES

1. The "Comprehensive Child Find System" must begin to include all deaf and hard of hearing infants and toddlers.

2. Personnel responsible for coordination, screening, evaluation, assessment and delivery of service programs must be "special educators" who are specifically trained in parent-infant education *and who are specifically trained in their area of expertise.*

3. Resulting from low incidence; screening, evaluation, assessment persons or agencies *MAY* be used for the delivery of services for deaf or hard of hearing infants and toddlers.

4. Specific disability definitions must be added or modified in these regulations to meet the unique needs of deaf and hard of hearing infants and toddlers.

ISSUES

General Provisions
4226.5 (6) Definitions.

Appropriate professional requirements
(i) Modify to read as, "Are based on the highest requirements in the profession or discipline in which a person is providing early intervention services, *specific to their area of expertise,* to enable the individual to obtain licensure, certification or registration in the profession.'

(ii) Modify to read as, "Establish suitable qualifications for personnel, *specifically trained in their area of expertise*, providing early intervention services under this part to eligible children and their families who are served by public and private agencies.

Deaf and hard of hearing infants and toddlers have specific needs. Coordination, screening, evaluation, assessment and services must be provided by people who are specially trained in this low incidence, specific disability.

Assistive technology service
(v) Training or technical assistance for a child with disabilities or, if appropriate, that child's family.
ADD: *A As in the case of deaf and hard of hearing infants, toddlers, their parents and their families, training may include instruction in a visual language such as American Sign Language.*

Communication
Definitions should include a definition for "Communication" that clarifies that communication *may* include sign language, for example, *"As used in this part, communication may include sign language."*

Sign language may be the primary mode of communication of many deaf and hard of hearing infants and toddlers. An important and specific need of a deaf or hard of hearing infant and toddler is communication. This must be included in the definitions.

Early intervention program
(vi) Provided by qualified personnel, including at a minimum, the following:
ADD: *(N) Sign language instructors*

Family training, counseling and home visits
Modify to read as, "Services provided by social workers, psychologists, <u>special educators</u> and other qualified personnel to assist the family of a child eligible under this chapter in understanding the special needs of the child and enhancing the child's development."

ADD: *(i) Special educators are specifically trained in parent-infant education <u>and who are specially trained in their area of expertise, such as a teacher of the deaf or a teacher of multiply disabled children.</u>*

Families should receive, where appropriate, visits from special educators to help them address the *specific needs* of their child. For example, families of deaf children should receive home visits from teachers of the deaf who assist them in communicating and interacting with the child during his or her every day activities.

ADD: *(ii) Family training means assisting parents in understanding the special needs of their child and providing parents with information about child development and with training that parents need in order to address their child's special needs, such training may include, for example, training in sign language or other forms of communication."*

ADD: *(iii) Families should receive information about resources available to them on learning about how to communicate with their children. This training may include information about assistive technology, augmentative communication, sign language or other forms of communication. Families should be provided with the opportunity to meet other parents and to participate in community activities, parent support groups and training classes which will benefit the family as a whole.*

It is not enough to provide parents only with assistance in understanding special needs and with information about child development. The needs of children served under IDEA are varied and can be intensive. Often parents need specialized, "hands on" training in order to address these needs. Including this addition in the regulations will help ensure parents receive this training. Information and opportunities to participate in activities will enhance parent's ability to meet the needs of their children.

Native language
This should be clarified as the "*Parent's native language*," or the "*Child's native language*."

In the case of a deaf child born to hearing parents, the languages may be different. The parent's language may be verbal and English and their child's may be visual and American Sign Language.
A clear definition of both must be included in these regulations.

Natural environment
Settings that are natural or normal for the child's age peers who have no disabilities.

ADD: *(i) For deaf or hard of hearing infants and toddlers, the natural environment may be a school or program for the deaf or any other environment where the child's language or mode of communication is used as the primary language or mode of communication.*

The infant and toddler years are the most critical ones for language development. Many deaf children are most successful at acquiring language in an environment where they interact with individuals who are already fluent in a visual language. Many deaf children require a specialized setting, which also functions as a natural environment for these children. The infant's home may not provide access to communication. In many instances, the parents do not communicate with their infants and toddlers, at an appropriate level, through a "language".
This must be made clear in the current regulations.

Sign Language Instructor
ADD: Definitions should include, *"Sign Language Instructor" is a person with certification from National Association of the Deaf (NAD) Level 3 (Average performance) and above or certification from Registry of Interpreters for the Deaf (RID) Levels -Certificate of Interpretation, Certificate of Transliteration, Comprehensive Skill Certificate, or Certified Deaf Interpreter.*

Currently there are no regulations governing sign language and sign language instructors in the Commonwealth, except for government agencies(see the Governor's Management Directive), therefore the quality of the language and the ability of the instructors vary. Deaf and hard of hearing infants and toddlers, their parents and families must be taught, at least with an "average" quality of communication and language to meet the needs of these children and their families.

Special Instruction
ADD: *(v) For children who do or may experience delays in spoken language, delivery of information may be through other forms of communication, such as sign language.*

Many deaf and hard of hearing children have difficulty acquiring speech and require access to a visual language. Further, some hearing children, such as some children with autism or mental retardation, benefit from exposure to sign language. Regulations should clarify that this is one type of special instruction that should be available to these children.

Financial Management

4226.14 Documentation of other funding source
(a) Modified to read as," Written documentation that all other private and public funding source available to the child and family, *with their knowledge, consent and the implications of using such funding sources,* have been accessed and exhausted shall be kept with the child and family's permanent legal entity's file.

General Requirements

4226.24 Comprehensive child find system
Add: (7) Newborn & Infant Hearing Screening Act.
Pennsylvania must accept responsibility for their "Comprehensive child find system." Pennsylvania must pass legislation that will find all deaf and hard of hearing infants and toddlers. Pennsylvania must follow the federal government's lead, that passed the "Newborn Infant Hearing Screening and Interventions Act of 1999," the Walsh bill. It is time for our Commonwealth to do the same.

The average age that children with hearing loss are identified in the U.S. is 2.5 years old. Yet, hearing loss is the most common congenital disorder in newborns; 20 times more prevalent than phenlyketonuria (PKU), a condition for which all newborns are currently screened.

A majority of hospitals only test infants considered "at risk for hearing loss," who have conditions such as low birth weight, a family history of hearing problems or other specific medical conditions. However, research indicates that testing only those babies considered "at risk" results in the identification of only 40 -50% of infants and toddlers with hearing loss.

Infants identified with hearing loss can be fit with amplification by an audiologist as young as 4 weeks of age. With appropriate early intervention, language, cognitive, and social development for these infants is very likely to develop on par with hearing peers. Those infants identified and given appropriate intervention before six months of age have significantly better language skills than those identified after six months of age. Eighty percent (80%) of a child's ability to learn speech, language and related cognitive skills is established by the time the child is thirty-six months of age, and hearing is vitally important to the healthy development of such language skills. Infants with appropriate intervention during infancy followed with appropriate intervention, minimizes the need for rehabilitation during the school years.

Personnel

4226.53 Activities (Service Coordinator)
This section should clarify that the Part C system may use early intervention funds to assist families to understand and access systems of financing early intervention and other health and social services needed by the family. Further, to facilitate family access to multiple sources of funding for early intervention and other health and social services related to the needs of the families. Access also should include informed consent on the implications of using such funding sources.

It is crucial for families to receive knowledge of how to finance early intervention and other health and social services needed.

4226.54 Requirements and qualifications (Service Coordinator)
(c) Modified to read as, "A Service coordinator, *specifically trained in their area of expertise*, shall have one of the following groups of qualifications:

Deaf and hard of hearing infants, toddlers, their parents and their families need to have knowledgeable recommendations for evaluations, assessments and services made by professionals with specific knowledge about deafness and hard of hearing.

DELETE: (3) Certification by the Civil Service Commission as meeting the qualifications of a Caseworker 2 or 3 classification.

This level of training is not an acceptable level for personnel who have so much responsibility to make the system work.

4226.56 Requirements and qualifications (Early Interventionist)
(a) Modified to read as, " An early interventionist, *specifically trained in their area of expertise*, shall have one of the following groups of qualifications:

Deaf and hard of hearing infants, toddlers, their parents and their families need to have knowledgeable recommendations for evaluations and assessments and services made by professionals with specific knowledge about deafness and hard of hearing.

4226.58

ADD: 4226.58. Good faith effort

The early intervention lead agency should have a policy which requires that early intervention provider agencies have established, implemented, and maintained outreach and recruitment measures to broaden candidate pools to include external geographical areas and personnel who meet the personnel standards and has documented the recruitment methods use.

Evaluation and Assessment

4226.62 Multidisciplinary evaluation (MDE)

(2) Modified to read as, "The initial MDE is conducted by personnel, *advising in their area of expertise*, who are independent of service provision.

ADD: *(i) In the case of an infant or toddler who is deaf or hard of hearing, the MDE may be conducted by personnel, advising in their area of expertise, who may also provide service.*

The low incidence rate of deafness and hard of hearing causes the availability of professional personnel or agencies, knowledgeable in the area of deafness and hard of hearing, to be limited. These professional personnel or agencies, *may provide both*, the most appropriate evaluations and assessments *and* the most appropriate services.

This exception *must* be included and clarified in the regulations.

4226.63 Nondiscriminatory procedures

(1) Modify to read as "Tests and other evaluation materials and procedures are administered in the native language of the parents *or the child or other mode of communication of the child*, unless it is clearly not feasible to do so."

For many deaf and hard of hearing children, American Sign language or another mode of communication is their native language or their mode of communication. This is true even though the native language or mode of communication of the parents may be different, such as the case of deaf or hard of hearing children with hearing parents. Regulations must clarify that these children should be tested and evaluated in the *child's* native language or mode of communication.

IFSPs

4226.74 Content of IFSPs
(4)(ii) A - N
ADD: *O Sign Language Instructors.*

4226.74 Content of IFSPs
(5) Natural environments.
Shall include the definition earlier stated in my comments, in 4226.6 Definitions, (i).
This section should clarify that, when considering the environments in which early intervention services are to be provided, the multidisciplinary team shall document and consider the preference of the parent.

The parent brings to the discussion knowledge of the child that no other IFSP participant possesses. Parental knowledge and information are important in determining appropriate placement. Parental consent for services would be rendered meaningless if parent preference were not considered on the important issue of placement.

Further, a Note should be added specifying that "Determination of the environment in which early intervention services are to be delivered is made through agreement by the IFSP team based on outcomes to be achieved." This lends support for the multidisciplinary team to determine placement based on the objective consideration of outcomes, not a subjective view point.

4226.74 Content of IFSP
Section of "Special factors" should be included.

*ADD: **(10) Special Factors.***
(i) In the case of an infant or toddler whose behavior impeded his or her development, consider, when appropriate, strategies, including positive behavioral interventions, strategies and supports to address that behavior.
(ii) In the case of an infant or toddler of a family with limited English proficiency, consider the language needs of the child and family as such needs relate to the child's IFSP.
(iii) In the case of a child who is blind or visually impaired, provide for instruction in Braille unless the IFSP team determines that instruction is Braille is not appropriate.
(iv) In the case of an infant or toddler who is deaf or hard of hearing, consider the communication needs of the child and opportunities for direct communication with peers, professional personnel and deaf adults in the child's language and communication mode, developmental level and full range of needs related to the child's language and communication mode.
(v) Consider whether the infant or toddler requires assistive technology devices and services.

"Special factors" considerations are critical to determining the child's educational needs. For example, deaf and hard of hearing children's unique communication and language needs cannot be appropriately addressed with out the assessment of the child's communication level, developmental level and other needs related to the child's language and communication mode.

CONCLUSION

I urge the Department to include the above clarifications, additions and modifications.

I sincerely thank the Department for the opportunity to comment and for all that it has done on behalf of deaf and hard of hearing infant and toddlers.

Public Comment 1

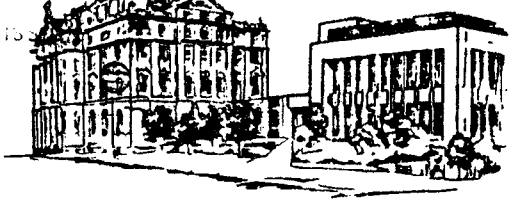
#14-452

Thomas C. Ceraso
Commissioner

Tom Balya
Chairman

Scott Conner
Commissioner

Westmoreland County Pennsylvania



MENTAL HEALTH AND
MENTAL RETARDATION PROGRAM
JOSEPH M. HAVRILLA
Administrator

Telephone
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TO: Mel Knowlton
Department of Public Welfare

FROM: Christopher R. Loughner
EI Program Coordinator

DATE: June 22, 2000

SUBJ: Proposed EI Amendments

After review of the proposed Early Intervention Regulations in PA Bulletin, Document No. 00-941, Westmoreland County would like to submit the following comments:

4226.36 Pre-service Training
The service coordinator, early interventionist, and other early intervention personnel who work directly with the child, including personnel hired through contract, shall be trained before working with children or families in the following areas:

(9) Training in fire safety, emergency evacuation, first aid techniques and child cardiopulmonary resuscitation (for all staff), as well as for the early interventionist and other personnel who work directly with the child.

Although the County is in agreement with the types of training that are required, we feel that the timeline for obtaining certified training in the areas of First Aid and CPR for new agencies or employees would impact negatively on providing direct care services in a timely manner.

Based on the availability of First Aid and CPR training in our County, it is suggested that from the date of employment, a minimum of 30 days (thirty) and no more than a maximum of 90 days (ninety) be designated as the acceptable time to obtain certification.

4226.74 Content of IFSP
The IFSP shall be in writing and the standardized formats will contain:

(6) Other services
(i) The IFSP shall include:

(B) The funding sources to be used in paying for those services or the steps that will be taken to secure those services through public or private sources.

Under the complete "content" section, the above paragraph is the only one that comes close to mentioning unit rates. It is our understanding that in the current standardized IFSP, the cost of each unit of service must

also be identified in writing, before the IFSP is considered complete and services can begin. Is this an oversight, or are unit costs no longer to be identified on the IFSP?

(9) Transition from early intervention services.

(B) Review the child's program options for the period from the child's 23rd birthday through the remainder of the school year.

This typo (23rd) was so obvious that we were afraid no other county would point it out. – Change to 3rd birthday.

If additional clarification is needed regarding our comments, please contact Chris Loughner at (724) 830-3686.

CC: Mary Puskarich
Ron Staszel
Kathy Clingan
Chris Fiorina

Public Comment 8
#14-452

Original: 2122

WESTERN COALITION OF EARLY INTERVENTION ADVOCATES AND FRIENDS

Testimony for Hearings on Proposed Infant and Toddler Regulations

Presented By

Stephanie Tecza
Parent and Advocate

Good morning, my name is Stephanie Tecza. I am a parent of a child with a disability, an educational advocate at ARC Allegheny and a member of the Western Coalition of Early Intervention Advocate and Friends.

The Western Pennsylvania Coalition of Early Intervention Advocates and Friends is a group of parents, advocates, providers and other stakeholders who care about infants and toddlers with disabilities and who work to ensure that state and local policies are written and implemented to benefit these children. We meet on a regular basis share information and concerns and when necessary, make our voices heard at the State and local level about important issues affecting infants and toddlers with disabilities. We have over thirty active members of our Coalition from all over Western Pennsylvania.

I am here today to express the concerns of the Coalition.

First, **we are asking that the Department extend the comment period and schedule additional hearings in the fall to accommodate more and better participation. And to extend these hearings to rural parts of the state, so parents and advocates in those areas can be heard.**

Many of our Coalition members wanted to be present today, but were unable to be here because of conflicts with their family vacation schedules. We are concerned that the Department encourage and facilitate the participation of families in the comment period for these regulations. Only three hearings have been scheduled and these are being held during the summer when many families are either on vacation or out of touch with their local ICCs.

Second, **we are asking that DPW make more and better efforts to circulate information about the regulations and the opportunities to comment.**

The LICC leadership has just changed and the new parents will need time and information to get up to speed. More efforts should be made to make this information available to parents and advocacy groups who may be interested in commenting.

Third, **we do not think the state regulations should merely re-state the federal regulations.**

This is not helpful to our Coalition members: parents, advocates, providers and other stakeholders: who rely on state regulations to make clear the federal mandates and explain how they are to be implemented in Pennsylvania. The regulations should include specific requirements that address local needs, and that will help families and children in Pennsylvania.

Forth, **we have multiple other concerns as a Coalition and individually about the content of the proposed regulations from the creation of the position of "early interventionist" to the lack of timelines for the implementation of IFSPs.** However, because it is the summer and many of our members are away on vacation and others have not had time to evaluate the proposed regulations, many of our specific comments on the content of the regulations will be submitted at a later time in writing.

It is our hope that not only will the Department extend the comment period and schedule additional hearings that are located in convenient places at times that make it possible for parents and families across Pennsylvania to participate, but that the Department will re-evaluate its current proposed regulations in light of what they mean for *families and children* who need early intervention services.

Thank you for your time.

8 continued

A PARENT'S PERSPECTIVE

Testimony for Hearing on Proposed Infant and Toddler Regulations

July 17, 2000

Presented by Stephanie Tecza

As a parent of Leah, a soon to be 16 year old daughter with down syndrome. I can truly say that there were not regulations or laws 16 years ago. My daughter had the unique experience with ARC Allegheny's Infant stimulation programs that where set up throughout the city.

Leah was able to get all of her therapies one or two days a week and all in one place. The staff taught Leah and myself a lot about the importance of early intervention and how important it is for young children to have these therapies. Leah was walking and moving around just like her non-disabled peers.

In that setting parents were able to meet one another. We were parents of **babies** with disabilities. If you have never experienced giving birth to a baby with a disability, and facing it daily, then I guess you would not really understand how important that contact is. It was nice to be able to see that I was not the only one in this world with a baby with a disability. And that other young parents are having the same experiences.

As an education advocate, I work with parents who have school aged children. When parents contact us the "TRUST" between school, and parent is usually broken. It is difficult for parents to regain the trust of a school district once that trust was jeopardized.

With DPW holding these hearings at the most incontinent times and places, and not providing much in the way of informing parents of young children with disabilities about the changes that will affect their lives, you are setting the "TRUST" between parents and the systems to be broken. What kind of message do you want to give to NEW PARENTS? I would urge this system to listen and include parents in this process. I assure you your system will be valued if everyone including parents' worked together.

Thank you for your time.