Original: 2122

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2000 JUL 20 AM 10:01

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The WESTMORELAND COUNTY CHAPTER of the PENNSYLVANIA ASSOCIATION FOR RETARDED CITIZENS, Inc.

July 17, 2000

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

Re: Proposed EI Regulations

Dear Mr. Knowlton:

I am writing on behalf of the 1,500+ families of children under three years of age in Westmoreland County who are effected by the abovereferenced Regulations. The Arc Westmoreland, an affiliate of The Arc of the U.S. and the Pennsylvania Arc, is Westmoreland County's leading not-for-profit provider of quality advocacy and support services for individuals with developmental disabilities. Our staff of 176 experienced professional and direct care workers provides service to 317 persons at 24 program sites and to over 300 children and adults and their family members throughout the county. We are governed by a 19-member Board of Directors. governs the agency. With the exception of advocacy services, our agency is primarily funded by the PA Office of Mental Retardation. General operating budget requirements for FY 2000-2001 are close to $6.8 million; our early intervention budget exceeds $600,000.

One issue of specific concern to consumers relates to professional qualifications. In the proposed Requirements and Qualifications for Service Coordinator, §4226.54 (c) (1), and for Early Interventionist, §4226.56 (a) (1), the "bachelor's degree or above from an accredited college or university…" falls short of ensuring professional quality. Certified professionals in each of these positions directly affect the lives of children and their families. You know, each is responsible for overseeing the proper coordination of evaluations and IFSP development and implementation for scores of children. Yet, unlike physical, occupational, speech and other therapists, there exists no state-recognized certification or licensing requirements for either position.

For the record, I recommend that the proposed regulations be amended to require a bachelor's degree or above specifically in education along with 1 year's work or volunteer experience working directly with children, families, or individuals with disabilities or in counseling, management, or supervision. Further, I strongly recommend that eligibility based on an associate's degree for service coordinators, §4226.54 (c) (2), and early interventionists, §4226.56 (a) (2), is woefully inadequate, and should be stricken from the regulations. Additionally, certification by the Civil Service Commission as meeting the qualifications for Caseworker 2 or 3 for service coordinators, §4226.54 (c) (3), hamstrings the casemanagement providers and continues to perpetuate an antiquated, overregulatory system.

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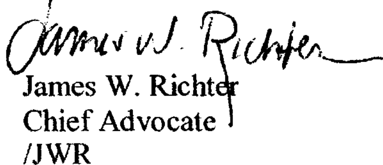
My last comment in this area relates to the Effective Date of Personnel Qualifications, §4226.57, wrongly grandfathers service coordinators and early interventionists ad infinitum. However much it is reasonable to give existing personnel some time to come into compliance, the regulations should require all staff to meet applicable standards within a certain time period. I argue that four years is adequate to allow qualified individuals to make progress toward completing applicable course work and certification.

In the area regarding Independent Evaluations, §4225.72, it should be made clear to the counties, service providers, and families that families can request one independent evaluation per year at the expense of the County program. This should be added to the 2000 draft.

Finally, from a procedural standpoint, the 60-day comment period following the June 1, 2000 announcement of the proposed regulations is inadequate for families. Many are involved with summer respite and recreation activities while many others are doing double duty at work to compensate for summer vacations. As such, the comment period should nort run over the summer. The comment period should start in early-September and run for no less than sixty days. In addition, there should be more opportunities for families to testify closer to their homes. This means adding several more hearings throughout the state in cities such as Erie, Indiana, York, and Scranton.

Thank you for your consideration in this all important matter.

Sincerely,



James W. Richter
Chief Advocate
/JWR

cc: Independent Regulatory Review Commission
Rep. Dennis M. O'Brien

Original: 2122

Mel
Public Comment 9
#14-452

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2000 JUL 25 PM 3:30
REVIEW COMMISSION

Proposed Early Intervention Regulations
"Additional Service Provider Training"
by Christy Deiner
Lebanon County Pennsylvania
7/14/00

Chrisy Diener
308 S. 12th st.
Lebanon, PA 17042
mld8@psu.edu
(717)-272-2805

The reason that I am writing this proposal is because of my concern about lack of qualifications of the teachers and therapists that deal with children receiving early intervention services. I feel that their lack of knowledge of early childhood development is potentially harmful to the child. Not only could it hinder current goals being set for the child, but it could possibly pose long term negative effects.

I am also concerned with the fact that many therapists have had a lack of training in dealing with the specific needs of the children on their case load. Again I feel this could be potentially harmful.

Finally, I would like to know that new college graduates that will be working with children in the three and under age group, in their homes, have had hands on exposure to children in this age group and have gone through a period of mentoring with an experienced person in the home environment. Working with children, under experienced supervision is, in my opinion, the best way to truly learn child behavior. If the services will take place in the home then the training should take place in the home. Just as working with a ten year old is different then working with a one year old, working in a classroom setting is different then educating in the home.

This is a very vulnerable period for both family and child. First of all, these are critical years of development. A foundation for all cognitive, emotional, and social development begins during these ages. Professionals need to be well trained to take optimal advantage of these stages, and to prevent doing harm. Secondly, the family is newly learning about their child's disability. They have not had enough time to learn what is and isn't acceptable practices in educating a child with their child's disability. They need to be able to trust that the professionals dealing with this age group are the most well trained professionals available.

This is my proposal. Give all service providers the option of specializing by offering in depth training sessions in the basic targeted impairments; visual impairments, hearing impairments, deaf blind, neurological disorders, behavioral disorders. Again these certifications are totally optional. Give the parent the option of requesting a person that is certified for their child's needs. Two things will happen with this proposal. The parents that feel that their provider is doing well with their child will not request someone else, and therefore saying that this professional is adequately trained. The parents that feel that the provider working with their child is not doing well will request a specialist. The provider has the option of becoming certified, or the county will need to provide the client with someone who is. This should protect the truly trained and experienced from going through unnecessary training.

Every service provider should be required to take a comprehensive early childhood education mini course if they will be working with children under the age of five. This course should be required to be taken every five years as a means of certification and recertification. Ideas for curriculum of this course could be taken from examples of "Head Start" training courses. My experience with training and retraining courses are that even though they may or may not be redundant educationally, they set an overall tone for what should and shouldn't be done.

Who will teach these training courses? The professionals with a formal educational degree in the specialized field. For instance, a training course for understanding children with Visual Impairment could be held at, and taught by, certified teachers for the visually impaired, at the Overbrook School for the Blind in Philadelphia, or on a mentoring on-one-basis with an experienced, certified, teacher for the visually impaired. (I would like to accentuate the word experienced, and add certified to work with children under the age of five.) The early childhood education training course could be held at one of the local Community Colleges, and taught by a degreed professional in the field of early childhood education.

These are my experiences and the reasons why I came to feel so strongly about this issue. As a general overview; I have an almost two year old son with visual impairment. I have found that because visual impairment is a low incidence disability, service providers

are unfamiliar with the appropriate teaching techniques for educating the blind. If the provider is certified to work with the visually impaired, they are not necessarily familiar with appropriate teaching techniques for small children.

I will begin with my experiences with occupational therapy. The first OT, that came to evaluate my son, asked me to open all of the blinds and turn on all of the lights. Her comment was that, "We want to give him every chance we can to see what we are doing." This is a common misconception. One of the major hindrances of a person with limited functional vision is excess light and glare. (Keep in mind she was to be evaluating him.) The OT that I was given to perform services, the goals were focused around feeding skills, was not familiar with basic, non-aggressive means of teaching spoon use to a visually impaired child.

Next, are my experiences with Speech Therapists. The ST that I was offered had a list of detrimental suggestions. The first was to gently slap may son's cheeks and mouth when he came to approach me for something, and to brush his teeth excessively. Her feeling was that this would heighten oral awareness. This would be taken as a negative stimulus by most children, especially visually impaired children who are normally prone to avoidance of physical and social contact. The second thing she asked me to do was to have my son, and the rest of my family, eat with small plastic toys. She felt that this would exercise his tongue muscles. If I would have taken this advise my son could have had tremendous set backs. Most of what I do to educate my son is based around teaching him appropriate uses for objects. Eating skills are ranked as being one of the most difficult tasks for a visually impaired person to learn. She also asked me to encourage him to be oral. As a rule visually impaired children are excessively oral. I asked her why she wanted me to do all of these bazaar exercises. She said they are exercises to improve muscle tone. My son is only visually impaired, he has LCA wich only effects vision, he has no muscle tone issues. I would have benefited by being given tips on how to encourage conversation in toddlers, or advise on listening skills, or being educated as to common successions in toddler language acquisition. The type of advise I was given could have had a negative trickle down effect. I may have found myself needing additional service, and possibly psychological intervention, to counteract the harm she caused.

I was offered a person trained to teach Orientation and Mobility. He is right out of college, and has no experience working with children. He has no idea how to teach a small child. Due to this fact my son does not respond to him well. My son drops his cane at the sound of his voice. The instructor's training is based around adult mobility skills, ex. crossing streets independently and using public transportation. My child should be learning simple concepts of sensory awareness, exploration, and safety skills.

The problem I have been running into as far as accessing appropriate services is that, the teachers and therapists, no matter what limited knowledge they have of how to educate my child, are considered qualified. This is what I'm offered by my early intervention program in Lebanon County Pennsylvania, this is what I get. Even though they are aware of all of these issues, the program is not required to provide me with anyone else or additionally train their service providers. My son, and hundreds of other children loose out. I truly hope something can be done about this.

Public Comment 10
#14-452

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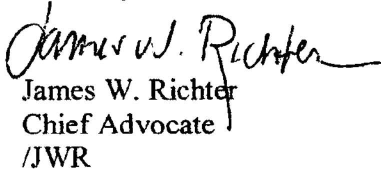

James W. Richter
Chief Advocate
/JWR

cc: Independent Regulatory Review Commission
Rep. Dennis M. O'Brien

Public Comment 7
#14-452

Original: 2122

Serving People With Retardation & Other Disabilities

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REVIEW COMMISSION

PUBLIC COMMENTS IN RESPONSE TO:

PA Department of Public Welfare (DPW) proposed regulations to govern PA's Early Intervention program for infants and toddlers, under three years of age with developmental delays.

July 17, 2000

Carrie P. Buchanan
Education Advocate
Family Supports Department
ARC Allegheny
711 Bingham Street
Pittsburgh, PA 15203
(412) 995-5000 (x492)
edadv@arcallegheny.org

Good morning. My name is Carrie Buchanan and I am an Education Advocate in the Family Supports Department of ARC Allegheny. I work primarily with families of children in Early Intervention, parts B and C providing technical assistance in the IFSP and IEP processes. I am also the parent of two children-one previously enrolled in the Infant and Toddler program. I was previously a member of the Fayette/Greene and Washington Local Interagency Coordinating Council and the State Interagency Coordinating Council. I participated in the Legislative Budget and Finance Committee's discussions in their review of the Commonwealth's early intervention programs in response to House Resolution 354. I am currently a member of the Allegheny/Pittsburgh Local Interagency Coordinating Council, the Parent Voices to the State Interagency Coordinating Council, and the Western Region Early Intervention Coalition organized by the Education Law Center.

We at ARC Allegheny appreciate the opportunity to participate in the process by which families, providers, community members and others interested in early intervention can offer oral and written comments on the proposed regulations.

Since the regulations, once finalized, will be the "legal" structure under which the infant and toddler program will operate the input from stakeholders is vital, especially from families. We feel strongly that there should be more opportunity for public input in geographic areas throughout the region-particularly for families who rely solely on public transportation which was not available for today's meeting. In addition, we have spoken to parent leaders of Local ICC's and families who have children currently enrolled in the infant and toddler programs throughout Allegheny and surrounding counties and they were not informed of the process. The leadership in many of the ICC's changed in the spring and many ICC's do not meet in the summer. Our State ICC does not meet in July. While we do applaud the Department of Public Welfare/Office of Mental Retardation for extending the comment period from 30 to 60 days, it is inadequate when compared to the more than 15 focus groups and hearings held by the PA Department of Education for the recent proposed changes to Chapter 14. Families and other stakeholders need time to ask questions, evaluate, and prepare their comments. If the State ICC and local ICC's are not meeting and with the summer being prime vacation time how can this comment period be appropriate? We are disheartened that the Department of Public Welfare/Office of Mental Retardation did not seek input in more consumer and family friendly ways.

We would like to thank the Department of Public Welfare/Office of Mental Retardation for not changing the eligibility criteria. Early

Intervention services are critical to the future of children, families, and communities. We feel strongly that keeping the eligibility criteria as it is today is vital.

A theme for our concerns with the proposed regulations is the notification of families concerning their rights. Families are often unaware that they and their infant or toddler have a **right** to early intervention services. Having clearly defined regulations would be a way to clarify this program for them.

*FINANCIAL MANAGEMENT (4226.12, 4226.13, 4226.16)

This section needs to be clarified to reflect that (1) **Parents cannot be required to apply for Medicaid in order to receive early intervention services** and (2) **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.** Although financial implications for counties, providers and ultimately the state are important, it is equally important to inform families of their rights, especially once an IFSP has been written and services should begin.

*GENERAL REQUIREMENTS

4226.24(f) (Timelines): This section is confusing. It does not make clear that **for a child determined to be eligible for services the IFSP must be developed within 45days of referral.**
4226.25-4226.29 (Screening): It is unclear whether the screening process outlined is to facilitate the MDE process. In the case of evaluations secured by the family, it is acceptable and mandatory for the MDE team, with the family's consent, to consider the results of prior evaluations. **For every child referred there should be an MDE and parents should be informed at the time of referral.**

*EVALUATION AND ASSESSMENT

4226.62(d): **This provision should make clear that families be informed that the initial IFSP must be held within the 45 day period from the date of referral.**

*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 and families should have written notice of this right.**
4226.73 (Participants in IFSP meetings and periodic reviews): This is the list of personnel required by the federal regulation. However, this provision should also state that the service coordinator has 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 must have the authority to make decisions as to what a child needs and what must be listed on the IFSP. Families do not know that decisions are to be based on the IFSP and all too often the team must wait for a decision from the county. Such a process violates the law.**
4226.74(7)(I)(Dates, duration of services): Timely implementation of the IFSP is paramount to the success of the whole system. The only way to make certain that **families are clear on their rights and the counties on their duties is to set a deadline.** It is not enough to say "as soon as possible after the IFSP meetings."
4226.74(9)(transition): In PA a lot of time and money are spent in the transition process which has continued to be problematic in many areas. Our LICC has spent the last fiscal year meeting, negotiating and ultimately attempting to draft a *workable* interagency agreement on transition. The provider agencies, the MAWA holders, Service Coordinators, EITA, parents, community members, and LICC members have spent valuable time and should be complimented for their commitment and effort. However, these regulations should provide guidance to the field. It is important that the requirements be explicitly listed. In addition, the state has agreed that **"pendency" applies between these systems, and that children cannot be dropped from the service in the IFSP because their parents do not agree with the services offered by the MAWA. We 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 and that parents be notified in writing of these rights.**

*PROCEDURAL SAFEGUARDS (4226.91)
The regulations make no mention of the complaint management system required by the 34 C.F.R. Sections 303.510-512. In fact, **contrary to the federal requirements it fails to state that the written notice must describe how to file a complaint and the timelines under those procedures. Parents simply do not know this system exists or how to use it. Under federal regulations the State has an *obligation* to "widely disseminate to parents and other interested individuals**

including parent training centers, protection and advocacy agencies...and other appropriate entities, the State's complaint management procedures..."(34 C.F.R. 303.510(a)(2).

Parents need to have appropriate, understandable information about the Early Intervention program that their child is referred to and ultimately may be eligible for service from. All too often, a family contacting ARC Allegheny's Family Support Team has little knowledge of the program(s) their child is involved in. They do not know they are a part of the **team**, can request a meeting or independent evaluation, or can file a complaint.

Thank you for the opportunity to speak today. As always, ARC Allegheny pledges to assist the early intervention community in our mutual commitment to provide quality supports to families.

Public Comment 14

TESTIMONY

Original: 2122

Early Intervention
55 PA. Code Chapters 4225 and 4226 Proposed Rulemaking
Presented at the July 24, 2000 hearing of the
Department of Public Welfare

by

Shirley Walker, Executive Director
Pennsylvania Association of Resources
for People with Mental Retardation (PAR)

Good morning, My name is Shirley Walker. I am the Executive Director of the Pennsylvania Association of Resources for People with Mental Retardation. Our members support tens of thousands of children and adults with mental retardation throughout the Commonwealth and we employ tens of thousands of citizens to provide direct services and supports. We provide the full range of mental retardation services and supports in 2200 locations in PA in addition to non-residential and in-home supports including early intervention for children and their families.

Thank you for the opportunity to testify today.

PAR commends the Department of Public Welfare for involving the association during the development of this proposed rulemaking. Some important assurances have been retained which we strongly support; namely, the eligibility criteria of 25% of the child's chronological age in one or more developmental areas, and the decision to retain the use of informed clinical opinion.

My testimony this morning will not be a complete accounting of our comments or recommendations. Rather, because of the time constraints common to these hearings, it will highlight some key areas in which we have made recommendations. Our written comments, however, which are due in August, will expand on this testimony and will also provide comment on some additional areas that we will not go into this morning.

The areas I would like to focus on are the following:

1. Requirements and qualifications of staff and the impartial hearing officer
2. Training requirements
3. Compensation
4. Clarification of the roles of the early interventionist, the service coordinator and the supervisor
5. Case load
6. Child abuse clearances and reporting procedures.
7. The Initial Screening and Screening Process, the MDE, and the IFSP
8. The timeline for the administrative resolution process
9. Foster parents as surrogates.
10. Financial impact

Our first recommendation relates to the requirements and qualifications of staff. In reviewing the requirements and qualifications of staff that are proposed, we have determined that they are not adequate for what is expected of the positions.

PAR's early intervention providers are having more and more difficulty finding staff who are able to carry out the job responsibilities. Qualifications that do not match the skill level required upon entering a job can easily result in failure in the job and early turnover which is disruptive to services. For example, for the position of service coordinator, PAR recommends that the individual have a bachelor's degree in a field related to early childhood, special education, psychology, social work, family studies, or a related field, and one year of experience working directly with children and families in a paid capacity, in addition to being able to demonstrate the skills identified in IDEA.

Early intervention is the first and best chance that we have of making a difference in the life of a little child, and we need to make the most of it with persons who have the skills to do it.

Our written comments will also suggest changes in the requirements and qualifications of other personnel mentioned in the proposed rulemaking.

Our second recommendation relates to grandfathering.

If the Department agrees to match the requirements and qualifications of staff to the skills needed, there will need to be a transition so that services will not be disrupted and people will not suffer loss of jobs.

Therefore, PAR recommends that all staff who are employed on or before the effective date of the regulations be grandfathered and allowed to remain employed with their current qualifications.

Our third recommendation is a logical result of increased staff qualifications and requirements; that is, PAR recommends that language be added to state that "the salaries of early interventionists, service coordinators and supervisors shall be at least competitive with other professionals with comparable qualifications and experience."

The compensation studies relative to people who provide mental retardation services and supports point to the inescapable fact that the state -- the payor and regulator -- has been willing to allow the continuance of abominably low rates of pay for services that require considerable skill.

The result has been unacceptable vacancy rates, high turnover, and the use of temporary staff in positions that should be filled with skilled people who are well educated and have the experience necessary to enable them to provide effective intervention that will make a difference in the lives of these infants and toddlers.

We urge the department to support the concept of adequate compensation and to encourage it by adding language such as the language we just proposed.

PAR's fourth recommendation relates to training.

Appropriate staff training is important in maintaining quality early intervention services. PAR suggests that the regulations attempt to compensate for lack of adequate education and qualifications for the job by inserting training requirements that are written arbitrarily and do not appear to relate to experienced staff.

PAR suggests that the early intervention services regulations require adequate qualifications on the front end – before staff are hired. With staff who are adequately qualified, the ongoing training necessary to improve and

maintain competent workers should be able to be accomplished well within a 24-hour annual training requirement if the training is focused on the right things.

Staff training can be used for the purpose of maintaining quality early intervention services -- and regulations should provide an appropriate baseline. However, the way the proposed rulemaking currently reads, the requirement, as written, sets up an unavoidable problem.

The provision states that the service coordinator, early interventionist and other personnel who work directly with the child, including the personnel hired through contract, shall have at least 24 hours of training annually.... PAR recommends that the words "at least" be removed from this proposed rulemaking. Otherwise, it will lead to a standard that is not reliable and one that will encourage arbitrariness.

Also, the 6 hour requirement doesn't seem to be at all related to one's qualifications or experience. There needs to be further discussion on the necessity of these hours and on the related cost.

Speaking again about qualifications, the qualifications and duties of the impartial hearing officer are missing. IDEA addresses such qualifications and duties, and PAR recommends that these be included in the regulations.

PAR's next recommendation is that the roles of the early interventionist, the service coordinator and the supervisor be clarified.

For example, the definition of early interventionist appears to include service coordination responsibilities and there are no definitions for therapists or supervisors. Also, there are no statements of requirements and qualifications for therapists or supervisors. We suggest that there is language in the waiver that could be considered for inclusion to address some of this need for clarification, and we are providing specific language for your consideration in our written comments.

Now, you can have good qualifications and training but if your caseload is unrealistic, the level of service will drop. Therefore, we recommend that the caseload for a service coordinator be no more than 35 children.

PAR's next recommendation relates to child abuse clearances and reporting procedures. This one is more complicated and will require the initiative of the Department with other Departments and the legislature to insure that it is addressed appropriately.

The proposed regulations reference Act 33 in the preamble when describing Section 4426.38 (criminal records history checks) to ensure that legal entities as well as service providers are aware of their existing obligations under Act 33.

We know that the provisions related to applicant and employee criminal history checks apply to mental retardation facilities for the Older Adults Protective Services Act purposes, hereinafter I will refer to the Older Adults Protective Services Act as OAPSA. In it, mental retardation facilities are considered "facilities" under the OAPSA's expansive definition of "home health care agency" because they "provide care to care-dependent individuals in the individual's place of residence."

We also know that OAPSA defines "care-dependent individual" as an adult – so it would seem that, assuming services were provided to 0-3 year olds in their places of residence, those services would not fall under OAPSA and therefore, those MR facilities that provided services only to children would not fall under OAPSA.

However, we also know that OAPSA is not internally consistent. At 35 Purdon's Section 10225.502, OAPSA also mandates a facility to require all applicants for employment and all administrators and operators who may have direct contact with a recipient to submit a criminal history check like those referenced in these proposed early intervention services regulations. Employees of less than one year had to meet the same requirement.

The point is that a "recipient' is defined by OAPSA as "an individual who receives care, services or treatment in or from a facility." An individual is a person of any age, as the most recent draft of the OAPSA regulations now specifically clarifies.

The bottom line is that we understand that any entity which falls under the broad definition of "facility" contained in the OAPSA and that provides services to children not only may have to meet the requirements of Act 33, for Child Protective Services, but also must be sure to meet the requirement

of Act 13 for Older Adult Protective Services, along with the respective regulations for each of the Acts, as well as the current proposed early intervention rulemaking under consideration.

Overlapping rules and reporting procedures that don't make sense (such as reporting child abuse to the Department of Aging whose authority relates to elderly people, not to infants and toddlers) lead to confusion and delay. Confusion, delay, and multiple layers of reporting lessen, rather than strengthen, safeguards.

My point here is that it is time that the administrative agencies and the legislature get together and get rid of the multiple overlapping and very confusing rules surrounding abuse clearances and reporting procedures.

Reporting should be simple, easy to understand, and effective so that children and adults are protected well.

Please get this one worked out so that it makes sense to everyone.

Regarding the processes of the initial screening, the MDE, the IFSP and the administrative resolution process, our recommendations include:

- that there be universal procedures for the initial screening and the screening process so that every child has the same opportunity to be considered for the MDE, which determines eligibility.
- That parents be informed of the screening results in writing, as well as to their right to an MDE in the event that they disagree with the screening results, and that the legal entity document in writing all contact with the family.
- That the expertise and understanding and experience of persons involved in service provision be utilized without conflict of interest in the initial MDE by rewording the section to read: The initial MDE is conducted by personnel independent of "future" service provision. In other words, add the word "future."
- That a new provision be added to allow for parental choice and consideration of geographic location.
- That the MDE team be expanded to reflect federal requirements regarding the definition of a multidisciplinary team. (Part C, Section 303.17: includes the -- "involvement of two or more disciplines or

professionals in the provision of integrated and coordinated services...")

- Regarding the IFSP, it needs to occur within 45 days of referral. It appears that a plan for further assessment and tracking would be considered an acceptable replacement for the IFSP. Is that what the department intends?
- Also, the regulations need to be clear that family members or other team members are allowed to request a review more often if they choose.
- Regarding participants in the IFSP meetings and periodic reviews, the service coordinator needs to have the authority to commit the resources of the legal entity to carry out the IFSP, or the process is flawed from the beginning.
- Also, since persons providing services to the child should participate in the IFSP meeting, the words, "as appropriate" in 4226.73 (6) should be deleted.
- The timeline for the administrative resolution process should specify that it shall be carried out within 30 days at a time and place that is reasonably convenient to the parents. The words added there are "within 30 days."

Regarding Foster parents as surrogates, PAR recommends that the language from several sections of the 1997 draft be restored, including:

- the opportunity for a foster parent to serve as a surrogate if all requirements for surrogate are met,
- that authorization be given to the County program to appoint a surrogate parent at the request of the parent under certain circumstances, and
- that the provision be added which protects surrogate parents from liability if they perform their duties in good faith.

Foster parents are often the best and only adults able to adequately perform the functon of a surrogate parent, therefore it is unclear why the proposed rulemaking removed those provisions and is willing to accept the delays that will occur if these limitations are put into effect.

Our final recommendation relates to the financial impact of this proposed rulemaking.

It is problematic that the Department has not recognized any increased costs related to implementing these rules.

You have established that payment for services is made according to rate per unit of service. Our understanding of how the rate per unit of service was established is that the initial study that formed the basis for establishing the rate did not include the cost of training, for example. However, training, as proposed, is a substantial cost.

Since the rate per unit of service must cover all unit expenses, which include direct, indirect and administrative costs, then it should follow that the rate per unit of service needs to be increased.

Therefore, we request clarification regarding how training was treated in the process which established the rate per unit of service, how it will be included in the rate, and whether the training costs along with our other comments will help the Department acknowledge that there is a significant financial impact relative to these regulations.

We have highlighted some complicated issues – the abuse reporting requirements, for example -- that are not possible to deal with adequately within the time allowed in this hearing or even in written comments. For that reason, PAR respectfully requests an opportunity to meet with the Department.

Thank you for considering our request and for listening to our comments and recommendations.

Public Comment 5
#14-452

Original: 2122

RECEIVED
2000 JUL 25 PM 3:30

Midwestern Local Interagency Coordinating Council

Working To Build Partnerships Among Families and Professionals in Early Intervention

Mailing Address: Kathy Shevetz
Lawrence County MH/MR
15 West Grant Street
New Castle PA 16101

The Midwestern Local Interagency Coordinating Council is pleased to present comments regarding the proposed Early Intervention Services Regulations. They have taken many years worth of bulletins, memos and myths and compiled them into one easily readable document. We extend our thanks and congratulations to all the individuals who participated in the development process.

There were several areas of concerns/need for clarification identified as members of the Midwestern LICC reviewed the document. It seems to indicate in 4226.13 (b) (1), (2), and (3) that the parents will not suffer financial losses if they volunteer to use their insurance. Those financial losses include a decrease in lifetime coverage or any other benefit under an insurance policy, an increase in premiums or the discontinuation of the policy, and an out-of-pocket expense such as the payment of a deductible amount in filing a claim. We would like to see clarification of how the State will ensure these losses do not occur when providers are dealing with private insurance companies.

An area of concern is found in 4226. 24 regarding the comprehensive child find system. The use of the term "ensure" throughout this section obligates the legal entity to activities and outcomes that cannot always be controlled by the legal entity. For example, it states under 4226.24 (a) that "The legal entity shall develop a child find system that will **ensure** that: (1) All infants and toddlers in the geographical area of the legal entity, who are eligible for services are identified, located and evaluated". The way this is stated, it appears that the legal entity must do this, or be out of compliance with the regulations. There is no way possible to ensure that this will happen, given the fact that this is a voluntary process for families and children. We are requesting that the term "ensure" in this section be replaced with something less obligatory.

Clarification is needed under section 4226. 24 (f) (2), which states that "Within forty-five 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

This seems to indicate that if only one of these is accomplished, the legal entity fulfills the requirements of this section. In 4226.72 (a) it states "For a child who has been

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Susan Black/Frank Cloud
Marlene Schell
Midwestern IU IV
453 Maple Street
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Penny Perkins
Farrell Early Intervention
1901 Memorial Drive
Farrell PA 16121
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evaluated for the first time and determined to be eligible, a meeting to develop the initial IFSP shall be conducted within the 45-day time period in 4226.24 (f) (relating to comprehensive child find system). Does this mean the legal entity has up to forty-five days to evaluate, then may take up to an additional forty-five days to complete the IFSP? If the IFSP must be completed within forty-five days of the initial referral, as is the current requirement, these two sections must be reworded to more accurately reflect the requirement for compliance with the regulations.

We are requesting clarification of 4226.28 (4). In this section, the legal entity is to make a recommendation to the child's parent as a result of the screening. Under (4), it states "The child is not eligible for early intervention or tracking services currently and the parents have been informed of their options for continued contact with the legal entity if the needs change". Does this mean that all children who have had a screening completed who do not meet eligibility for services or tracking must be offered the option of tracking funded through county dollars?

This is the current practice, and there is no way to count these children under the EIRS data. Therefore, we are unable to secure funds for additional service coordinators. A large number of families choose this option, and it is becoming burdensome to the service coordinators. If this is the meaning of this section, will there be a way to count these children so that funding may be allocated for additional service coordinators if the need is justifiable?

Section 4226.34 covers community evaluations. For the past several years we have been using the Self-Assessment Tool developed by Dr. Jeffri Brookfield. This section seems to be indicating that a separate self-assessment process be developed and implemented with the input from the legal entity advisory board and the LICC. It further states that at least half the persons who are involved in the development and application of the community evaluation must be family members of children who are receiving or have received early intervention services. We are requesting clarification in two areas. First, is this community evaluation in addition to or replacing the standard Self-Assessment Tool currently being used? Second, does the term "legal entity advisory board" refer to the County MH/MR Advisory Board?

The Midwestern Local Interagency Coordinating Council is fully supportive of the need for standardized training, both pre-service and on an annualized basis. We do anticipate additional costs and paperwork to meet this requirement. The current rates for early intervention do not always adequately cover the cost for the service. When individuals are attending training, they must still be paid, and this is time taken away from billable direct service to the families. Providers are projecting a substantial negative financial impact from this requirement. We are asking that data is collected from providers regarding the actual costs, and consideration is given to the creation of a training fee specific to this requirement.

Our final area for clarification is in section 4226.54 (c) (2) as it relates to service coordinator qualification. It states there that an associate's degree, or sixty credit hours,

from an accredited college or university and three years' work or volunteer experience working directly with children, families or people with disabilities, or in counseling, management or supervision would be sufficient qualifications for a service coordinator. Are we correct to assume that it would still be at the discretion of the legal entity to require at least a bachelor's degree as a minimum educational requirement?

This concludes the comments of the Midwestern Local Interagency Coordinating Council on the proposed Early Intervention Services Regulations. Once again, we applaud the efforts of the committee to develop these regulations, and thank you for this opportunity to provide comment.

University of Pittsburgh

School of Medicine
Autism Research Project and Social Disabilities Clinic
An NICHD Collaborative Program of Excellence in Autism

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November 26, 2000

Mr. Robert Nyce
Executive Director
Independent Regulatory Review Commission
14th Floor, Harristown 2
333 Market Street
Harrisburg, PA 17101

Original: 2122

Dear Mr. Nyce,

I am writing to provide comments on the proposed amendments to the Early Intervention Services Act contained in Chapter 4226. By way of introduction, I am a pediatric neurologist and Associate Professor of Psychiatry and Neurology at the University of Pittsburgh School of Medicine. I am also director of one of the nation's 10 Collaborative Programs of Excellence in Autism, which focus on investigating the genetic and neurobiologic basis of autism. This network also responds to important public health issues by providing urgently needed research on issues such as intravenous secretin as a treatment for autism and measles vaccination as a purported cause of autism. My comments therefore pertain to the limitations of the proposed amendments for intervention in autism.

#1. Qualifications for service coordinator (4226.54) and early interventionist (4226.55)
It is proposed that the service coordinator (case manager) and early interventionist have a bachelors degree and 1 years work experience or an associates degree and 3 years work experience. These requirements are inadequate to ensure adequate and appropriate services to a child with a low prevalence disorder such as autism (also called autism spectrum disorder or pervasive developmental disorder).

I would recommend that the service coordinator and early interventionist for children with autism spectrum disorder have a bachelors degree, one year of general experience with children with developmental disabilities, and at least one year's full time experience or training with an autism program recognized by the professional and parent community as having the appropriate knowledge and skills in the area of autism. In addition, I would recommend that this individual have at least 24 hours of training per year in autism with attendance at one major autism training conference once per year during the first 3 years of attaining this position, and at least every other year thereafter.

The justification for this recommendation is that autism was viewed until recently as rare, and consequently the education and training in all disciplines regarding this disability was extremely

limited. Knowledge about autism has also increased dramatically in the past 5 years. In addition, autism is not cognitively or behaviorally like other disabilities; thus, the needs and treatment of these children have many features unique to this disorder that only a person experienced with autism would be able to identify and appropriately manage. Given that there is evidence that early intervention can effectively improve long term outcome and evidence of the radically rising prevalence of autism spectrum disorders, it is critical that this disorder be correctly addressed as early in the child's life as possible.

#2. Natural environment
It is proposed that services be provided in the environment typical of a child of that age. However, this is not always appropriate or even optimal. It is recommended that services be provided in the environment in which the child will receive the most benefit. For examples, the child with a severe social or language disability may need to be in a group setting smaller than the typical nursery school or day care or in a one-to-one setting.

#3 Other comments:

a. Early interventionist not clearly differentiated from service coordinator (4226.55)
It is not entirely clear how this person differs, on the one hand, from the service coordinator and, on the other, from those providing intervention.

b. Duties for service coordinator are comprehensive
The description of duties for the service coordinator sound more like an intensive case manager. Will the case load of these individuals allow them to fulfill these?

c. Funding sources not clear (4226.13, 4226.14)
4226.13 (a) and (b) and 4226.14 concern state funds, public and private funding sources sound contradictory, the first and the last suggesting that parent insurance should be considered and the middle that it should not.

d. Definition of delay non-standard (4226.22, 4226.3)
The use of percentages to express delays is non-standard; 1.5 or 2.0 (both are used in this document) standard deviations below the mean is the more accepted characterization. Also, in (i) and (ii), reference is made to a standardized general intelligence test. It is difficult to accurately measure general intelligence in the 0-3 age group, especially in the presence of developmental delay. It is also not clear why (i.) and (ii.) are considered separately.

e. Definition of functional limitation too limited and not age-appropriate (4226.3)
A number of the functional life activities are not relevant to 0-3 year olds, particularly capacity for independent living, economic self-sufficiency, and self-direction. Conversely, social competence and age-appropriate problem solving or judgement are not listed.

f. Use of the term mental illness archaic (4226.23)

Under (2), ...other related conditions that include cerebral palsy and epilepsy, as well as other conditions—such as autism—other than mental illness—that result in impairment of general intellectual functioning... It is not entirely clear what the term "mental illness" is referring to, but it does not seem appropriate to any of the conditions being considered for early intervention. These disorders are all neurologically or brain based.

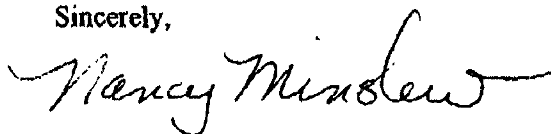
g. Child find system should include pediatrician & parent education (4226.24)
The pediatricians would seem to be a logical point of identification of developmental delay or at-risk status but are not mentioned here. Generally, they are probably poorly educated about the availability of such services. Parents also need to be directly aware of such programs, since they are often aware of problems long before pediatricians, and are more often correct than the pediatrician and the Denver Developmental Screening Test.

h. Practice parameters for screening, diagnosing and assessing toddlers for autism spectrum disorder. These guidelines have been recently published and include screening for autism beginning at 18 months. This screening should be incorporated into the 0-3 assessments of delayed and at-risk toddlers and young children.

i. Error in specifying age in 4226.74 (B)
This section refers to 23rd birthday, which must be a typographical error.

Thank you for considering these comments. If there any questions about these comments, please don't hesitate to call me.

Sincerely,



Nancy J. Minshew, M.D.
Associate Professor of Psychiatry and Neurology
Director,
NICHD Colloaborative Program of Excellence and
The Center For Autism Research (CeFAR)

cc: Representative Dennis O'Brien
Senator Tim Murphy
Mr. Mel Knowlton

FAX

RECEIVED
2000 NOV 28 PM 4:41
REGULATORY REVIEW COMMISSION

Autism Project
3811 O'Hara Street
430 Bellefield Towers
Pittsburgh, PA 15213

Date 11/28/00

Number of pages including cover sheet 4

Original: 2122

To:		**From:**	
Mr. Robert Nyce		**Evelyn Herbert**	
Phone		Phone	(412) 624-0818
Fax Phone	(717) 783-2664	Fax Phone	(412) 624-0930
CC:			

REMARKS:

☒ Urgent ☐ For your review ☐ Reply ASAP ☐ Please comment

Following are comments from Dr. Nancy Minshew on the proposed amendments to the Early Intervention Services Act contained in Chapter 4226.

From:

Subject: FW: DPW Early Intervention #14-452

Early Intervention Services Re...

Please handle this on Reg #2122. Thanks.

-----Original Message-----
From: IRRC
Sent: Monday, November 27, 2000 2:10 PM
To: Shomper, Kris
Subject: FW: DPW Early Intervention #14-452

-----Original Message-----
From: Wilson, Nia [mailto:NWilson@pahouse.net]
Sent: Monday, November 27, 2000 1:57 PM
To: 'IRRC@irrc.state.pa.us'
Cc: 'eyarnell@pahousegop.com'
Subject: DPW Early Intervention #14-452

cc:

<<Early Intervention Services Regulation Comments.doc>>

November 20, 2000

Department of Public Welfare
ATTN: Mr. Mel Knowlton
Bureau of Quality Improvement and Policy
P.O. Box 2675
Harrisburg, Pennsylvania 17105-2675

RE: Early Intervention Services
Regulation # 14-452

We are submitting the following comments on the proposed early intervention services regulation as an addition to, and which we are in support of, the Early Intervention Stakeholders comments.

§4226.25 – 4226.29. Initial Screening.

This provision adds a prerequisite to a child receiving a full evaluation. This prerequisite screening is in conflict with federal law, 34 CFR 303.321(e), which states, that within 45 days of the date the county receives a referral, the county must complete the evaluation. This screening process would result in recommendations, which can be made only after a full MDE. If such recommendations would result in children not receiving the full MDE, these screening provisions should be removed from the regulation.

§4226.54 – 4226.56. Personnel Requirements and Qualifications.

The regulation has further reduced, from the two previous drafts, the level of expertise required of the service coordinator. The qualifications contained in the proposed regulation are inadequate and do not in any way reflect the level of expertise needed to do this job competently. The regulation also creates a new type of early intervention service and provider. It is unclear how this service differs from that provided by the service coordinator. It appears, from the unclear and ambiguous language used in the regulation, that this position substitutes for the service coordinator and should, therefore, comply with federal law, which requires that personnel standards be based on the "highest requirements of the state applicable to a specific profession of discipline." 20 U.S.C. 1435(a)(9)(B). We support the "competency based" approach previously used by the Department.

§4226.74 et al – Content of IFSP
This section of the regulation cites a phrase from the federal law, "as soon as possible after the IFSP meetings" but does not set a time limit. We suggest that a specific deadline, such as 14 days, be set. The proposed regulations do not insure a smooth transition when a child reaches three years of age. This section should include the transitions components contained in federal law, 34 CFR 303.344(h), which states the extent to which the IFSP must provide for training and discussions with parents, the steps to help children adjust to new settings, and clarifies whether records can be transmitted. These requirements should be explicitly listed in the regulation. Also, "pendency" requirements, that children cannot lose services in the IFSP at age 3 because the parent does not agree with the MAWA services, should be in the regulation.

We appreciate the Department's efforts to elicit comments on this regulation, public meetings and an extended public comment period. We trust that the same degree of effort will be applied in your review of these comments and their inclusion in the final regulation in order to best meet the needs of infants and toddlers with special needs.

Sincerely,

Rep. Frank L. Oliver, Democratic Chairman
House Health and Human Services Committee, and

Rep. Babette Josephs, Democratic Appropriations
Sub-Committee Chair – Health & Human Services

Original: [illegible]

The Pennsylvania School for the Deaf

100 W. School House Lane, Philadelphia, PA 19144 • (215) 951-4700 / 951-4703 TDD / FAX 951-4708

RECEIVED
2000 NOV 27 AM 10: 17
REVIEW COMMISSION

November 20, 2000

Ms. Nancy Thaler
Depute Secretary of Mental Retardation
Office of Mental Retardation
Pennsylvania Department of Public Welfare
Room 512 Health & Welfare Building
Harrisburg, PA 17105

Dear Ms. Thaler:

I am writing as a follow-up to the recent hearings concerning proposed DPW Early Intervention Regulations held by the PA House Health and Human Services Committee on November 20, 2000 in Harrisburg, PA. I was pleased that we had the chance to talk, albeit briefly, at the conclusion of your testimony and wanted to follow-up with more in-depth information concerning the relationship of the proposed Federal regulations and the Pennsylvania proposed regulations.

First, I was especially pleased to hear your statement that the Pennsylvania regulations should be "based in and consistent with the Federal regulations that govern the [Part C] program." I am very much in support of this statement and the comments I will offer are intended to support that intention and goal. The following will outline the specific language from the proposed Federal regulations which I am suggesting be added to specific sections of the proposed DPW regulations.

1. DPW section 4226.72. Procedures for IFSP development, review and evaluation. This section is similar in title to section 383.342 Development, Review and Revision of IFSP's in the proposed Federal regulations. I suggest that the language in the proposed Federal regulations published in the September 5, 2000 Federal Register which addresses *consideration of special factors* be added to this section of the DPW regulations, specifically the consideration of special factors paragraph and the following paragraphs that describe the special factors. (page 53844, Federal Register, September 5, 2000.)

2. DPW section 4226.74. Content of the IFSP. I am suggesting that the brief statement in the DPW proposed regulations, "(5) *Natural environments. A statement of the natural environments in which early intervention services shall appropriately be provided including justification of the extent if any to which the services will not be provided in a natural environment*" be replaced with language from section 383.344 in the proposed Federal regulations, also entitled "Content of the IFSP." That

language is on page 53845 of the September 5, 2000 Federal Register, "(3) *Natural Environments – location of services*." This is the section which clarifies that specification of natural environments be related to particular services.

3. Section 383.341. Policies and Procedures on Natural Environments (page 53843 of the September 5, 2000 Federal Register) is an extensive clarification of the Federal position on natural environments. I believe that this language should be reviewed carefully, especially paragraph (B), *determination of natural environment of each IFSP service*, and that information be included in the proposed DPW Early Intervention Regulations. Perhaps that language could be included under DPW proposed regulation section 4226.71, General.

I believe the addition of language from the Federal Register cited above will strengthen the section on IFSPs in the proposed DPW regulations, create even greater consistency with IDEA and provide clear guidance to local agencies, service coordinators and providers with respect to the natural environments issue. While I understand that this is proposed Federal language, I think it can be reasonably assumed that most of the language in the proposed Federal regulations will be included in the final rule making. If this language is proactively included in DPW regulations, there will be less of a need to revisit DPW regulations after final Federal regulations are published and will also improve consistency with IDEA. Another option might be to wait until the Federal regulations are finalized so that the exact language can be included in the DPW regulations. However, the comment period for Federal proposed rule making does not end until December 4, 2000 and it is difficult to ascertain at this point how soon after the public comment period final Federal regulations will be proposed.

Thank you very much for your interest in providing greater consistency with IDEA and clarity with respect to the natural environments issue. I would be very happy to work with you or your staff in determining how the proposed Federal language could be successfully integrated with the proposed DPW regulations or with any other issue related to early intervention services for deaf or hard of hearing children. Thank you again for your consideration.

Sincerely,

Joseph E. Fischgrund
Headmaster

JEF:jh

Cc: Representative Dennis M. O'Brien, Chairman, Pennsylvania House Health and Human Services Committee
Honorable Robert Nyce, Executive Director, Independent Regulatory Review Commission
Mel Knowlton, Office of Mental Retardation, Department of Public Welfare

University of Pittsburgh

Original: 2122

School of Medicine
Autism Research Project and Social Disabilities Clinic
An NICHD Collaborative Program of Excellence in Autism

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November 26, 2000

Mr. Robert Nyce
Executive Director
Independent Regulatory Review Commission
14th Floor, Harristown 2
333 Market Street
Harrisburg, PA 17101

RECEIVED
2000 DEC -4 AM 10:03
REVIEW COMMISSION

Dear Mr. Nyce,

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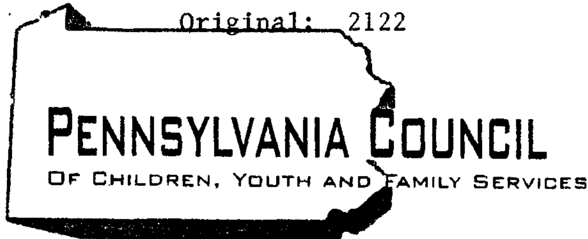
Thank you for considering these comments. If there any questions about these comments, please don't hesitate to call me.

Sincerely,

Nancy J. Minshew, M.D.
Associate Professor of Psychiatry and Neurology
Director,
NICHD Colloaborative Program of Excellence and
The Center For Autism Research (CeFAR)

cc: Representative Dennis O'Brien
Senator Tim Murphy
Mr. Mel Knowlton



117

2040 LINGLESTOWN ROAD, SUITE 109
HARRISBURG, PENNSYLVANIA 17110
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FAX (717) 651-1729

November 2, 2000

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

Re: Proposed Rules for Early Intervention: 55 PA. CODE CHS 4226

Dear Mr. Knowlton:

I write on behalf of the Pennsylvania Council of Children, Youth and Family Services (PCCYFS) to comment on the proposed rulemaking on early intervention services. PCCYFS represents a significant number of private child welfare agencies serving children and families across Pennsylvania. Many of the children served by PCCYFS member agencies are dependent children who were placed in substitute care (foster care, kinship care, or residential care) because of findings of abuse and neglect. The Council's mission is to support and enhance the ability of member agencies to improve the quality of children's and families' lives through in-home supports, foster care, residential services, outpatient treatment programs, alternative educational programs, and adoption services.

Our concern about the proposed regulations centers on how they support and advance accessibility to early intervention services for the thousands of Pennsylvania infants and toddlers currently in the custody of county children and youth agencies. We strongly recommend that the proposed regulations be modified to permit foster parents to act as educational surrogates in those instances where natural parents are unavailable or unwilling to participate in making early intervention service decisions yet their parental rights have not been terminated.

Research has shown that in the past decade the number of young children, particularly the number of children under the age of one, entering the foster care system has increased dramatically. These dramatic increases have not been linked to the changes in the general population. As a group, these children are much more likely to have reports of substantiated maltreatment, and to be placed in foster care. Children four and under, remain in foster care longer than older children, and have less chance for reunification.[1]

[1] George, R.M. & Wulczyn, F., "Placement Experiences of the Youngest Foster Care Population: Findings of the Multistate Foster Care Data Archive", Zero To Three, 19:3,8-18, 1999.

Several pediatric research studies have shown that foster children have three to seven times as many acute and chronic health conditions, developmental delays, and emotional adjustment problems as children from low-income families. Additional research has found that 50% of children in foster care under the age of three qualify for early intervention services. Data from the Starting Young Program, a multidisciplinary developmental follow-up program for infants and toddlers receiving services from the Philadelphia Department of Human Services, indicated that approximately one half the children evaluated by a multidisciplinary team, including a pediatrician, met the Pennsylvania criteria for early intervention services.[2]

Although data demonstrate that a disproportionate number of young foster children qualify for early intervention services, foster children often do not access early intervention services for which they are eligible. Foster parents and social workers report that their efforts to secure early intervention services are often delayed or thwarted. From the onset, confusion exists among child welfare professionals with regard to who has the authority to consent to screenings and/or assessments. Additionally, delays in obtaining evaluations and services occur when birth parents cannot be located to consent to them. These delays in obtaining services mean a child's development continues to lag and perhaps the delays become even more significant. While the regulations provide the appointment of educational surrogates, this alternative currently is neither well understood nor widely utilized.

Under the Department's proposed regulations, foster parents cannot be considered for appointment as surrogates unless they meet the standards set out in §4226.105(f), which states, in part, "A foster parent qualifies under this part if the following apply: The natural parents' authority to make early intervention or educational decisions on the child's behalf has been relinquished under state law." Many of the infants and toddlers living in foster care have natural parents who are unavailable to participate in the early intervention service decision making process, but whose parental rights have not been terminated. The proposed regulations will require that an adult, other than the foster parent and perhaps someone who does not even know the child, assume the responsibility for early intervention services for foster children. Foster parents who have physical custody of children often are most familiar with their children's developmental progress. Moreover, they are the persons best positioned to support and enhance recommendations of the child's early intervention specialists. Many foster parents are ready and willing to assume this responsibility, but will be precluded from becoming educational surrogates under this proposed regulation.

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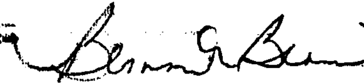
[2] Silver, J., et al. "Starting Young; Improving the Health and Developmental Outcomes of Infants and Toddlers in the Child Welfare System", Child Welfare, 78: 148-165.

Mr. Mel Knowlton
November 2, 2000
Page #3

Again, we strongly urge you to consider revising the draft regulations so that foster parents can act as educational surrogates.

If you have any questions, please do not hesitate to contact me.

Sincerely,



Bernadette M. Bianchi, LSW
Executive Director

BMB/mz

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Original: 2122

ARC of Montgomery County
Administrative Offices
Continental Plaza
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King Of Prussia
Pennsylvania, 19406

Tel: 610.265.4700
Fax: 610.265.3439

October 28, 2000

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

Dear Mr. Knowlton:

On behalf of The ARC of Montgomery County I am writing to express our concerns regarding the proposed PA Infant and Toddlers Early Intervention Regulations. We are very concerned that about the following issues:

The proposed regulations won't help us find all of the children who need help. For one thing, the regulations include a "screening" process that a child must pass before he/she is guaranteed a full evaluation. There are no assurances that the "screeners" will be trained professionals who will really be able to tell which children should get more extensive evaluations. The new regulations don't refer to the federal requirement that there be a "public awareness" effort to advertise the early intervention program, and the regulations don't offer much help to the counties in carrying out their "child find" duties.

The proposed regulations do not guarantee that the children will receive help from adequately qualified personnel. "Service coordinators" make sure that families are fully informed about the program and their rights; help out at the education planning meetings; and serve as the key person for families. But the proposed regulations do not ensure that service coordinators have an adequate educational background or experience. The proposed regulations also create a position called an "early interventionist;" give these folks very broad duties; and again set inadequate levels of education and experience.

The proposed regulations do not guarantee that the children will receive services reasonably promptly. The proposed regulations state that services in the children's education plans must be provided, "as soon as possible." We continue to urge that a specific deadline, such as 14 days, be set.

The proposed regulations do not ensure a smooth transition when the children turn three. The proposal doesn't contain the federal requirement to include in children's

education plans training and discussions with parents; the steps needed for the child to adjust to the new setting; and clarification of whether records can be sent to the next early intervention agency. *And the regulations don't contain a guarantee that the child's services will continue while any disputes are worked out.*

Many folks believe that, with these regulations, the state is failing to live up to historic position of leadership in the education of children with disabilities. Here are some ideas that could be incorporated into the regulations that could move the state in this direction:

- The state could give the local interagency coordinating councils (LICCs) money to hire independent parent "ombudpersons" whose job would be to inform families about the program and their rights. Service coordinators, who have similar roles, are not "independent" since they work for the counties.

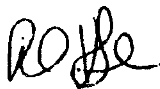
- The state could let families use any therapist or other service provider that meets state standards, and that is willing to accept the rate set by the county -- rather than limiting families only to the service provider offered by the County.

- The state could give the LICCs money to support additional parent training and support activities.

We strongly believe that there are many additional ideas for the improvement of these regulations. We urge you to listen to these ideas from the agency that will serve our families and the families who will benefit from these services.

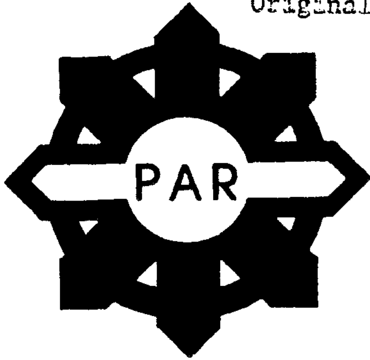
Thank you for taking into consideration these concerns. If you would like further discussion on any of these ideas I can be reached at 610-265-4700.

Sincerely,



Paul Stengle
Executive Director

Original 2122



Pennsylvania Association of Resources
for People with Mental Retardation

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INDEPENDENT REGULATORY REVIEW COMMISSION

October 27, 2000

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

Re: Comments by The Pennsylvania Association of Resources for People With Mental Retardation (PAR) on the Proposed Rulemaking by the Department of Public Welfare – 55 PA. Code Chapters 4225 and 4226, Early Intervention Services – Published in *The Pennsylvania Bulletin* on June 3, 2000

Dear Mr. Knowlton:

The Pennsylvania Association of Resources for People with Mental Retardation (PAR) thanks the Department of Public Welfare for requesting comments to the above-referenced proposed rulemaking. PAR is an association which represents organizations providing the full range of mental retardation supports and services including early intervention statewide.

PAR endorses the spirit of regulatory reform as set forth in Governor Ridge's Regulatory Reform Initiative (Executive Order 1996-1). We will continue to base our comments on these and future regulations and measurement instruments on the principles outlined in this Order.

We examined this proposed rulemaking for consistency among its authorizing laws and the various regulations which interrelate with it or which are similar in scope. We found inconsistencies related to the Older Adults Protective Services Act (OAPSA)/Act 13.

We looked for instances in this proposed rulemaking where the regulatory burden will be eased on the provider community without sacrificing essential public health and safety issues since this is a key goal of the Governor's initiative. We found that the regulatory burden has been increased with this proposed rulemaking. We also, however, found ways the Department should increase requirements related to getting qualified staff to provide effective intervention.

Following are our comments and recommendations which can be reviewed along with our earlier testimony presented at the July 24, 2000 hearing of the Department of Public Welfare. We also included three letters dated December 1999 to March 2000, sent to the Department of Aging regarding OAPSA/Act 13.

COMMENTS:

General Requirements
§§4226.35-37 (relating to training; preservice training; and annual training)
"The Department will determine how many hours of training early intervention staff will receive on annual basis. At least 24 hours of training on annual basis seems to be the most appropriate."

In order to plan and budget for training, providers need to have a firm minimum number of hours of training that staff are required to take each year. A variable standard can lead to arbitrariness. Regulations are intended to be minimum requirements which providers can use and build upon as individual needs require.

Recommendation: The number of training hours should be a fixed number, not a variable standard which can be changed at will by the Department.

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Procedural Safeguards
Summary of Fiscal Note
"In drafting proposed Chapter 4226, consideration was given to the effect the regulations will have on the cost of providing early intervention services. These regulations incorporate requirements already imposed under the act, Part C of the IDEA, and accompanying regulations, and the infants, toddlers and families Medicaid waiver approved by the Health Care Financing Administration, all of which is currently in place. Therefore, no additional cost or savings is anticipated."

The requirements of the above referenced funding sources (IDEA, Part C and the Infants, Toddlers and Families Medicaid waiver approved by the Health Care Financing Administration) were not a factor when rates were originally formulated. An adjustment for the increase in cost to the provider for increased documentation and monitoring activities was never made.

The costs to the provider for staff training requirements have also not been recognized. Currently, in-service hours are not billable. Since the rates were not calculated with the two funding sources in mind, and since the service hours are not billable, the costs of these proposed regulations are significant for this single provision alone.

Further, if the requirement of six college credit hours annually for every early interventionist becomes a mandate, it will cost the employer/provider the price of the six credits and hourly rates while in class, plus travel expense, plus staff coverage for the individual. If this requirement becomes a condition of employment, the financial burden will fall on the employer/provider.

There should be clear recognition that there will be additional costs for employers/providers. The rate per unit of service needs to cover all unit expenses, which include direct and indirect administrative costs. Training is currently paid out of administrative cost. Therefore, the rate per unit of service needs to be increased.

We request clarification regarding how "training" was treated in the process which established the original rate per unit of services, how it will be included in the rate, and whether the training costs along with our other comments will help the Department acknowledge that there is a significant financial impact relative to these regulations.

Recommendation: Since the initial study that formed the basis for establishing the rates did not include training, and its related costs, authorize a rate adjustment to fund this mandate which adds substantial administrative costs to early intervention.

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Annex A Title 55. Public Welfare
Part VI. Mental Health and Mental Retardation Manual
Subpart C. Administration and Fiscal Management
§4226.22 (1)
"The child is experiencing a developmental delay, as measured by appropriate diagnostic instruments and procedures indicating that the child is delayed by 25% of the child's chronological age in one or more developmental areas."

Recommendation: PAR strongly supports the 25% eligibility criteria for early intervention services.

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§4226.22 (3)(b) Eligibility for early intervention services
" Informed clinical opinion may be used when there are no standardized measures or the standardized procedures are not appropriate for a child's chronological age or developmental area. Informed clinical opinion makes use of qualitative and quantitative information to assist in forming a determination regarding difficult-to-measure aspects of current developmental status and the potential need for early intervention."

Recommendation: PAR strongly supports the decision to retain the use of informed clinical opinion.

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§4226.23 (1)(ii) Waiver eligibility
"Performance that is slightly higher than two standard deviations below the mean of a standardized general intelligence test during a period when the person manifests serious impairments or adaptive behavior."

What is the purpose of the use of the word "slightly?" It is redundant and can be deleted.

Recommendation: Delete the term "slightly."

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§4226.24 (f)(2) Comprehensive child find system
(f)(2) "Within 45 days after it receives a referral, the legal entity shall do one of the following:
- *(i) Complete the evaluation activities in §4226.062*
- *(ii) Hold an IFSP meeting in accordance with §4226.72*
- *(iii)Develop a plan for further assessment and tracking."*

This section is not clear that, for a child determined to be eligible for services, the IFSP must be developed within 45 days of referral. It allows the development of the IFSP to occur past the 45-day timeframe required in IDEA. Under the language of this section, the timeline is satisfied if the child is only evaluated within the 45-day period. It also suggests that the IFSP can be avoided altogether as long as a plan for further assessment and tracking is developed.

Recommendation: Revise the language in order to clarify that the IFSP must occur within 45 days of referral and that a plan for further assessment and tracking does not replace the IFSP.

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§4226.26 Purpose of initial screening
"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."

§4226.27 Content of screening
"The initial screening shall include a review of at least one of the following completed within 6 months prior to the child's referral to the legal entity and family reports of identified concerns:
(1) A review of written professional reports that are based upon systematic observation or informed clinical opinion, including reports from referring physicians, neonatal intensive
(2) care units, health care workers, a community-wide screening program or well baby clinic, early periodic screening diagnosis and treatment examinations, social service departments, child protection programs, early intervention programs or any other source.
(3) Information about a child's developmental status obtained through a formalized screening process developed and conducted by the legal entity or an agency under contract with the legal entity."

While the purpose and content of initial screening are listed, initial screening is not defined clearly, nor is there a universal process described for use throughout the state. The screening process should not be used to determine eligibility, which is what it does indirectly if a child is refused an MDE based on the results of the screening. However, since the screening can determine that a child is not eligible for an MDE, there is a need to further insure that children have equal opportunity to services.

Recommendation: Clearly define screening by providing universal procedures for initial screening and the screening process so that every child has the same opportunity to be considered for the MDE, which determines eligibility.

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§4226.28 Recommendation to parents
"As a result of the initial screening, the legal entity shall make one of the following recommendations to the child's parent."

In this section, parents should be given the option of requesting the MDE if one is not recommended for the child. Also, parents should be informed of the screening results.

Recommendation: Add the following language: "(5) "The parent must be informed of the screening results in writing, as well as their right to an MDE in the event that they disagree with the screening results."

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§4226.32 Contacting families

(a) *"The legal entity shall contact families by telephone, in writing, or through a face-to-face meeting at least every 4 months after a child is referred to the tracking system, or until a parent requests no further contact by the legal entity.*

(b) *" The contact shall offer reevaluation to determine the need and eligibility for early intervention services."*

Recommendation: Add the following language: *"(c) The legal entity shall document in writing all contact with the family."*

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§4226.35 Training

"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 they are providing."

It is unclear to whom this section applies. We assume the section applies to therapists, but are not certain since "paraprofessionals" are included in the provision.

Recommendation: Clearly identify to whom this section applies.

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§4226.36 (9) Preservice training

"Training in fire safety, emergency evacuation, first aid techniques and child cardiopulmonary resuscitation (for all staff), as well as for the early interventionists and other personnel who work directly with the child. The date of the completion of training shall be documented by the signature of a representative of the training entity. Documentation shall be retained in the agency's personnel file. Recertification will be required on or before expiration of specific certification."

A secretary or billing clerk who is part of the program will never be in direct contact with the child or family in a home/community based program. Staff in a community setting may not be regulated, and if they are, may not have these regulations for training. How would this provision be applied? Also, why is "for all staff" in parentheses?

This is a community-based program, not an institutional program. "For all staff" represents an institutional rather than community model. We agree that early interventionists and other personnel who work directly with the child should receive this training.

Recommendation: Delete the phrase "for all staff as well as."

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§4226.37 (a); (b) Annual training

(a) "The service coordinator, early interventionist and other personnel who work directly with the child, including the personnel hired through contract, shall have at least 24 hours of training annually, relevant to early intervention services, child development, community resources or services for children with disabilities. Specific areas shall include cultural competence, mediation, procedural safeguards and universal health procedures.

(b)The training specified in §4226.36(9) (relating to preservice training) shall be renewed annually, unless there is a formal certification for first aid or cardiopulmonary resuscitation by a recognized health source valid for more than 1 year. If there is a formal certification by a recognized health source valid for more than 1 year, the time period specified on the certification applies."

Requiring employers to provide 24 hours of training in addition to the training requirements specified in §4226.36(9) represents a significant financial burden on employers, which the rates have not recognized. Agencies already provide extensive training to their employers. Refer to our comments on §4226.56.

Also, why should home based staff be required to receive CPR and first aid training when another primary caregiver is present during their work activities? Who is responsible (and liable) for providing CPR and first aid in a home based setting – the early intervention staff person, or the primary caregiver? Who is responsible in a community setting (e.g. a day care center) – the early intervention staff person, or the day care center staff?

Recommendation: Combine (a) and (b) so that the total amount of annual training time amounts to 24 hours. The section would read: *"Specific areas shall include cultural competence, mediation, procedural safeguards, universal health procedures and the training specified in §4226.36(9)."*

Recommendation: Delete the phrase "at least" for the same reasons stated in the *General Requirements* section relating to §§4226.35-37.

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§4226.38 Criminal history records check

These regulations include requirements for criminal history checks.

The proposed regulations reference Act 33 in the preamble when describing Section 4226.38 (criminal records history checks) to ensure that legal entities as well as service providers are aware of their existing obligations under Act 33.

We know that the provisions related to applicant and employee criminal history checks apply to mental retardation facilities for the Older Adults Protective Services Act (OAPSA) purposes. In it, mental retardation facilities are considered "facilities" under the OAPSA's expansive definition of "home health care agency" because they "provide care to care-dependent individuals in the individual's place of residence."

We also know that OAPSA defines "care-dependent individual" as an adult – so it would seem that, assuming services were provided to 0-3 year olds in their places of residence, those services would not fall under OAPSA and therefore, those MR facilities that provided services only to children would not fall under OAPSA.

However, we also know that OAPSA is not internally consistent. At 35 Purdon's Section 10225.502, OAPSA also mandates a facility to require all applicants for employment and all administrators and operators who may have direct contact with a recipient to submit a criminal history check like those referenced in these proposed early intervention services regulations. Employees of less than one year had to meet the same requirement.

The point is that a "recipient' is defined by OAPSA as "an individual who receives care, services or treatment in or from a facility." An individual is a person of any age, as the most recent draft of the OAPSA regulations now specifically clarifies.

The bottom line is that we understand that any entity which falls under the broad definition of "facility" contained in the OAPSA and that provides services to children not only may have to meet the requirements of Act 33, for Child Protective Services, but also must be sure to meet the requirement of Act 13 for Older Adult Protective Services, along with the respective regulations for each of the Acts, as well as the current proposed early intervention rulemaking under consideration.

Overlapping rules and reporting procedures that don't make sense (such as reporting child abuse to the Department of Aging whose authority relates to elderly people, not to infants and toddlers) lead to confusion and delay. Confusion, delay, and multiple layers of reporting lessen, rather than strengthen, safeguards.

Recommendation: Reporting should be simple, easy to understand, and effective so that children and adults are well protected. The Department of Public Welfare should work with the Department of Aging to develop clarifying amendments to OAPSA or a Memorandum(s) of Understanding (MOU's) to get rid of the multiple overlapping and very confusing rules surrounding abuse clearances and reporting procedures.

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§4226.54 (a); (c) Requirements and qualifications

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

(c) *A service coordinator shall have one of the following groups of qualifications:*

   (1) *A bachelor's degree or above from an accredited college or university and 1 years' work or volunteer experience working directly with children, families or people with disabilities, or in counseling, management or supervision.*

   (2) *An associates degree, or 60 credit hours, from an accredited college or university and 3 years' work or volunteer experience working directly with children, families or people with disabilities, or in counseling, management or supervision.*

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

Is there a typographical error in part (a) which reads: "one service coordinator intervention service?"

Comment: Correct the typographical error or clarify what "one service coordinator intervention service" means.

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There are no provisions for caseload size in this section. Case coordination has traditionally suffered when caseloads are too large for the service coordinator to manage.

Recommendation: A maximum caseload of 35 children per service coordinator should be added. Reword §4226.54a): *"a minimum of one service coordinator per 35 children shall be employed directly or through subcontract by the legal entity."*

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The qualifications as stated are inadequate for the job responsibilities. A service coordinator should have at least a B.A. with a year of experience directly related to children and families in a paid capacity. State Civil Service Commission does not recognize volunteer work. Volunteer work is insufficient experience for the nature of this work.

PAR's early intervention providers are having more and more difficulty finding staff who are able to carry out their job responsibilities. Qualifications that do not match the skill level required upon entering a job can easily result in failure in the job and early turnover which is disruptive to services. Early intervention is the first and best chance we have of making a

difference in the life of a little child, and we need to make the most of it with persons who have the skills to do it.

A logical extension of increased staff qualifications and requirements relates to compensation. The compensation studies relative to people who provide mental retardation services and supports points to the inescapable fact that the state - the payer and the regulator - has been willing to allow the continuation of abominably low rates of pay for services that require considerable skill. The result has been vacancy rates, high turnover, and the use of temporary staff in positions that should be filled with skilled people who are well educated and have the experience necessary to enable them to provide effective intervention that will make a difference in the lives of these infants and toddlers.

Service coordinators should be able to demonstrate the skills identified in Part C, Section 303.344(g) of IDEA.

Recommendation: Revise the language to read as follows: ***"A service coordinator shall have the following: (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 in a paid capacity. (2) The ability to demonstrate the skills identified in Part C, Section 303.344(g) of IDEA."***

Recommendation: Add a section (d) which reads: ***"(d) The salaries for service coordinators shall at least be competitive with other professionals with comparable qualifications and experience."***

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§4226.55 Early interventionist
"An early interventionist is responsible for the following:
(1) Participating in the development of the child's IFSP
(2) Implementing the child's IFSP directly or by supervising the implementation of services provided by other early intervention personnel
(3)Working with the family to assure that the needs of the child and family are met
(4)Completing written communication reviews and 6-month IFSP reviews in accordance with this chapter."

The title of early interventionist needs to be clarified. Is this the person who provides special instruction? Is it all persons who provide direct service of any type to a child and/or the family (excluding the service coordinator?) If by early interventionist it is meant the person(s) who carries out special instruction, then part "(2) implementing the child's IFSP directly or by supervising the implementation of services provided by other early intervention personnel" presents a question: who are "other early intervention personnel?" The person who provides special instruction is usually not in a supervisory capacity in most provider agency structures and

would not be qualified to supervise. In part (3), the statement "working with the family to assure that the needs of the child and family are met," is a service coordination function.

Recommendation: Clarify the role of the early interventionist. Delete "*(2) implementing the child's IFSP directly or by supervising the implementation of services provided by other early intervention personnel*" and move "*(3) working with the family to assure that the needs of the child and family are met*" to §4226.54 relating to the requirements and responsibilities of the service coordinator. We suggest the following language: *"An early interventionist is responsible for the following: (1) Providing special instruction to the child; (2) Participating in the development of the child's IFSP; (3) Completing written communication reviews and 6-month IFSP reviews in accordance with this chapter."*

Recommendation: Add a new section to follow §4226.55 titled "Other early intervention personnel." This new section should include therapists, management personnel and supervisors. We suggest the following language: *Other early intervention personnel include such personnel as therapists and supervisors. (1) A supervisor is responsible for overseeing early interventionists and other early intervention personnel; (2) A therapist is responsible for implementing the part of the IFSP that relates to their particular area."*

Recommendation: Following the section titled "other early intervention personnel", add a new section titled "Requirements and qualifications," relating to other early intervention personnel. This new section should include a provision for compensation to reflect the qualifications needed to perform the job. We suggest the following language: *"Other early intervention personnel shall have the following qualifications: (a) A supervisor shall have 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 and one year of paid experience working directly with children and families (b) A therapist shall be certified, licensed or registered, as approved by the Department of State, for the discipline that they are providing."*

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§4226.56 Requirements and qualifications
(a) "An early interventionist shall have one of the following groups of qualifications:
(1)A bachelor's degree or above from an accredited college or university and 1 year work or volunteer experience working directly with children, families or people with disabilities or in counseling.
(2)An associates degree or 60 credit hours, from an accredited college or university and 3 years work or volunteer experience working directly with children, families or people with disabilities or in counseling.

(b)An early interventionist shall obtain a minimum of 6 credit hours annually in the field of infant and toddler developmental services, early childhood services, or any specific areas that relate to infant and child disabilities."

These qualifications are inadequate to carry out the responsibilities of the position, and volunteer work is not a good indicator of the acquisition of needed skills since there is not usually a formal evaluation of a volunteer's work to use as a reference point for hiring.

With regard to the 6 credit hour requirement, the following questions arise: what is its purpose; to whom does it apply; is this requirement for professionals who already have degrees in those areas and does it apply for every year of employment, even after 5, 10, or 15 years of working under this title? Further, mandating an early interventionist to obtain a minimum of 6 credit hours annually would impose a huge financial burden on the employer.

Unlike the Department of Education requirement to obtain a permanent teaching certificate within six years of active classroom teaching, this regulation is stated as a condition of employment, which becomes the financial burden of the employer, not the employee. Thus, the employer would be required to pay for the six credits annually for all early interventionists employed. In addition, many of these credits would be at the graduate level, which is more costly than undergraduate credits. The employee would be entitled to hourly pay for time in class and travel expenses. The cost of this is prohibitive.

Appropriate staff training is important in maintaining quality early intervention services. However, PAR suggests that the regulations have attempted to compensate for lack of adequate education and qualifications for the job by inserting training requirements that are written arbitrarily and do not relate to experienced staff.

We suggest that early intervention services regulations require adequate qualifications on the front end – before staff are hired. With staff who are adequately qualified, the ongoing training necessary to improve and maintain competent workers should be able to be accomplished well within a 24-hour annual training requirement if the training is focused on the right areas.

Recommendation: Delete all references to "volunteer experience."

Recommendation: Delete the allowance of experience for early interventionists; the field needs to compete with the education system for these people and needs strong educational requirements. Revise the qualifications provisions to read as follows: *"An early interventionist shall have the following qualifications: (1) A bachelor's degree or above in a field related to special education, early childhood education, psychology or other fields which relate directly to child development or child disability. (2) The compensation for early interventionists shall at least be competitive with other professionals with comparable qualifications and experience."*

Recommendation: Delete section (b) relating to the 6 credit hour requirement. If this requirement is not deleted, it needs further clarification and explanation regarding its purpose and applicability to professionals who already have degrees in the areas described. Also, the fiscal impact of this requirement must be clearly recognized.

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§4226.57 Effective date of personnel qualifications
"Sections 4226.54(c) and 4226.56(a) (relating to requirements and qualifications) apply to service coordinators and early interventionist hired or promoted after ______ (Editor's Note: The blank refers to the effective date or adoption of this proposal)."

If the Department agrees to match the requirements and qualifications of staff to the skills needed, there will need to be a transition so that services will not be disrupted and people will not suffer loss of jobs.

Recommendation: Grandfather existing personnel as of the effective date of the regulations.

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§4226.62 (a)(1) and (2); (C)(2) MDE
(a) "Requirements for MDE: The legal entity shall ensure that the following conditions are met:
(1) The performance of a timely, comprehensive, MDE of each child under 3 years of age, referred for evaluation, including assessment activities related to the child and the child's family.
(2)The initial MDE is conducted by personnel independent of service provision.
(C)(2) The annual MDE will composed of the family, service coordinator, anyone whom the parent would like to invite and at least one other professional who meets State approved or recognized certification, licensing, registration or other comparable requirements, if applicable, in which the person is providing services."

Professionals who do the MDE for an individual child should not be prohibited from providing services to other children, since that presents no conflict of interest. Also, there may be appropriate exceptions to the independent MDE provision. An exception should be made for parents who request that the evaluator also provide service to their child. Another exception should be made in certain geographic areas where there is not more than one specialist in an area needing evaluation.

With regard to section (C)(2), a multidisciplinary team is not described, due to the fact that only one discipline is required to be represented. Service coordination is not a discipline; it is a service and can only evaluate the family section of the evaluation. Refer to the federal definition of multidisciplinary (Part C, Section 303.17): "...means involvement of two or more disciplines or professionals in the provision of integrated and coordinated services..."

Recommendation: Revise section (a)(2) to read as follows: *"The initial MDE is conducted by personnel independent of future service provision to the individual child."* Add a new provision to allow for two exceptions: parental choice and geographic location.

Recommendation: Revise section (C)(2) to reflect federal requirements regarding the definition of a multidisciplinary team. Expand the MDE team to include two disciplines.

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§4226.72 (b) Procedures for IFSP development, review and evaluation
(a) "The IFSP shall be evaluated once a year and the family shall be provided a review of the plan at 6-month intervals, or more often based on infant or toddler and family needs."

Family members or other team members should be allowed to request a review more often if they so choose.

Recommendation: After *"family needs,"* add the phrase *"and as requested by the family or other team member."*

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§4226.73 (4); (6) Participants in IFSP meetings and periodic reviews
(4) "The service coordinator who has been working with the family since the initial referral of the child for evaluation, or who has been designated by the legal entity to be responsible for the implementation of the IFSP."
(6) "Persons who will be providing services to the child or family as appropriate."

Recommendation: Add the phrase *"and who has the authority to commit the resources of the legal entity to carry out the IFSP"* to the end of section (4).

Recommendation: Delete the phrase *"as appropriate"* from the end of section (6). Persons providing service to the child should participate in the IFSP meeting.

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§4226.74 (5); (7)(i); (iii)(A),(B); (iv); (8); (B); (C)(ii) Content of IFSP
(5) "Natural environments: A statement of the natural environments in which early intervention services shall appropriately be provided, including a justification of the extent, if any, to which the services will not be provided in a natural environment."
(7)(i) "The projected dates for initiation of services..."
(iii)(A) "Frequency" and "intensity"...
(B) "Method is how a service is provided."
(iv) "Location is the actual place where a service will be provided."
(8) "Service coordinator: The identification of the service coordinator from the profession most immediately relevant to the infant's or toddler's or family's needs (or who is otherwise qualified to carry out all applicable responsibilities under this chapter), who will be responsible for the implementation of the IFSP and coordination with other agencies and persons."
(B) "Review the child's program options for the period from the child's 23rd birthday through the remainder of the school year."
(C)(ii) "The local educational agency, which is responsible for providing preschool programs..."

The IFSP team should make decisions related to the appropriate natural environment.

The projected dates for implementation of the IFSP should occur in a reasonable, but specified timeframe. The phrase "as soon as possible" is too subjective.

Regarding sections (iii)(A),(B); and (iv), in the past, it has been known that team decisions around these three areas have not been honored by the legal entity. The IFSP team becomes driven by cost factors or other agendas. The team's decisions must be respected 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 IFSP team, which includes the parent(s), regarding the services to be provided to an infant or toddler..."

While service coordination should take place with a truly multidisciplinary team, it is not the reality of the system in Pennsylvania and has difficult implications for independence and cost. The language of this section is a transdisciplinary approach and there is reference to this in IDEA, but it could give parents the mistaken idea that the physical therapist on their child's team should be the service coordinator. If a physical therapist were a service coordinator, he or she could not bill for service coordination. Thus, this section is confusing and could be misleading.

There is a typographical error in section (B); "23rd" should read "3rd."

Although the issue of pendency is addressed in §4226.104, it should be addressed in section (C)(ii) in the event a family does not accept the provisions of the IEP.

Recommendation: Add the following language to section (5) relating to natural environments: *"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 during the yearly IFSP meeting."*

Recommendation: Delete the phrase "as soon as possible." We suggest the following language: *"The IFSP must be implemented within 21 days of the IFSP meeting unless otherwise requested by the parents."*

Recommendation: Add a statement that indicates respect and commitment to the teams' decisions by the legal entity.

Recommendation: Delete the language in section (8) in order to avoid confusing families who may believe that the physical therapist on their child's team should be the service coordinator, especially since the physical therapist cannot bill for service coordination.

Recommendation: Correct the typographical error in section (B) by changing "23rd" to "3rd."

Recommendation: Address the issue of pendency in section (C)(ii) since it has to do with transition.

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§4226.101 (1) Parent rights in administrative proceedings
(1) "To be accompanied and advised by counsel and by individuals with special knowledge or training with respect to early intervention services for children eligible under this chapter."

Many families cannot afford legal counsel or feel that the individual(s) with special training with respect to early intervention services can adequately represent them.

Recommendation: Add *"or"* after *"by counsel and."*

~ ~ ~ ~

§4226.102 (b) Impartial hearing officer
(c) "A person who otherwise qualifies under this section tion is not an employe... "

There is a typographical error: "section tion" should read "section."

Recommendation: Correct typographical error by deleting "tion."

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A list of qualifications and a description of duties of the impartial hearing officer is missing from this section. Section 303.421 of IDEA, Part C, addresses qualifications and duties related to impartial hearing officers. Since IDEA's language on impartiality included in this section, it makes sense to include language on qualifications and duties as well.

Recommendation: Include the language from Section 303.421 regarding qualifications and a description of duties of the impartial hearing officer.

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§4226.103 Convenience of proceedings; timelines
"A proceeding for implementing the administrative resolution process shall be carried out at a time and place that is reasonably convenient to the parents."

This section should include the timeline from the federal requirements.

Recommendation: Revise §4226.103 to read: *"A proceeding for implementing the administrative resolution process shall be carried out within 30 days and at a time and place that is reasonably convenient to the parents."*

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§4226.105 (f) Surrogate parents
(f) "A foster parent qualifies under this part if the following apply:"

Under this section, a foster parent can serve as a surrogate only if the natural parents' "authority to make early intervention or educational decisions on the child's behalf has been relinquished under State law," and the foster parent "has an ongoing, long-term parental relationship with the child." Federal requirements do not mandate these limitations on foster parents serving as surrogate parents. The requirements referred to above significantly limit the use of foster parents as surrogate parents. Foster parents are responsible for the daily care of these children, and are often the best and only adults able to perform the function of a surrogate parent. Counties rarely maintain a pool of surrogate parents, and many delays occur because no one is legally competent to give consent or to authorize services.

Recommendation: Restore the language from the 1997 draft, section 4225.196(d), which stated: *"A foster parent is eligible to serve as a surrogate if all requirements for surrogate...are met."*

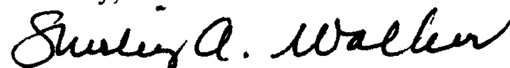
Recommendation: Restore section 4225.194(b) of the 1997 draft, which authorized the County program to appoint a surrogate parent at the request of the parent under certain circumstances.

Recommendation: Restore section 4225.201 of the 1997 draft, which protects surrogate parents from liability if they perform their duties in good faith.

~ ~ ~

Thank you for the opportunity to comment on these proposed regulations. We are available to discuss any of our recommendations.

Sincerely,



Shirley A. Walker
Executive Director

Enclosure(s):

PAR's Early Intervention Testimony Presented to the DPW on 7.24.00
PAR Comments on OAPSA to Department of Aging 3.31.00
PAR Comments on OAPSA to Department of Aging 1.18.00
PAR Comments on OAPSA to Department of Aging 12.21.99

cc: Dr. Richard Price, Chief
Bureau of Special Education

Peter H. Garland, Executive Director
State Board of Education

John R. McGinley, Chairman
Independent Regulatory Review Commission

Jeffrey Woods, Chief Counsel
Department of Aging

Robert Hussar, Chief
Division of Program and Regulatory Coordination
Department of Aging

Senator James J. Rhoades, Chair
Senate Education Committee

Representative Jess M. Stairs, Chair
House Education Committee

Senator Harold F. Mowery, Chair
Senate Public Health and Welfare Committee

Representative Dennis M. O'Brien, Chair
House Health and Human Services Committee

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REVIEW COMMISSION

PAR Document #00-1031: PAR's Testimony on Early Intervention Proposed Rulemaking (Ch. 4226)

TESTIMONY

Early Intervention
55 PA. Code Chapters 4225 and 4226 Proposed Rulemaking
Presented at the July 24, 2000 hearing of the
Department of Public Welfare

by

Shirley Walker, Executive Director
Pennsylvania Association of Resources
for People with Mental Retardation (PAR)

Good morning, My name is Shirley Walker. I am the Executive Director of the Pennsylvania Association of Resources for People with Mental Retardation. Our members support tens of thousands of children and adults with mental retardation throughout the Commonwealth and we employ tens of thousands of citizens to provide direct services and supports. We provide the full range of mental retardation services and supports in 2200 locations in PA in addition to non-residential and in-home supports including early intervention for children and their families.

Thank you for the opportunity to testify today.

PAR commends the Department of Public Welfare for involving the association during the development of this proposed rulemaking. Some important assurances have been retained which we strongly support; namely, the eligibility criteria of 25% of the child's chronological age in one or more developmental areas, and the decision to retain the use of informed clinical opinion.

My testimony this morning will not be a complete accounting of our comments or recommendations. Rather, because of the time constraints common to these hearings, it will highlight some key areas in which we have made recommendations. Our written comments, however, which are due in August, will expand on this testimony and will also provide comment on some additional areas that we will not go into this morning.

The areas I would like to focus on are the following:

1. Requirements and qualifications of staff and the impartial hearing officer
2. Training requirements
3. Compensation
4. Clarification of the roles of the early interventionist, the service coordinator and the supervisor
5. Case load
6. Child abuse clearances and reporting procedures.
7. The Initial Screening and Screening Process, the MDE, and the IFSP
8. The timeline for the administrative resolution process
9. Foster parents as surrogates.
10. Financial impact

Our first recommendation relates to the requirements and qualifications of staff. In reviewing the requirements and qualifications of staff that are proposed, we have determined that they are not adequate for what is expected of the positions.

PAR's early intervention providers are having more and more difficulty finding staff who are able to carry out the job responsibilities. Qualifications that do not match the skill level required upon entering a job can easily result in failure in the job and early turnover which is disruptive to services. For example, for the position of service coordinator, PAR recommends that the individual have a bachelor's degree in a field related to early childhood, special education, psychology, social work, family studies, or a related field, and one year of experience working directly with children and families in a paid capacity, in addition to being able to demonstrate the skills identified in IDEA.

Early intervention is the first and best chance that we have of making a difference in the life of a little child, and we need to make the most of it with persons who have the skills to do it.

Our written comments will also suggest changes in the requirements and qualifications of other personnel mentioned in the proposed rulemaking.

Our second recommendation relates to grandfathering.

If the Department agrees to match the requirements and qualifications of staff to the skills needed, there will need to be a transition so that services will not be disrupted and people will not suffer loss of jobs.

Therefore, PAR recommends that all staff who are employed on or before the effective date of the regulations be grandfathered and allowed to remain employed with their current qualifications.

Our third recommendation is a logical result of increased staff qualifications and requirements; that is, PAR recommends that language be added to state that "the salaries of early interventionists, service coordinators and supervisors shall be at least competitive with other professionals with comparable qualifications and experience."

The compensation studies relative to people who provide mental retardation services and supports point to the inescapable fact that the state -- the payor and regulator -- has been willing to allow the continuance of abominably low rates of pay for services that require considerable skill.

The result has been unacceptable vacancy rates, high turnover, and the use of temporary staff in positions that should be filled with skilled people who are well educated and have the experience necessary to enable them to provide effective intervention that will make a difference in the lives of these infants and toddlers.

We urge the department to support the concept of adequate compensation and to encourage it by adding language such as the language we just proposed.

PAR's fourth recommendation relates to training.

Appropriate staff training is important in maintaining quality early intervention services. PAR suggests that the regulations have attempted to compensate for lack of adequate education and qualifications for the job by inserting training requirements that are written arbitrarily and do not appear to relate to experienced staff.

PAR suggests that the early intervention services regulations require adequate qualifications on the front end – before staff are hired. With staff who are adequately qualified, the ongoing training necessary to improve and

maintain competent workers should be able to be accomplished well within a 24-hour annual training requirement if the training is focused on the right things.

Staff training can be used for the purpose of maintaining quality early intervention services -- and regulations should provide an appropriate baseline. However, the way the proposed rulemaking currently reads, the requirement, as written, sets up an unavoidable problem.

The provision states that the service coordinator, early interventionist and other personnel who work directly with the child, including the personnel hired through contract, shall have at least 24 hours of training annually.... PAR recommends that the words "at least" be removed from this proposed rulemaking. Otherwise, it will lead to a standard that is not reliable and one that will encourage arbitrariness.

Also, the 6 hour requirement doesn't seem to be at all related to one's qualifications or experience. There needs to be further discussion on the necessity of these hours and on the related cost.

Speaking again about qualifications, the qualifications and duties of the impartial hearing officer are missing. IDEA addresses such qualifications and duties, and PAR recommends that these be included in the regulations.

PAR's next recommendation is that the roles of the early interventionist, the service coordinator and the supervisor be clarified.

For example, the definition of early interventionist appears to include service coordination responsibilities and there are no definitions for therapists or supervisors. Also, there are no statements of requirements and qualifications for therapists or supervisors. We suggest that there is language in the waiver that could be considered for inclusion to address some of this need for clarification, and we are providing specific language for your consideration in our written comments.

Now, you can have good qualifications and training but if your caseload is unrealistic, the level of service will drop. Therefore, we recommend that the caseload for a service coordinator be no more than 35 children.

PAR's next recommendation relates to child abuse clearances and reporting procedures. This one is more complicated and will require the initiative of the Department with other Departments and the legislature to insure that it is addressed appropriately.

The proposed regulations reference Act 33 in the preamble when describing Section 4226.38 (criminal records history checks) to ensure that legal entities as well as service providers are aware of their existing obligations under Act 33.

We know that the provisions related to applicant and employee criminal history checks apply to mental retardation facilities for the Older Adults Protective Services Act purposes, hereinafter I will refer to the Older Adults Protective Services Act as OAPSA. In it, mental retardation facilities are considered "facilities" under the OAPSA's expansive definition of "home health care agency" because they "provide care to care-dependent individuals in the individual's place of residence."

We also know that OAPSA defines "care-dependent individual" as an adult – so it would seem that, assuming services were provided to 0-3 year olds in their places of residence, those services would not fall under OAPSA and therefore, those MR facilities that provided services only to children would not fall under OAPSA.

However, we also know that OAPSA is not internally consistent. At 35 Purdon's Section 10225.502, OAPSA also mandates a facility to require all applicants for employment and all administrators and operators who may have direct contact with a recipient to submit a criminal history check like those referenced in these proposed early intervention services regulations. Employees of less than one year had to meet the same requirement.

The point is that a "recipient' is defined by OAPSA as "an individual who receives care, services or treatment in or from a facility." An individual is a person of any age, as the most recent draft of the OAPSA regulations now specifically clarifies.

The bottom line is that we understand that any entity which falls under the broad definition of "facility" contained in the OAPSA and that provides services to children not only may have to meet the requirements of Act 33, for Child Protective Services, but also must be sure to meet the requirement

of Act 13 for Older Adult Protective Services, along with the respective regulations for each of the Acts, as well as the current proposed early intervention rulemaking under consideration.

Overlapping rules and reporting procedures that don't make sense (such as reporting child abuse to the Department of Aging whose authority relates to elderly people, not to infants and toddlers) lead to confusion and delay. Confusion, delay, and multiple layers of reporting lessen, rather than strengthen, safeguards.

My point here is that it is time that the administrative agencies and the legislature get together and get rid of the multiple overlapping and very confusing rules surrounding abuse clearances and reporting procedures.

Reporting should be simple, easy to understand, and effective so that children and adults are protected well.

Please get this one worked out so that it makes sense to everyone.

Regarding the processes of the initial screening, the MDE, the IFSP and the administrative resolution process, our recommendations include:

- that there be universal procedures for the initial screening and the screening process so that every child has the same opportunity to be considered for the MDE, which determines eligibility.
- That parents be informed of the screening results in writing, as well as to their right to an MDE in the event that they disagree with the screening results, and that the legal entity document in writing all contact with the family.
- That the expertise and understanding and experience of persons involved in service provision be utilized without conflict of interest in the initial MDE by rewording the section to read: The initial MDE is conducted by personnel independent of "future" service provision. In other words, add the word "future."
- That a new provision be added to allow for parental choice and consideration of geographic location.
- That the MDE team be expanded to reflect federal requirements regarding the definition of a multidisciplinary team. (Part C, Section 303.17: includes the -- "involvement of two or more disciplines or

professionals in the provision of integrated and coordinated services...")

- Regarding the IFSP, it needs to occur within 45 days of referral. It appears that a plan for further assessment and tracking would be considered an acceptable replacement for the IFSP. Is that what the department intends?
- Also, the regulations need to be clear that family members or other team members are allowed to request a review more often if they choose.
- Regarding participants in the IFSP meetings and periodic reviews, the service coordinator needs to have the authority to commit the resources of the legal entity to carry out the IFSP, or the process is flawed from the beginning.
- Also, since persons providing services to the child should participate in the IFSP meeting, the words, "as appropriate" in 4226.73 (6) should be deleted.
- The timeline for the administrative resolution process should specify that it shall be carried out within 30 days at a time and place that is reasonably convenient to the parents. The words added there are "within 30 days."

Regarding Foster parents as surrogates, PAR recommends that the language from several sections of the 1997 draft be restored, including:

- the opportunity for a foster parent to serve as a surrogate if all requirements for surrogate are met,
- that authorization be given to the County program to appoint a surrogate parent at the request of the parent under certain circumstances, and
- that the provision be added which protects surrogate parents from liability if they perform their duties in good faith.

Foster parents are often the best and only adults able to adequately perform the function of a surrogate parent, therefore it is unclear why the proposed rulemaking removed those provisions and is willing to accept the delays that will occur if these limitations are put into effect.

Our final recommendation relates to the financial impact of this proposed rulemaking.

It is problematic that the Department has not recognized any increased costs related to implementing these rules.

You have established that payment for services is made according to rate per unit of service. Our understanding of how the rate per unit of service was established is that the initial study that formed the basis for establishing the rate did not include the cost of training, for example. However, training, as proposed, is a substantial cost.

Since the rate per unit of service must cover all unit expenses, which include direct, indirect and administrative costs, then it should follow that the rate per unit of service needs to be increased.

Therefore, we request clarification regarding how training was treated in the process which established the rate per unit of service, how it will be included in the rate, and whether the training costs along with our other comments will help the Department acknowledge that there is a significant financial impact relative to these regulations.

We have highlighted some complicated issues – the abuse reporting requirements, for example -- that are not possible to deal with adequately within the time allowed in this hearing or even in written comments. For that reason, PAR respectfully requests an opportunity to meet with the Department.

Thank you for considering our request and for listening to our comments and recommendations.