Code Chapter 15, Protective Services for Older
Adults 12.21.99 5 pages

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Pennsylvania Association of Resources
for People with Mental Retardation

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December 21, 1999

Robert F. Hussar, Chief
Division of Program and Regulatory Coordination
Department of Aging
555 Walnut Street, 5th Floor
Harrisburg, PA 17101-1919

Re: Comments by The Pennsylvania Association of Resources for Persons With Mental Retardation ("PAR") on the Proposed Rulemaking By the Department of Aging – 6 Pa. Code Chapter 15, Protective Services for Older Adults -- Published in The Pennsylvania Bulletin on November 27, 1999

Dear Mr. Hussar:

I am writing to you on behalf of PAR, an association composed of service providers dedicated to serving the needs of people with mental retardation in Pennsylvania, to comment upon the amendments to Title 6, Chapter 15 of the Pennsylvania Code regarding Protective Services for Older Adults. PAR members provide a full range of services and supports to individuals with mental retardation of all ages at more than 2000 sites in Pennsylvania in addition to numerous non-residential and in-home supports.

SCOPE AND AUTHORITY
Section 15.1

Our first comment addresses the general issue regarding the applicability of these regulations to mental retardation service providers and their employees. As noted above, PAR members provide services to people of all ages who have mental retardation; however, the statements of scope and authority at Section 15.1 continue to emphasize the application of these provisions to older adults even though the training that has been provided by the Department of Aging regarding the applicability of the related statutes have included mental retardation providers of services to individuals age 21 and over. If the proposed rulemaking and this chapter are to apply to adults under age sixty (60), additional statements should be inserted to clarify their application. Otherwise, there will be confusion regarding the applicability of these regulations beyond older adults.

By making this recommendation, we are not suggesting that the proposed regulations need to be applied to facilities and employees that provide services to people with mental retardation in order to insure appropriate protections. Mental retardation service providers already are required to report not only allegations of abuse, but any unusual incidents encountered by facility residents to the Office of Mental Retardation ("OMR") of the Department of Public Welfare, among others, depending upon the location of the facility and the placement of the individual. For that reason, to apply the requirements to report suspected abuse at Section 15.141 through 15.145 to mental retardation service providers largely duplicates existing reporting requirements.

[redacted]

REPORTING SUSPECTED ABUSE
Sections 15.141-15.149

In addition, the requirement to make an immediate oral report to the local area agency on aging, or its designee that provides protective services for older adults in its service area, unfortunately serves to delay and confuse the system of reporting. Such incidents, and more, are already reported to OMR. While we intend to do all we can to protect the individuals who live in community mental retardation facilities, we do not believe their best interests are served through mandating immediate reporting to an agency that is neither trained or equipped to cope with the report. We believe the local AAAs will refer that report to OMR or the county MH/MR to whom PAR members also report, and in fact, in the absence of regulations, this has been occurring. We suggest that this suspected abuse reporting system will duplicate efforts and cause confusion that will slow the response by the appropriate agency. Instead of creating that confusion and delay, we suggest that the reporting system be revised by allowing designation of OMR by all of the local AAA's for reports by mental retardation services facility employees to help achieve the goals of uncovering and preventing any suspected abuse.

[redacted]

CRIMINAL HISTORY RECORD INFORMATION REPORTS
Sections 15.131-15.137

Our comments regarding criminal background checks do not question the wisdom of conducting criminal background checks of job applicants or employees who have direct contact with individuals who receive services at mental retardation facilities. Our initial concern focuses upon the requirements of Act 13 of 1997 and reiterated in the proposed regulations at Section 15.133 to implement a lifetime ban for an individual convicted of one of the listed offenses. While we agree that the life-time ban from employment for individuals convicted of offenses against people such as homicide, aggravated assault, kidnapping, rape and indecent assault may be appropriate, we do not believe that a lifetime ban should be imposed against individuals convicted of property offenses such as theft, forgery and securing execution of documents by deception or against individuals convicted of possession of illegal drugs.

We believe people convicted of any offense are capable of rehabilitation and that individuals convicted of these types of offenses should have the opportunity to seek and obtain employment at a facility as defined by the regulations. We believe the ten (10) year ban from employment for individuals convicted of offenses against property or under the Drug Device and Cosmetic Act contained in the law before the enactment of Act 13 of 1997, finds the right balance between protecting the interests of individuals served at facilities and promoting opportunity for rehabilitated individuals to obtain employment. There simply is no good reason to deny employment to a person who was convicted of two (2) misdemeanor counts of theft forty (40) years ago. The hiring discretion of the facility provider should not be so restricted to require that otherwise caring and competent individuals who made mistakes and paid for those mistakes decades ago may not help provide services today.

[redacted]

As regards the mechanics of the criminal background check procedure, mental retardation providers' main concern is the time required by the state police or FBI to process criminal record information requests. We are very pleased to see that Section 15.137(d) extends the period of provisional employment if processing by the state police or FBI is not achieved within the mandated time frames to address this concern. This will be of tremendous practical assistance to PAR members in conducting hiring and orientation.

We also ask for additional clarification regarding what constitutes "direct contact" with residents or clients and what constitutes "unsupervised access to their personal living quarters" in order to better determine to whom these regulations are to be applied. For example, do those qualifications apply only to administrators, operators and contract employees or do they also apply to a custodian worker who may need to repair plumbing in a bathroom used by facility residents on occasion or a person employed in an administrative capacity or office of a facility provider who may on occasion have contact with facility residents, although that is not the purpose of either position.

[redacted]

We also request clarification of the provision regarding the applicant's and facility personnel's opportunity to question the Department's determination at Section 15.134(g). Is requesting this review the same as appealing the accuracy of the criminal history record information? What is the purpose of this provision if it is not an appeal provision?

We favor the establishment of an appeal right that will permit applicants and facility personnel a prompt and inexpensive procedure to resolve their questions and correct errors. Otherwise, if an employee has been terminated to comply with these provisions and that position is filed, how can facility providers comply with the requirement to reinstate the employee to the employee's former position or an equivalent one as required at Section 15.136(b). We believe employees in those circumstances should have redress against the agencies that made the error, not the facility providers who had to implement it or violate the proposed rules.

[redacted]

I thank you for the opportunity to comment upon the proposed rulemaking and hope these comments will be helpful in those areas we have addressed, particularly with regard to clarifying the applications of these provisions to mental retardation services facilities and the individuals who receive their services.

Sincerely,
Shirley A. Walker
Shirley A. Walker
Executive Director

cc: John R. McGinley, Chairman
Independent Regulatory Review Commission

The Honorable Feather O. Houstoun, Secretary
Department of Public Welfare

Senator Timothy Murphy, Chair
Senate Committee on Aging and Youth

Senator Christine Tartaglione, Democratic Chair
Senate Committee on Aging and Youth

Representative Jere Schuler, Chair
House Committee on Aging and Youth

Representative Frank Pistella, Democratic Chair
House Committee on Aging and Youth

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Comments on 6 Pa. Code Chapter 15,
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January 18, 2000

Robert F. Hussar, Chief
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Department of Aging
Commonwealth of Pennsylvania
555 Walnut Street, 5th Floor
Harrisburg, PA 17101-1919

Re: **Addendum to the Comments by The Pennsylvania Association of Resources for Persons With Mental Retardation ("PAR") on the Proposed Rulemaking by the Department of Aging – 6 Pa. Code Chapter 15, Protective Services for Older Adults – Published in The Pennsylvania Bulletin on November 27, 1999**

Dear Mr. Hussar:

I am writing to you again on behalf of PAR, an association composed of service providers dedicated to serving the needs of people with mental retardation in Pennsylvania, to provide an addendum to the comments upon the amendments to Title 6, Chapter 16 of the Pennsylvania Code regarding protective services for older adults that PAR submitted on December 21, 1999. The focus of one of our comments at that time, and again in this writing, is the duplication and confusion that will result from the provisions of the proposed rulemaking pertaining to reporting suspected abuse at Sections 15.141-149.

In our comments of December 21, 1999, we suggested that any reports of suspected abuse or suspected serious abuse be made to the agency ("AAA") or the facility licensing agency, as appropriate. We made that suggestion to eliminate unnecessary and duplicative steps that both slow the reporting process and delay the response to those reports by creating the need for an additional report to the local area agency on aging for individuals who live in community mental retardation facilities.

We write now to further support our suggestion that in order to coordinate the reporting and investigating of suspected abuse by the Department of Aging, the Department of Health and the Department of Public Welfare to implement the suspected abuse reporting provisions of the Older Adults Protective Services Act ("Act"), the three Departments also need to coordinate their regulatory development processes. Section 708 of the Act mandates that the three Departments shall promulgate the regulations necessary to carry out those provisions. We believe that in placing regulatory authority in all three Departments, the Legislature recognized that to implement the provisions of the Act and avoid unnecessary and duplicative rulemaking that would establish rules without adding corresponding benefits, all three Departments need to work together and coordinate their rulemaking efforts. We fully support that sensible approach and reiterate our suggestion that the department which licenses the facility where abuse or serious abuse is suspected to have occurred is the appropriate department to receive and act upon that report. The protocol for coordination and sharing of information among the Departments could be worked out through a memorandum of understanding to ensure that all reports are received and acted upon promptly by the appropriate Department without the delay and duplication caused by referrals back and forth between those Departments that currently occurs.

We make these additional comments out of our strongly held belief that a coordinated regulatory approach will avoid duplication, delay and unnecessary costs in the provision of services at mental retardation facilities that will clearly benefit the individuals who receive those services. We thank you for the opportunity to comment again upon the proposed rulemaking and hope that these comments will be useful in developing a coordinated regulatory approach among the Department of Aging, the Department of Health and the Department of Public Welfare with regard to improving the system for reporting and investigating suspected abuse.

Sincerely,

Shirley A. Walker

Shirley A. Walker
Executive Director

cc: John R. McGinley, Chairman
Independent Regulatory Review Commission

The Honorable Feather O. Houstoun, Secretary
Department of Public Welfare

The Honorable Robert S. Zimmerman, Secretary
Department of Health

Charles Zogby, Director of Policy
Office of the Governor

Howard A. Burde, Deputy General Counsel
Office of General Counsel

Senator Timothy Murphy, Chair
Senate Committee on Aging and Youth

Senator Christine Tartaglione, Democratic Chair
Senate Committee on Aging and Youth

Representative Jere Schuler, Chair
House Committee on Aging and Youth

Representative Frank Pistella, Democratic Chair
House Committee on Aging and Youth

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PAR Comments on 6 Pa. Code Chapter 15,
Protective Services for Older Adults 3.31.00

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March 31, 2000

Robert F. Hussar
Chief
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555 Walnut Street, 5th Floor
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Re: **Comments by The Pennsylvania Association of Resources for Persons With Mental Retardation ("PAR") on the Proposed Rulemaking By the Department of Aging Published in The Pennsylvania Bulletin on November 27, 1999, 6 Pa. Code Chapter 15, Protective Services for Older Adults**

Dear Mr. Hussar:

I want to thank you, as well as James Bubb, Jeffrey Wood and Jacqueline Welby, for the helpful discussion that Bill Lenahan and I had at your offices on January 28th and the follow-up discussions Mr. Lenahan has had with Mr. Wood and Ms. Welby and my follow-up discussion with you. We very much appreciate the openness and cooperation that we have encountered with everyone at the Department of Aging in responding to the comments I submitted on behalf of PAR. I especially appreciate your offer to contact me regarding those areas that are the main focus of PAR's December 21, 1999 and January 18, 2000 comments pertaining to Sections 15.131 through 15.137 and Sections 15.141 through 15.149 of the proposed rulemaking.

We remain concerned regarding the scope of the criminal history reporting requirements that impose a lifetime ban upon individuals who have shown themselves to be competent and caring staff in providing services at facilities for individuals with mental retardation. As you know, PAR has questioned the fundamental soundness of the statutory policy that imposes the lifetime ban on employment. We were encouraged by your willingness to consider adding the appeal provision for those applicants who are subject to the FBI background check that we suggested in our comments. We are also pleased that you have proposed an extension upon the timeframes specified in the statute for a new employee when the necessary Pennsylvania State Police or FBI report has not been returned within the established timeframes due to no fault of the employee. While these sensible approaches will not resolve the underlying problem, in certain instances they will help avoid further unnecessary disruption in the provision of services.

Regarding the reporting suspected abuse provisions, we continue to request the revision of the proposed rulemaking or the adoption of an inter-departmental memorandum of understanding as discussed in our January 18, 2000 supplement to our comments. We believe such an agreement would avoid the delay and confusion which will be prompted by the duplicative requirements of reporting to the local Area Agency on Aging ("AAA"), as well as the agency that licenses the facility. PAR's position that mandating immediate reporting of suspected abuse to the local AAA does not serve the best interests of individuals who live in community mental retardation facilities is fully discussed in my December 21, 1999 comments. I am writing at this time to enclose the incident reporting requirements which will help illustrate the point made in the December 21, 1999 comments. As you will see from a review of the materials, the provider of services to individuals with mental retardation must meet exacting standards in reporting any suspected abuse to the licensing agency. The additional requirement of reporting to the local AAA does not add any additional protection to those that have been in existence and followed for some time. To the contrary, the additional requirements of the statute and proposed rulemaking will only prompt confusion and corresponding delay in reporting suspected abuse where none presently exists.

At Section 708 of the Older Adults Protective Services Act ("Act"), the General Assembly has directed the Department of Aging, the Department of Health and the Department of Public Welfare to promulgate regulations necessary to carry out the Act's reporting provisions. PAR asks the Department of Aging to coordinate this effort with the Department of Health and the Department of Public Welfare to find a common, practical solution to this circular reporting problem, rather than pursue a path that will make reporting suspected abuse more difficult. I realize that reaching such a solution may require discussion with the General Assembly about revisions to certain requirements of the Act. If that is necessary, PAR is prepared to work with you in that effort.

Lastly, I want to thank you for notifying us that the Department of Aging does not intend to pursue the provisions of Section 15.146 of the proposed rulemaking that would require facilities develop and submit generic supervision/suspension plans. We agree that a plan of supervision or suspension should be developed and implemented to fit the particular circumstances regarding a specific report of suspected abuse, rather than to meet a regulatory requirement which may or may not result in a plan that fits a specific situation. Likewise, in response to our inquiry regarding suspension or termination of employees, we are also pleased that the Department of Aging does not interpret the Act to require approval by the local AAA or the licensing Department before an employee may be suspended or terminated.

I thank you again for the opportunity to provide further comment upon these concerns that are so important to PAR member organizations and the individuals with mental retardation whom they serve.

Sincerely,

Shirley A. Walker

Shirley A. Walker
Executive Director

Enclosure

cc:
Jeffrey J. Wood, Esquire
Chief Counsel
Department of Aging

Jacqueline M. Welby, Esquire
Assistant Counsel
Department of Aging

James Bubb
Aging Specialist
Bureau of Home and Community-Based Services

John R. McGinley, Chairman
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The Honorable Feather O. Houstoun, Secretary
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The Honorable Robert S. Zimmerman, Secretary
Department of Health

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Senator Timothy Murphy, Chair
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INDEPENDENT REGULATORY
REVIEW COMMISSION

Kathy L. Nornhold
1265 Risser Mill Road
Mount Joy, PA 17552

October 27, 2000

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

I am writing to you as a provider of therapeutic services to children who receive such services through the early intervention system in the state of Pennsylvania. I am a speech language pathologist, and work in Lancaster County.

After reviewing the proposed regulations for Early Intervention Services (55 PA Code CHS, 4225 & 4226), as formulated by the Department of Public Welfare, I wish to express the following concerns.

First of all, I wish to refer to the term, "Early Interventionist", used in several locations including Sections 4226.5 and 4226.36. This is an undefined term, with no specifications as to the training or skill levels such a person would possess. To my knowledge, the job title of "early interventionist" is not presently recognized by any educational institutions or licensing agencies. Furthermore, I see no explanation as to how the role of a person with this job title would differ from that of other providers in the field of early intervention.

While I have this opportunity to voice my concerns regarding the future of early intervention services, I wish also to express my concerns regarding how the current system is threatening the care and welfare of the children I serve. For one, as a professional, it is my understanding that I am not permitted to provide education to families regarding the nature of certain behaviors, delays or difficulties with which the child presents. If I, along with other professionals working with a child believe that he or she shows the characteristics of a certain diagnosis, I may not discuss, and especially not mention the possible diagnosis, with the parents. This has been a guideline communicated to my fellow colleagues and me. It greatly concerns me, as I believe it can drastically hurt families, not to mention damage their trust and rapport with the therapists of their child. I have already been in a situation in which this restriction did not help, and only made things harder for the family. I was providing speech therapy services for a little boy in his home. The boy was around two-and-a-half years of age and was not talking. During my visits, I observed that he showed numerous behaviors that reflected characteristics of PDD or an Autistic Spectrum Disorder. But, of course, I could not mention any of these terms or explain what I was observing in the child's behavior. A psychologist finally saw the boy for a developmental assessment, as part of his age three transition. It was when the psychologist was discussing the results of his assessment that the parents heard the term "autism" for the first time. To complicate things further, they had the challenge of English being their second language, and depended on an interpreter to help explain the meaning of this new term. This was added to the stress they were already experiencing over caring for and wanting to help their child, as well as trying to understand the transition from the Birth to Three Early Intervention system to the services that would now be provided through the Intermediate Unit. Because of the restriction in which I was not permitted to help them learn about their child's needs, I felt I was providing a great disservice to this family.

There have been other examples in which the guidelines of the current early intervention system have hurt, and even failed the families of the children we serve. Whether this has been the result of actual state regulations, or the interpretation by the local funding agencies, I am not certain. All I know is that while it is said that the system is supposed to help families play a more active role in their child's development, it is often doing just the opposite. I'd like to give one other example of a young boy with whom I work and his highly supportive family. I was providing speech therapy services once a week in the boy's home. The intelligibility of his speech was significantly affected, and had the classic signs of a specific motor planning disorder called verbal apraxia. His mother was very self motivated to learn as much as she could about apraxia, and how best to help her son. Through all the information she gathered, she learned that children benefit best from consistent and frequent speech sessions, and regular practice. This can mean several speech sessions a week. At the time of her son's IFSP review, she requested increasing his therapy to two times per week. She, herself, provided the sound reasoning, including referencing studies and documentation, which supports the regular speech sessions. In response, the service coordinator opposed her request, challenging the mother that all she needs to do is work more with her son on her own, during their family routines. The reality was that she was extremely dedicated to working with her son on his speech, and always applied the ideas throughout their daily activities. But she knew that the type of speech disorder her son had also required the frequent training and strategies attained through the speech sessions. The service coordinator finally did approve the mother's request, but only after much resistance, which literally stressed the mother to tears. This is an example in which the child's and family's best interest was not honored, and I was embarrassed to see a parent have to fight so hard just to do what was best for her own son. It was, furthermore, an example of how members of the IFSP teams are restricted in making decisions about how the most appropriate services may be provided to best meet each child's individual needs.

In closing, I would like to express my sincere thanks to the Department for providing this opportunity to convey my thoughts regarding the regulations that directly affect the children and families with whom I work on a daily basis. My hope is that all considerations will be accounted for in the development of the guidelines, which determine how we can best serve the children.

Sincerely,

Kathy L. Nornhold, M.A, CCC/SLP

Kathy L. Nornhold, M.A., CCC/SLP
Speech Language Pathologist

Cc: Mr. Robert Nyce

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October 27, 2000

Mel Knowlton
Department of Public Welfare
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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~~: Mel,

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.

~ ~ ~ ~

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.

~ ~ ~ ~

§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.

~ ~ ~ ~

§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.

~ ~ ~ ~

§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."

~ ~ ~ ~

§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."*

~ ~ ~ ~

§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."*

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§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.

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

Sincerely,
Shirley
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

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.

Code Chapter 15, Protective Services for Older
Adults 12.21.99 5 pages

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PAR
Pennsylvania Association of Resources
for People with Mental Retardation

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POST OFFICE BOX 11820
HARRISBURG, PENNSYLVANIA 17108
TELEPHONE (717) 236-2374
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December 21, 1999

Robert F. Hussar, Chief
Division of Program and Regulatory Coordination
Department of Aging
555 Walnut Street, 5th Floor
Harrisburg, PA 17101-1919

Re: Comments by The Pennsylvania Association of Resources for Persons With Mental Retardation ("PAR") on the Proposed Rulemaking By the Department of Aging – 6 Pa. Code Chapter 15, Protective Services for Older Adults – Published in The Pennsylvania Bulletin on November 27, 1999

Dear Mr. Hussar:

I am writing to you on behalf of PAR, an association composed of service providers dedicated to serving the needs of people with mental retardation in Pennsylvania, to comment upon the amendments to Title 6, Chapter 15 of the Pennsylvania Code regarding Protective Services for Older Adults. PAR members provide a full range of services and supports to individuals with mental retardation of all ages at more than 2000 sites in Pennsylvania in addition to numerous non-residential and in-home supports.

SCOPE AND AUTHORITY

Section 15.1

Our first comment addresses the general issue regarding the applicability of these regulations to mental retardation service providers and their employees. As noted above, PAR members provide services to people of all ages who have mental retardation; however, the statements of scope and authority at Section 15.1 continue to emphasize the application of these provisions to older adults even though the training that has been provided by the Department of Aging regarding the applicability of the related statutes have included mental retardation providers of services to individuals age 21 and over. If the proposed rulemaking and this chapter are to apply to adults under age sixty (60), additional statements should be inserted to clarify their application. Otherwise, there will be confusion regarding the applicability of these regulations beyond older adults.

By making this recommendation, we are not suggesting that the proposed regulations need to be applied to facilities and employees that provide services to people with mental retardation in order to insure appropriate protections. Mental retardation service providers already are required to report not only allegations of abuse, but any unusual incidents encountered by facility residents to the Office of Mental Retardation ("OMR") of the Department of Public Welfare, among others, depending upon the location of the facility and the placement of the individual. For that reason, to apply the requirements to report suspected abuse at Section 15.141 through 15.145 to mental retardation service providers largely duplicates existing reporting requirements.

[redacted]

REPORTING SUSPECTED ABUSE
Sections 15.141-15.149

In addition, the requirement to make an immediate oral report to the local area agency on aging, or its designee that provides protective services for older adults in its service area, unfortunately serves to delay and confuse the system of reporting. Such incidents, and more, are already reported to OMR. While we intend to do all we can to protect the individuals who live in community mental retardation facilities, we do not believe their best interests are served through mandating immediate reporting to an agency that is neither trained or equipped to cope with the report. We believe the local AAAs will refer that report to OMR or the county MH/MR to whom PAR members also report, and in fact, in the absence of regulations, this has been occurring. We suggest that this suspected abuse reporting system will duplicate efforts and cause confusion that will slow the response by the appropriate agency. Instead of creating that confusion and delay, we suggest that the reporting system be revised by allowing designation of OMR by all of the local AAA's for reports by mental retardation services facility employees to help achieve the goals of uncovering and preventing any suspected abuse.

[redacted]

CRIMINAL HISTORY RECORD INFORMATION REPORTS
Sections 15.131-15.137

Our comments regarding criminal background checks do not question the wisdom of conducting criminal background checks of job applicants or employees who have direct contact with individuals who receive services at mental retardation facilities. Our initial concern focuses upon the requirements of Act 13 of 1997 and reiterated in the proposed regulations at Section 15.133 to implement a lifetime ban for an individual convicted of one of the listed offenses. While we agree that the life-time ban from employment for individuals convicted of offenses against people such as homicide, aggravated assault, kidnapping, rape and indecent assault may be appropriate, we do not believe that a lifetime ban should be imposed against individuals convicted of property offenses such as theft, forgery and securing execution of documents by deception or against individuals convicted of possession of illegal drugs.

We believe people convicted of any offense are capable of rehabilitation and that individuals convicted of these types of offenses should have the opportunity to seek and obtain employment at a facility as defined by the regulations. We believe the ten (10) year ban from employment for individuals convicted of offenses against property or under the Drug Device and Cosmetic Act contained in the law before the enactment of Act 13 of 1997, finds the right balance between protecting the interests of individuals served at facilities and promoting opportunity for rehabilitated individuals to obtain employment. There simply is no good reason to deny employment to a person who was convicted of two (2) misdemeanor counts of theft forty (40) years ago. The hiring discretion of the facility provider should not be so restricted to require that otherwise caring and competent individuals who made mistakes and paid for those mistakes decades ago may not help provide services today.

[illegible]

As regards the mechanics of the criminal background check procedure, mental retardation providers' main concern is the time required by the state police or FBI to process criminal record information requests. We are very pleased to see that Section 15.137(d) extends the period of provisional employment if processing by the state police or FBI is not achieved within the mandated time frames to address this concern. This will be of tremendous practical assistance to PAR members in conducting hiring and orientation.

We also ask for additional clarification regarding what constitutes "direct contact" with residents or clients and what constitutes "unsupervised access to their personal living quarters" in order to better determine to whom these regulations are to be applied. For example, do those qualifications apply only to administrators, operators and contract employees or do they also apply to a custodian worker who may need to repair plumbing in a bathroom used by facility residents on occasion or a person employed in an administrative capacity or office of a facility provider who may on occasion have contact with facility residents, although that is not the purpose of either position.

[redacted]

We also request clarification of the provision regarding the applicant's and facility personnel's opportunity to question the Department's determination at Section 15.134(g). Is requesting this review the same as appealing the accuracy of the criminal history record information? What is the purpose of this provision if it is not an appeal provision?

We favor the establishment of an appeal right that will permit applicants and facility personnel a prompt and inexpensive procedure to resolve their questions and correct errors. Otherwise, if an employee has been terminated to comply with these provisions and that position is filed, how can facility providers comply with the requirement to reinstate the employee to the employee's former position or an equivalent one as required at Section 15.136(b). We believe employees in those circumstances should have redress against the agencies that made the error, not the facility providers who had to implement it or violate the proposed rules.

[redacted]

I thank you for the opportunity to comment upon the proposed rulemaking and hope these comments will be helpful in those areas we have addressed, particularly with regard to clarifying the applications of these provisions to mental retardation services facilities and the individuals who receive their services.

Sincerely,

Shirley A. Walker

Shirley A. Walker
Executive Director

cc:

John R. McGinley, Chairman
Independent Regulatory Review Commission

The Honorable Feather O. Houstoun, Secretary
Department of Public Welfare

Senator Timothy Murphy, Chair
Senate Committee on Aging and Youth

Senator Christine Tartaglione, Democratic Chair
Senate Committee on Aging and Youth

Representative Jere Schuler, Chair
House Committee on Aging and Youth

Representative Frank Pistella, Democratic Chair
House Committee on Aging and Youth

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Orignal: 2122

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Kathy L. Nornhold
1265 Risser Mill Road
Mount Joy, PA 17552

October 27, 2000

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

I am writing to you as a provider of therapeutic services to children who receive such services through the early intervention system in the state of Pennsylvania. I am a speech language pathologist, and work in Lancaster County.

After reviewing the proposed regulations for Early Intervention Services (55 PA Code CHS, 4225 & 4226), as formulated by the Department of Public Welfare, I wish to express the following concerns.

First of all, I wish to refer to the term, "Early Interventionist", used in several locations including Sections 4226.5 and 4226.36. This is an undefined term, with no specifications as to the training or skill levels such a person would possess. To my knowledge, the job title of "early interventionist" is not presently recognized by any educational institutions or licensing agencies. Furthermore, I see no explanation as to how the role of a person with this job title would differ from that of other providers in the field of early intervention.

While I have this opportunity to voice my concerns regarding the future of early intervention services, I wish also to express my concerns regarding how the current system is threatening the care and welfare of the children I serve. For one, as a professional, it is my understanding that I am not permitted to provide education to families regarding the nature of certain behaviors, delays or difficulties with which the child presents. If I, along with other professionals working with a child believe that he or she shows the characteristics of a certain diagnosis, I may not discuss, and especially not mention the possible diagnosis, with the parents. This has been a guideline communicated to my fellow colleagues and me. It greatly concerns me, as I believe it can drastically hurt families, not to mention damage their trust and rapport with the therapists of their child. I have already been in a situation in which this restriction did not help, and only made things harder for the family. I was providing speech therapy services for a little boy in his home. The boy was around two-and-a-half years of age and was not talking. During my visits, I observed that he showed numerous behaviors that reflected characteristics of PDD or an Autistic Spectrum Disorder. But, of course, I could not mention any of these terms or explain what I was observing in the child's behavior. A psychologist finally saw the boy for a developmental assessment, as part of his age three transition. It was when the psychologist was discussing the results of his assessment that the parents heard the term "autism" for the first time. To complicate things further, they had the challenge of English being their second language, and depended on an interpreter to help explain the meaning of this new term. This was added to the stress they were already experiencing over caring for and wanting to help their child, as well as trying to understand the transition from the Birth to Three Early Intervention system to the services that would now be provided through the Intermediate Unit. Because of the restriction in which I was not permitted to help them learn about their child's needs, I felt I was providing a great disservice to this family.

There have been other examples in which the guidelines of the current early intervention system have hurt, and even failed the families of the children we serve. Whether this has been the result of actual state regulations, or the interpretation by the local funding agencies, I am not certain. All I know is that while it is said that the system is supposed to help families play a more active role in their child's development, it is often doing just the opposite. I'd like to give one other example of a young boy with whom I work and his highly supportive family. I was providing speech therapy services once a week in the boy's home. The intelligibility of his speech was significantly affected, and had the classic signs of a specific motor planning disorder called verbal apraxia. His mother was very self motivated to learn as much as she could about apraxia, and how best to help her son. Through all the information she gathered, she learned that children benefit best from consistent and frequent speech sessions, and regular practice. This can mean several speech sessions a week. At the time of her son's IFSP review, she requested increasing his therapy to two times per week. She, herself, provided the sound reasoning, including referencing studies and documentation, which supports the regular speech sessions. In response, the service coordinator opposed her request, challenging the mother that all she needs to do is work more with her son on her own, during their family routines. The reality was that she was extremely dedicated to working with her son on his speech, and always applied the ideas throughout their daily activities. But she knew that the type of speech disorder her son had also required the frequent training and strategies attained through the speech sessions. The service coordinator finally did approve the mother's request, but only after much resistance, which literally stressed the mother to tears. This is an example in which the child's and family's best interest was not honored, and I was embarrassed to see a parent have to fight so hard just to do what was best for her own son. It was, furthermore, an example of how members of the IFSP teams are restricted in making decisions about how the most appropriate services may be provided to best meet each child's individual needs.

In closing, I would like to express my sincere thanks to the Department for providing this opportunity to convey my thoughts regarding the regulations that directly affect the children and families with whom I work on a daily basis. My hope is that all considerations will be accounted for in the development of the guidelines, which determine how we can best serve the children.

Sincerely,

Kathy L. Nornhold, MA, CCCSLP

Kathy L. Nornhold, M.A., CCC/SLP
Speech Language Pathologist

Cc: Mr. Robert Nyce

Original: 2122

112

ALLEGHENY COUNTY DEPARTMENT OF HUMAN SERVICES
Marc Cherna, Director

Office of Behavioral Health
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October 27, 2000

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

Dear Mr. Knowlton:

I would like to thank the Department of Public Welfare for this opportunity to comment on the proposed rulemaking for Early Intervention Services. My comments will follow the order in which the proposed regulations are written.

4226.5: County MH/MR program (legal entity) is defined as an entity that " provides a continuum of care for the **mentally disabled.**" This language is not reflective of the population that Early Intervention serves. I would suggest "persons with disabilities" or "infants and toddlers with developmental delays."

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

4226.22.3(b): Federal policy states that informed clinical opinion is important when standardized measures do not exist or are not appropriate, but does not restrict the use of clinical opinion to only those instances. I would advise that the language in this section be revised to more accurately reflect what I believe to be the intent of the federal regulations.

4226.24: Comprehensive child find system: The proposed regulations simply pass on to the County the responsibility for child find functions, including coordination with and avoidance of duplication among child serving agencies. Clearly, there is an important role for the county, but the state has to create the infrastructure through, e.g. memoranda of understanding or interagency agreements. The regulation should state that the legal entity will perform these functions, "with the assistance of the State."

4226.24(f): This section dealing with timelines appears to be inconsistent with IDEA. Federal law mandates that within 45 days the county **completes** evaluation and assessment activities **and** holds an IFSP meeting. The way the proposed regulation are written, the county would only have to complete an evaluation within 45 days and would not have to hold an IFSP meeting. I would advise removing the words; "one of" so that it is clear that all three activities must be completed by the end of the 45 days.

4226.28(4): It appears that children can be found ineligible for services through screening alone and could possibly be denied access to an MDE, which is not the intent of IDEA.

4226.36(9): This section requires preservice training in fire safety, emergency evacuation, first aid techniques and child CPR. Because most early intervention services are provided in the home or day-care setting, I feel that these requirements should be dropped. Issues such as liability of direct care staff and the feasibility/appropriateness of developing fire and evacuation plans for every home raise many concerns.

4226.54: In Allegheny County, we make it a practice to hire individuals with a Bachelors Degree, if not a Masters, as service coordinators. While educational background is certainly an important criteria in hiring, I think demonstrating competencies in the field of early intervention and being qualified to work with families and children are the most important qualifications an individual can bring to the position.

I also think the regulations should include a caseload maximum for service coordinators so that they can perform their complex responsibilities adequately. In the early years of the EI program, the state informally used 35 children with active IFSPs as a guideline. This should be added to the regulations.

4226.55-56: This section is unclear. Who is the Early Interventionist-a developmentalist, a service coordinator,or is this a new position entirely? I believe that the creation of this position, and in particular the setting of qualifications for this position that are less than those of a special educator, are in violation of, among other things, the federal requirement that the state's personnel standards for early intervention be based n the "highest requirement of the state applicable to a specific profession or discipline>" The Early Interventionist position should be dropped from the proposed regulations.

4226.74(7): I recommend changing the provision stating that services must start "as soon as possible" after the IFSP takes place. I recommend changing this provision to read that services must start "as soon as possible after the IFSP, but not to exceed 21 days unless requested by the family."

While I know that the most of the proposed state regulations incorporate the federal early intervention regulations, it would be helpful to include the federal citations where appropriate. It is difficult to crosswalk the state and federal regulations in their current form.

Sincerely,

Karen A. Webb

Karen A. Webb
Early Intervention Coordinator

Original: 2122

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Eileen M. Retamal
1420 Woodland Road
Baden, PA 15005
October 25, 2000

Independent Regulatory Review Commission
14th floor
333 Market Street
Harrisburg, PA 17101

Dear Sirs and Madams:

I am writing to express my views and my son's story as reflected upon the recent proposals to the State special education and early intervention Pre-School regulations.

Firstly, the proposals would have the MH/MR program defined as an entity that would provide a "continuum of care for the *mentally disabled*". This is much too limiting. There is rapidly expanding research being done on the human brain that is reclassifying many mental disabilities. My son is autistic, as is one in every 250 children. In his Allegheny County DART classroom alone, there are four high functioning autistic children out of 15; (eight are 'model' or 'normal' children. Autism used to be defined as mental disability. However, with new research in the last twenty years, this definition has changed. Now autism is referred to as a broad spectrum developmental disability. This spectrum includes genetic malformities such as fragile X, attention deficit hyperactivity disorder, Aspergers syndrome, Rhetts syndrome, and others. With very few exceptions, there is no specific cause and no medical treatment other than expensive therapy. These children would go unserved under the new proposals. These are also children, who if not identified as having these disorders, become the "problem" children of the school system and, later in life, probably will be the alcoholic, drug addicted, repeat offender adults in society. Identifying these children as early as possible, getting them into treatment immediately, and tracking them while maintaining the continuity of service saves society huge costs in money, services and lost potential.

This leads me to my next point. The people who identify and service these children must be familiar with children with special needs. It is horrifying that I could be a service coordinator. I exceed the educational requirements and the management and supervision requirements. Nevertheless, my 7 years as a retail manager and my MBA did not prepare me to identify or effectively deal with my son's disability. The owner of the daycare center where my son attends is a licensed teacher and mother of a developmentally delayed son as well as six other children. Until the diagnosis of my son, she labeled him as **stubborn, <u>not</u> autistic**. However, she would qualify as a service coordinator.

Standards for these positions must be much higher to get maximum efficiency. Also there must be a regulated limit to the caseload that each professional handles.

My third point is timeliness. The phrase "as soon as possible" is much too vague. Within the ages we are discussing, namely birth to three years, development is rapid. The sooner the course of development can be corrected the less remedial work will need to be done. There must be specific number of days written into the law in which these services are to be provided. These services also must be continued uninterrupted when the services are transitioned to another entity. Files must handed to the new agency seamlessly, and retesting must be done while the child is receiving the same service originally provided.

My last point is the initial screening and identifying process. This process has to be aggressive in finding these children and in identifying them. It also should be specifically cited in the regulations as to how this is done, who is to perform it and who will pay for it. I am extremely grateful to Lifesteps of Butler County for coming into my son's daycare center. These professionals identified him as having language difficulties and recommended further evaluation. This caused me to go to my county to get him evaluated. The language problems turned out to be the symptom of echoalia. This led him to the services needed. However, because I dealt with two different counties I know that the process is far from uniform. Going into Daycare centers and YMCAs very good approaches for reaching a vast number of children. In addition, public announcements in pediatrician offices and local papers would be effective.

I thank you for your efforts on behalf of the children of Pennsylvania. It is my hope that you will seriously consider the recommendations brought forth and expand the scope of these regulations and specify their execution.

Sincerely,
Eileen M. Retamal

cc. Tom Ridge
Eugene Hickok
Mel Knolton

Original: 2122

Kimberly L. Stacy
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Smithfield, NC 27577

919/264-6933

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Concerns of Proposed Chapter 14 Regulation Changes
By Kimberly L. Stacy, M.Ed., DPDS East Coast Migrant Head Start Project

First of all I must commend the state of Pennsylvania for reviewing an updating their regulations in reference to provision of services for children with disabilities. However as an Early Interventionist and Head Start Disability Program Development Specialist I have some concerns of the proposed changes.

In relation to Early Intervention services the proposed regulations would prevent some children from receiving a complete multidisciplinary evaluation which may in turn not give educators a complete picture of the child as well as not address all area of development. As a we all know child development in young children every discipline is interrelated in a child's overall development. Therefore if a child is denied a complete multidisciplinary evaluation then the child is not being looked at as a whole picture.

The requirements and qualifications for service coordinators is not clear nor are the complete. Therefore my concern is the level and background of experience and knowledge of these service coordinators in actually providing the best practices for the children and families that are entitled to services. Along the lines of personnel issues the new position of "early interventionist" requirements are lacking and not striving for quality personnel to assist families and children with disabilities in receiving quality services. If you pursue allowing individuals that are not truly knowledgeable in providing quality and comprehensive early intervention services, then the children with disabilities are not being given quality services. If allowed to go with the proposed changes then these children will be given low quality or mediocre services.

If the requirement for a written evaluation report is not part of the state regulations then federal requirements are not being met. All evaluations must have a written report as documentation as well as ease of dissemination of information on the child's abilities/ inabilities. In today's society people are more transient than in years past. Parents need written evaluations to be able to share with all providers that may be a part of the child's life, especially if moving from one school district to another. If there are no written evaluations then there is no actual documentation of previous evaluations. When there is no documentation as such then the child and the family have to start the process of obtaining services again, which in turn delays services that child with disabilities in entitled to. Therefore prolonging resolution of the child's needs and possibly increasing the delay in which the child already has, which in turn then means more work for the child to catch up to their developmental age, thus increasing the gap of delay.

The IFSP team under the proposed regulations has no authority to make decisions about the most appropriate services and environments in which those services should be received. Therefore as it is proposed you are allowing individuals that may not have any direct knowledge of a child and his/her abilities and deficiencies make decisions about what is best for that child. This is not a good practice because those individuals who know the child best may not be a part of the decision making process for that child.

One of the proposed regulations to change the frequency of re-evaluation is stated to change them from every year to once every two years. During the first five years of life a child's development is expanding rapidly. If you wait every two years to evaluate this child then services that are being offered may not be appropriate, nor can documentation truly take place as it should following best practices of a child's progress during their rapid developmental ages.

Another issue with the proposed legislation is that of reviewing the IEP on an annual basis versus biannually. If this is done only once a year than teachers won't be able to determine progress towards goals but only once per year. And as mention above young children especially those under the age of six are developing at such rapid paces that goals may be met prior to the annual review of the IEP. If one is wanting to practice best practices versus what is being done currently than the state of Pennsylvania would look at keeping some of their higher standards and not slacking to the level of mediocracy.

Under the proposed regulations there is no mention of the role in which the school system must be a part of the transition process of children transitioning from Part C to Part B services. When transition services are outlined in the proposed regulations it currently only addresses transitioning from school to the real world after school. Under IDEA (34CFR part 300.132 (a)) children who will participate in preschool programs under Part B of the Act must experience a smooth and effective transition to those preschool programs in a manner consistent with section 637(a)(8) of the Act. Therefore because of this I feel that the following also needs to be acknowledged by the school system as part of their responsibility.

The state of Pennsylvania currently has a respectable time line in obtaining services for children that are eligible. Why should something so commendable be changed The proposed changes increase the time in which it take for a family to access services for their child. This is time being wasted. I urge you to not increase the time of evaluation from 40 days to 60 days from the written consent of a parent. It is agreed that the parents are to be a part of the entire evaluation process and need to give consent for one to occur but if another 20 days is added to the current number, then it may be another month of the school year gone by before services are even to be considered. This especially important for those children beginning the process in the second half of the school year, if another month is tacked on to the time line, it may not be until the next school year that the child will receive the necessary services that he/she is entitled to.

As mentioned above there are many concerns with the current proposed regulations that are being reviewed. I urge and challenge the State of Pennsylvania to look at best practices in the field instead of current practices occurring within the state. As documented in many studies through out the nation it is proven that early intervention with children with disabilities is the key to their successes. Consideration must be taken that best practices are being implemented to assure these children of the best possible services. A well known fact in brain development research today is that 85% of what a person learns occurs during the first 3 years of a persons life. So the challenge that this state has is ensuring the best and most effective services for these children with disabilities and their families.

Original: 2122

99

Heidi J. Schran B.S.
Developmental Specialist
ARC COMPRO
260 Nantucket Dr
Pgh. PA 15236

I would first like to thank you for the opportunity to discuss these proposed regulations with you here today. My name is Heidi Schran and I'm a Developmental Specialist. I had concerns with some of the terms and language used, the label mentally disabled and the position called Early Interventionist caused confusion. The qualifications for these Interventionist's pose potential problems and could impact on the quality of service for children. The last area of concern is limiting foster parents ability to serve as a surrogate parent.

I saw how MH/MR was described as providing care for the Mentally Disabled. People that are being served by this agency have the right to be addressed before their disability. The other problem is the children, in birth to three Early Intervention, often have only a physical impairment or other delay that does not qualify as mentally disabled. I would hope the regulations would be sensitive to the families and use people first language to address persons with disabilities. If the regulations come across as not being sensitive to how families feel; the insensitive terms could take the focus off of the child and services available because you can not get passed the improper term.

The position of Early Interventionist left me confused; it was not the Service Coordinator; and their responsibilities were unclear. Could the Early Interventionist be the equivalent of the Special Educator in the school age regulations? If I am confused working in the field imagine how confusing it must be to families. I guess this could be the position referring to my position as a *Developmental Specialist*. I find this term to be much more accurate and describes what expertise it takes to work with the birth to three population.

Assuming that the Early Interventionist does my job, the qualifications or lack there of, concern me greatly. When I was hired at ARC the role of a classroom aide or some one with associate level degree and experience was used when we had toddler groups and there was always a more qualified bachelor level teacher as part of the team. When we began only seeing children in their natural environment; usually the home or day care; the aide positions disappeared. When I read that a person with an (associate's degree and 3 years of experience working with children, families, people with disabilities, or counseling); could hold the position I felt like we are putting less importance on the children by asking less of professionals who work with them. The most important time of development and basic learning occurs in the first five years of life. Let's not trust those crucial years to less qualified individuals. When looking at the development of young children it makes sense to have a strong base in child development. So when I read the proposed regulations on requirements and qualifications for the Early Interventionist I was concerned that Special Education and or Early Childhood or Child Development was not the preferred degrees. In my experience; knowledge of Child Development has been my biggest contribution to the teams I have worked with. Knowledge of Child development is crucial when you are working with such young infants and toddlers. I know the trend in Childcare has been to increase the standards for caregivers. So why would we send less qualified staff out to families who some times have children with significant needs. When we have teams that include Speech Therapists with Masters degrees and Occupational Therapist and Physical Therapists who have licenses, why would we put an Early Interventionist who may only have a 2-year degree and some "related" experience on this team. The team becomes unbalanced and the role of child development and the way children learn appears less important. I have to be able to listen and collaborate with the other professionals and communicate the ideas to the family. We communicate with day care professionals and it is important to understand and have a background that supports them in their efforts to provide the best care possible to the children they care for.

I just want us to take the quality of personnel into consideration for the sake of these children and the families looking for help and answers.

The last concern I had was with the Foster Parents. I see a lot of children in foster homes and the foster parent is who spends most of the day with the children so they are integral in the implementing plans to help the children grow and develop. If limitations were made that make it harder for these caring parents to get help, for the children, the only ones we hurt are the children we so desperately try to protect. We are all here because we want to do what is in the best interest of the children. Thank you for listening.

Original: 2122

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My name is Maria Caldone Eshelman, and I have an 18-month-old son with Down syndrome. Zachary was evaluated and started in the Early Intervention Program at three weeks old.

You may ask, what could you possibly do with a three-week-old? The initial sessions were with a Developmental Specialist whom provided a great deal of support, and education for my family and me. She demonstrated techniques, and after observing me with my child she provided me with new ideas to attempt.

Zachary now has a Developmental Specialist, a Physical Therapist, and an Occupational Therapist. The goal of all of these disciplines is to assist Zachary to meet his developmental milestones within an age appropriate time frame. Children with special needs learn differently, but they do learn. It is extremely important that the personnel with whom they work understands them and how they learn. These individuals need to have a formal education in Early Childhood, and Special Education. My first child is a typical child and with just normal interaction developed, learned, and exceeded our expectations. I have a Bachelor's degree in nursing, and fifteen years work experience. I knew little about Down syndrome and how these children learn and grow. I strongly believe without the support of the highly educated and specialized individuals within early Intervention Zachary would not be doing as well as he is currently. It is an insult to me that these individuals with high qualifications, currently providing services, could be lowered. My child and all children deserve the highest quality of education. Why would I allow someone to come into my home with less education than myself and work with Zachary? If I felt overwhelmed and unprepared how could they not?

A society whom educates all it's members benefits in the long run. The burden on society is much less when people are allowed to be productive members.

I would like to read a portion of an article published in Family Circle magazine March 7, 2000. Down syndrome Doesn't Mean "I Can't" Four Success Stories. I believe this reinforces the need to continue the current high standards in early intervention.

Thank-You,

Maria Caldone Eshelman

Maria Caldone Eshelman

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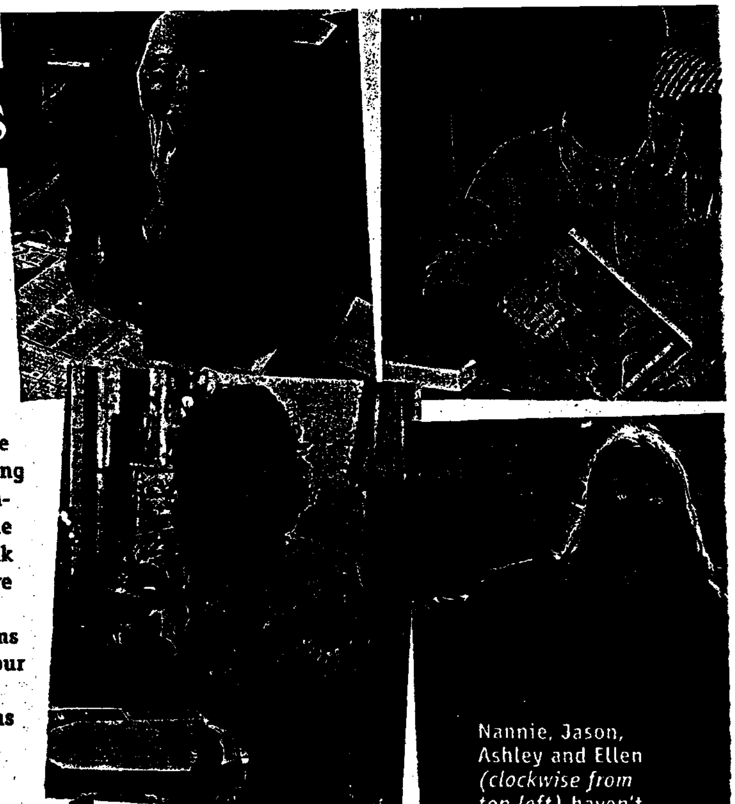
REVIEW COMMISSION

Special Triumphs

Imagine how proud you'd be if, before the age of 23, your child had run for public office, or had a book published to good reviews, or been in demand as a keynote speaker, or received national awards, or appeared on network TV. Now imagine that your child also had Down syndrome.

Increasingly, young people with Down syndrome are achieving great things, by holding down full-time jobs or making the honor roll at school. Yet not so long ago, doctors routinely advised new parents to institutionalize a baby born with Down syndrome: "Go home and forget about her. She will never sit or stand, walk or talk, have a meaningful thought or be a productive citizen. Tell relatives and friends your baby died at birth." Sadly, even today some ill-informed physicians give parents the same advice. But as the following four stories show—and as Nannie Sanchez articulates—"Down syndrome doesn't mean 'I can't.' It just means it takes me a little longer."


Nannie, Jason, Ashley and Ellen *(clockwise from top left)* haven't let Down syndrome stop them from making their dreams come true.

Down Syndrome Doesn't Mean "I Can't"

Four Success Stories

By Jan Goodwin

NANNIE SANCHEZ, age 24, Albuquerque, New Mexico

When Nannie was in high school, taunts of "retard" from other students, and even from teachers, were common. One classmate made her life hell, frequently sending Nannie home in tears. Last year she spotted him in a fast-food restaurant wiping tables for a living. The irony wasn't lost on her adoptive mother, RoseMarie Sanchez. "Look where you are today, and where he is," she advised.

Where Nannie was, was campaigning for the New Mexico Board of Education—the first time in the United States that a person with Down syndrome had ever run for public office. Like any other candidate, Nannie was intent on winning the hearts and minds of the people—and by all accounts, she was doing a great job. She walked the streets of Albuquerque canvassing, raising campaign funds and giving compelling speeches. Though ultimately she lost to a bilingual special ed teacher almost twice her age, with 18 years of experience, Nannie won a respectable 38 percent of the vote.

"I lost on that occasion, but I won in many ways," says Nannie. "I've opened the door for people with disabilities who'd like to run for office. I've had experience in organizing a campaign and getting my message—safer schools, better facilities and school-to-work programs—across. I ran because I had concerns about our school system and how people with disabilities are treated. I'll run again next time and, eventually, I'll try for the state legislature. I want people like me to have full inclusion in the community."

Nannie says she learned early that when you're born with Down syndrome, people try to put you in a box. "Forcing you into special ed is easier for the schools, but it's not the best thing for you," says Nannie. Her mom had to sue to get her mainstreamed, and then sue again to get her into college even though Nannie had passed the entrance exam. "When you graduate, you're told there are only three suitable kinds of work for people with Down syndrome: fast food, cleaning up after others, or planting flowers. I think we deserve more choices," says Nannie. ▶▶▶▶▶▶▶

Award-winning journalist and author Jan Goodwin is a frequent contributor to FAMILY CIRCLE.

Photos (clockwise from top left): Darren [illegible]; Dwight [illegible]; Angela Coppola; [illegible]/Black Star.

INFORMATION FOR THE PATIENT

EVISTA® (Ĕ-VISS-tah) Tablets
Generic name: raloxifene hydrochloride

Important Information for Patients Using EVISTA for the Treatment and Prevention of Osteoporosis after Menopause

Read this information carefully before you start taking EVISTA tablets. It is also important to read this information each time you get your refill in case new information is available. This summary does not tell you everything about EVISTA. Talk with your doctor or pharmacist if there is something you do not understand or if you want to learn more about EVISTA. Be sure to talk with your doctor before you start taking EVISTA and during your regular checkups. Your doctor is your best source of information about this medicine. Always follow your doctor's instructions on how to take EVISTA.

What is EVISTA?

EVISTA is a prescription medicine used by women after menopause to treat or prevent a condition called osteoporosis. You should take calcium and vitamin D along with EVISTA if you do not get enough calcium and vitamin D in your diet.

EVISTA **treats** osteoporosis by helping make bones stronger and less likely to break. It helps **prevent** osteoporosis by building bone and stopping the thinning of bone that occurs after menopause.

When a woman goes through menopause, her body produces less estrogen. One result of having less estrogen is that the bones of some women get thinner and weaker. This thinning of the bone is called osteoporosis. Osteoporosis can lead to broken bones (fractures). This is why women should learn what they can do to treat or prevent osteoporosis.

Your doctor may suggest other ways to help treat or prevent osteoporosis, in addition to taking EVISTA and getting the calcium and vitamin D you need. These may include getting certain types of exercise, quitting smoking and drinking less alcohol.

Who should not take EVISTA?

Do not take EVISTA if:

- your doctor has not told you that you have passed menopause. EVISTA is for use only by women **after menopause**.
- **you are pregnant or could become pregnant. EVISTA could harm your unborn child.**
- **you are nursing a baby. It is not known if EVISTA passes into breast milk or what effect it might have on the baby.**
- you have or have had blood clots that required a doctor's treatment. This may include clots in the legs, lungs or eyes. Taking EVISTA may increase the risk of getting these blood clots. While infrequent, these clots can cause serious medical problems, disability or death. If anyone in your family has a history of blood clots, or if you are now being treated for congestive heart failure or cancer, talk with your doctor about whether it is all right to take EVISTA.
- you have severe liver disease, unless your doctor says it is all right to take EVISTA.
- you are allergic to EVISTA or any of its ingredients. The active ingredient in EVISTA is raloxifene hydrochloride. See **"What else should I know about EVISTA?"** for a list of the inactive ingredients.

How should I take EVISTA?

Keep taking EVISTA for as long as your doctor prescribes it for you. EVISTA can treat or prevent osteoporosis only if you take it regularly. This is why it is important to get your refills on time so you do not run out of the medicine.

- Take one EVISTA tablet each day.
- EVISTA can be taken at any time of the day with or without food.
- To help you remember to take EVISTA, it may be best to take it at about the same time each day.
- Calcium and/or vitamin D may be taken at the same time as EVISTA.
- If you miss a dose, take it as soon as you remember. However, if it is almost time for your next dose, skip the missed dose and take only your next regularly scheduled dose. Do not take two doses at the same time.

What should I avoid if I am taking EVISTA?

Immobility

Being still for a long time (such as during prolonged travel or being in bed after surgery) can increase the risk of blood clots. EVISTA may add to this risk. If you will need to be still for a long time, you should talk with your doctor about ways to reduce the risk of blood clots. On long trips, you should move around periodically. You should stop taking EVISTA at least 3 days before a planned surgery or before you plan on being still for a long time. You should start taking EVISTA again when you return to your normal activities. (See **"What are the possible side effects of EVISTA?"**)

Some Other Medicines

Always tell your doctor and pharmacist about all the medicines you are taking or start taking, including EVISTA. These include all prescription medicines as well as over-the-counter (non-prescription) and herbal medicines. Your doctor and pharmacist need this information to help prevent drug interactions that might harm you.

Some medicines that should not be taken with EVISTA are:

- any form of estrogen therapy that comes as a pill, patch or injection
- cholestyramine or colestipol

If you are taking warfarin or other coumarin blood thinners, your doctor may need to do a blood test when you first start or if you need to stop taking EVISTA. Names for this test include "prothrombin time", "pro-time" or "INR". Your doctor may need to adjust the dose of your warfarin or other coumarin blood thinner.

What are the possible side effects of EVISTA?

An infrequent but serious side effect of taking EVISTA is the development of blood clots in the veins. These blood clots can stop blood flow and cause serious medical problems, disability or death. Call your doctor right away if you have or have had any of the following signs of blood clots in the legs, lungs or eyes:

- leg pain or a feeling of warmth in the calves
- swelling of the legs, hands or feet
- sudden chest pain, shortness of breath or coughing up blood
- sudden change in your vision, such as loss of vision or blurred vision

Most of the side effects of EVISTA are mild and usually do not cause women to stop taking EVISTA. The most common side effects of EVISTA are hot flashes and leg cramps. Hot flashes are more common during the first 6 months after starting treatment.

If you have any problems or questions that concern you while taking EVISTA, ask your doctor or pharmacist for more information.

What else should I know about EVISTA?

Women who have hot flashes can take EVISTA. However, EVISTA does not treat hot flashes and it may cause hot flashes in some women. (See **"What are the possible side effects of EVISTA?"**)

EVISTA has not been found to cause breast tenderness or enlargement. If you notice any changes in your breasts, you should contact your doctor to find out the cause.

EVISTA should not cause spotting or menstrual-type bleeding. If you have any vaginal bleeding, you should contact your doctor to find out the cause. EVISTA has not been found to increase the risk for cancer of the lining of the uterus.

In clinical studies, EVISTA did not increase the risk for breast cancer.

EVISTA lowers total cholesterol by about 7% and LDL ("bad") cholesterol by about 11%, on average. It does not change triglycerides or HDL ("good") cholesterol.

Call your doctor if you become pregnant while taking EVISTA.

Keep EVISTA and all medicines away from children. In case of overdose, call your doctor, hospital or poison control center right away.

Medicines are sometimes prescribed for purposes not listed in this patient information. EVISTA has been prescribed just for you. Do not share your medicine with anyone else even if she has a similar condition. Her doctor should decide if EVISTA is right for her.

If you have any questions, ask your doctor. If you want to read more about EVISTA, ask your doctor or pharmacist to give you the information on EVISTA written for health professionals. The EVISTA web site (www.evista.com) also has this detailed information.

Inactive Ingredients: anhydrous lactose, carnauba wax, crospovidone, F D & C Blue No. 2 aluminum lake, hydroxypropyl methylcellulose, lactose monohydrate, magnesium stearate, modified pharmaceutical glaze, polyethylene glycol, polysorbate 80, povidone, propylene glycol, and titanium dioxide. EVISTA does not contain enough lactose to cause symptoms in women who have lactose intolerance.

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EVISTA® (raloxifene HCl)

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Dynamic, passionate and clearly unstoppable, Nannie is also a much-in-demand keynote speaker at international conferences, for which she receives professional speaker fees. Recently she returned from Israel after wowing a large audience of physicians and Down syndrome professionals. Constantly on the go, she juggles appointments that run months ahead. Nannie also holds a full-time job in the finance department of Youth Development Inc., a Head Start office in Albuquerque. She fluently uses three computer programs there and is "treated as part of a team, with respect and dignity." She also sits on the board of another development center, is a lobbyist for disabled people in the New Mexico legislature, is taking Spanish and driving lessons, and, for fun, is learning to tango.

> “What really counts in being successful is early intervention, drive and personality.”

Nannie has broken many barriers for people with mental disabilities, but,"It's been a long fight," she admits. "When I was born with Down syndrome, my birth mother was told I'd never be able to do what normal people do as they grow up. Based on that fallacious advice she gave me up for adoption," she explains, "but my adoptive family never gave up on me."

Nannie is in the first generation of children with Down syndrome who benefited from early intervention programs, beginning shortly after birth, that enable them to reach their full potential. Offering constant sensory stimulation with color, sound and touch, including massage—and even dunking in washtubs full of Jell-O—these programs immerse kids in a hyperenriched environment. Later, most children require speech therapy, and while they may learn slowly, learn they do.

"Our society needs to move beyond our prejudices, eliminate our stereotypes and give these kids a chance in school and in work," says Arden Moulton, president and cofounder of the National Down Syndrome Society. "Why would we want to pay for such kids to be institutionalized when, if given a chance, they can be wonderful additions to any community." Yet even today, "some doctors and nurses still need educating," she says. "They should be advising parents to learn about Down syndrome before making any decision about their child's future. We've found that, in fact, more of these kids excel than don't."

Moulton points out that to be born academically gifted does not guarantee success in life. "There are many C students who end up running a lot of the world," she notes. "What *really* counts in being successful is early intervention, drive, determination, passion and personality." All of which apply to Nannie. Refusing to recognize obstructions, she sees only opportunities. "Whether they're disabled or not, I want to help young people to be the best they can be," she says.

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ASHLEY WOLFE, age 21, Simsbury, Connecticut

When Ashley addressed a National Down Syndrome Congress luncheon last year, she introduced herself by saying, "I'm not 'Ashley Down Syndrome Wolfe.' I'm 'Ashley Wonderful Wolfe!'" And while she is certainly that, she could also have introduced herself as "Ashley Courageous Wolfe." The early years of Ashley's life were spent coping with visual problems and hips that constantly dislocated. Ashley underwent seven corrective surgeries and at various times had to wear a body cast and a metal A-frame brace. "It squeaked badly," says her mother, Nancy, "and the custodian at her kindergarten was forever chasing her around with an oil can trying to stop it." Yet despite Ashley's multiple disabilities, the many weeks spent hospitalized and learning how to walk again, she still managed to read at grade level. "She has an amazing spirit," says Nancy, an actor and film and theater teacher. It was that indomitable spirit that enabled Ashley to make honor roll seven times in high school, to receive an award for Spanish, and to be one of three commencement day speakers—the first time a special ed student had been selected. The audience rose to their feet and applauded.

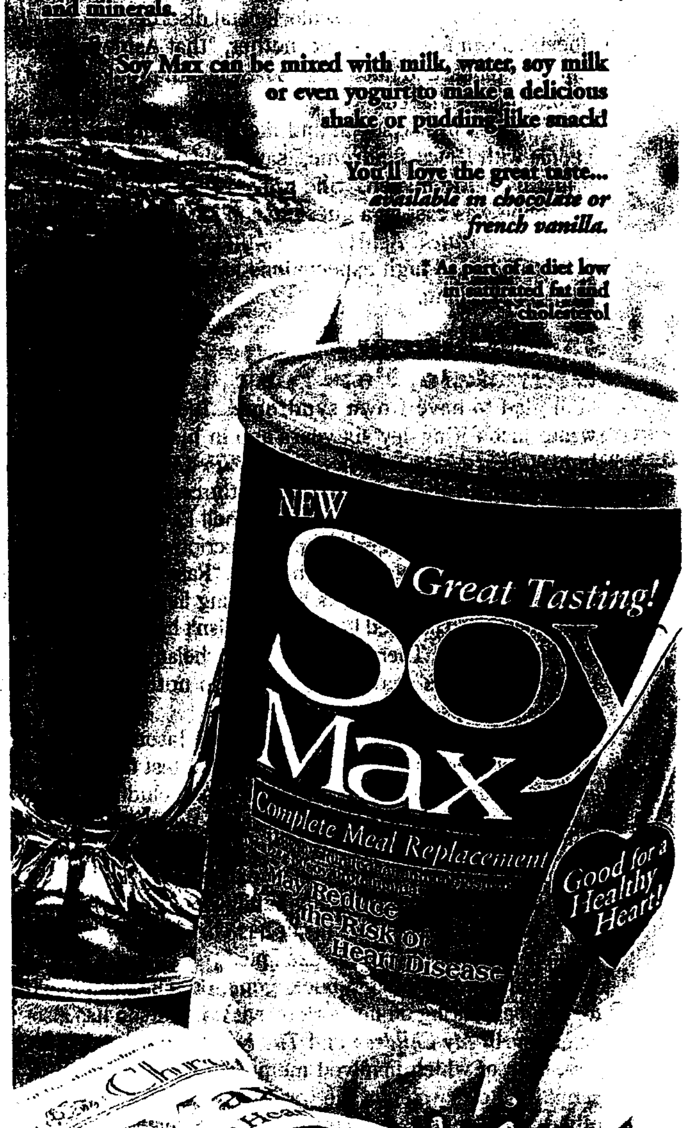
Ashley is currently enrolled at Lesley College in Cambridge, Massachusetts, where she has just completed the two-year Threshold Program for young adults with learning disabilities. She studied health and human services and is continuing this work for an optional third year. The Connecticut Down Syndrome Congress recently awarded her their first ever scholarship for post-secondary training. Three afternoons a week, she also works at the Massachusetts Eye and Ear Infirmary as a clerical assistant. The high points of being in college, says Ashley, have been learning to be independent and to make her own decisions.


Ashley has overcome many obstacles to become the active college student she is today.

"I was nervous at first about whether I would be socially acceptable," she says. "People label you when you have Down syndrome. At times they decided without knowing me that I'm dumb, which clearly, I'm not."

Dorm life was hard at first, she admits. "In those early days I was insulted and put down by the regular students," she says, "but things have changed a lot since then. I've learned that I needn't try to mask who I am. It also got easier with the other students when I started speaking up in class, and they realized I have a lot to contribute."

Ashley says she still gets lost from time to time traveling around Cambridge. "I have difficulties with spatial relations and need written or oral directions, or landmarks. And I still have trouble with mental math, but then, so do a lot of people." She enjoys ▶▶▶▶▶▶▶



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swimming, basketball, horseback riding and hiking. She's a gold medallist Special Olympics swimmer and has performed dances that she choreographed. She dates occasionally.

"I never knew if Ashley would have that," said Nancy, "and it's been lovely that she has had the attention of young men. One day last summer, in fact, both of us were sitting on my bed having a time-honored discussion about the opposite sex. It ended with the pair of us shaking our heads and saying, 'Men!' "

Ashley says she'd like to marry someday, "but for now, I'm single and happy." Recently, life threw her another medical challenge. She was diagnosed with fibromyalgia, a complex and painful musculoskeletal disorder. "It doesn't seem fair," says her mother, "that Ashley will have to learn to manage this new health problem." But no one doubts that she will.

"I plan to break social and media stereotypes about people with Down syndrome," says Ashley. "And I can do it just by being myself." She proved that last December when she was cast as a guest star in an episode of NBC-TV's *Third Watch.* Ashley knows that by "having a positive attitude and high expectations for myself," she'll just keep on excelling.

Jason, a gifted actor and author, poses with actress Roma Downey of the television series *Touched by an Angel.*

JASON KINGSLEY, age 25, Hartsdale, New York

"I'm glad to have Down syndrome...it's not that bad," wrote Jason Kingsley six years ago in his well-reviewed book *Count Us In—Growing Up With Down Syndrome* (Harcourt, Brace), which he coauthored with another teenager with Down syndrome, Mitchell Levitz.

His mother, Emily Perl Kingsley, a scriptwriter for *Sesame Street,* shares his sentiment. "Raising a child with Down syndrome is like landing in Holland when you'd planned to visit Italy. It isn't horrible, just different. There may not be Michelangelos, but you look around and begin to notice windmills, tulips—and Rembrandts."

When Emily was 34 and pregnant with Jason, she was offered amniocentesis, a prenatal test that can diagnose a number of genetic conditions, including Down syndrome. She decided to pass because the test itself carried some risk. "And I am so glad I did. Having Jason has been the most enriching experience of my life. If I'd terminated that pregnancy, what my family would have missed out on is incalculable. And Jason has enriched the lives of millions of people just by his example."

In addition to writing a book, going on a national book tour and appearing on network television, her son has also acted on *All My Children* and *The Fall Guy* with Lee Majors, both of which involved memorizing many pages of script. And every step of the way Jason has been teaching others that "people with Down syndrome have the same hopes, dreams, goals and feelings as other people."

In his book he even has a message for the obstetrician who had told his parents to institutionalize him because he would never learn or even be bright enough to understand his condition. "I think that was wrong," wrote Jason. "I would tell him how smart I am. Like learning new languages, going to foreign nations, becoming independent, being a lighting board operator, an actor. I would tell him that I play the violin and the piano, that I can sing, that I'm in the drama group and compete in sports, that I make paintings and relationships, and that I have many friends and a full life."

Jason lives independently in his own apartment, pays his own bills, does his own banking, cooking and cleaning. He dates, works out at a gym with a personal trainer, bowls and enjoys *karaoke.* Professionally, he has been assistant cultural arts program coordinator for the Westchester Association for Retarded Citizens, traveling with art shows, cataloging art, doing computer work. Now he has a computer job in the Westchester County Clerk's office.

"Jason excels in some things and less in others," says his mother. "He will never be able to drive a car, for example, because his reaction time and coordination are not good enough, but that doesn't mean he won't write poetry." If there is one message both Jason and Emily want to get across, it is this: "Don't write a child off ahead of time or make assumptions about how far he will go."

"So much of the medical literature that asserts these kids can't learn is based on children in institutions," says Emily. "But place anyone in an institution with no stimulation, no affection, no exercise, no education, and terrible food, and even Einstein would come out as uneducable. Not all kids with Down syndrome will accomplish on Jason's level, but they can still make a contribution, as long as parents keep expectations high, encourage them to reach for more and refuse to let anyone keep them from trying."

> "Don't write a child off ahead of time or make assumptions about how far he or she will be able to go."

ELLEN KUHN, age 20, Bethany, Pennsylvania

With her red cap and gown, beaming smile, and aura of self-confidence, Ellen Kuhn strode across the stage last summer to receive her high school diploma. She was making history as the first child with Down syndrome in her county in rural northeastern Pennsylvania to graduate from high school after being mainstreamed. And it is Ellen's self-confidence that has marked her every accomplishment. When she didn't have a date for ▶▶▶▶▶▶▶

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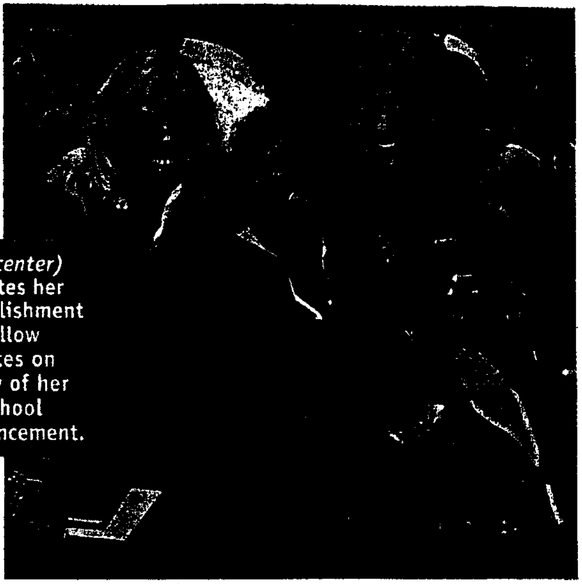
the junior prom, she chose not to do what generations of dateless girls have done: stay home out of embarrassment. "I like to dance," she says, so she bought her own ticket and went alone. At the senior prom, a date was no problem, and Ellen and her partner danced the night away. "She was dazzling," says her mother, Johnna.



Ellen *(center)* celebrates her accomplishment with fellow graduates on the day of her high school commencement.

Ellen's self-assurance has its roots in advice given to her parents when she was born. "Pick her up, take her home, and treat her like any other child," their progressive physician told them. "That's exactly what we did," says Ellen's father, Paul. "And since she was our first child, she was 'normal' to us."

Like many children with Down syndrome, Ellen was born with a hole between the chambers of her heart, which required corrective surgery when she was two. "Until then, she only weighed 12 pounds and had little energy," says Johnna. "She stood up for the first time in her hospital crib after surgery. After that, she started galloping around. We gloated over all of her achievements—feeding herself, talking, walking. It was as if a door had been opened, and Ellen had stepped through it.

Later, however, Ellen's parents ran into the same problem many Down syndrome families face of having to fight school authorities who wanted to confine Ellen to special ed. "When I tried to enroll her in first grade, they said, 'There are special schools for that kind of child,'" says Johnna. "So I told them to just give it a try. It went very well, better than anyone expected. Ellen adjusted and found her way. But then she always does. She's so outgoing. It's impossible not to like her. Years later, the elementary school principal told me that he'd thought we were crazy to mainstream her. He'd kept quiet at the time, and now he says it was the best thing we could have done."

"Ellen could turn your mood around. She has a talent for bringing out the best in people."

Ellen has always been high functioning. She fits in well wherever she goes and she has an astounding memory. "She'll watch a video or musical, and tell you every word and motion afterward," says her mother. "That may be why she's a great performer—and has never had stage fright."

The Kuhns found that as they battled to have Ellen accepted, school authorities frequently treated them as though they, too, were retarded. "They'd talk down to us, and sometimes people even behaved as though Down syndrome were contagious. People are clearly fearful of something they don't understand. But then, you know, I've just been through breast cancer, and a lot of people behaved the same way. One way or another, however, we Kuhns are survivors."

In Honesdale High School Ellen bloomed. At the Kuhns first meeting with the principal and vice principal, they were treated like dignitaries. "Oh, the difference," recalls Johnna, smiling. "They seemed to recognize that if Ellen did well there, it was a feather in their cap, too. One teacher told us: 'Whatever you need, we're going to make it happen.' Consequently, Ellen loved her teachers."

"We were always being told that when people were having a horrible day, Ellen would come bopping into a class and, with her wonderful social skills, just turn everyone's mood around. She has a talent for bringing out the best in people. Ellen doesn't think twice, for example, before giving a hug to the principal, or even to the tough teacher everyone else is terrified of."

Johnna says she tries not to wonder why Ellen was born with a disability, "but sometimes I think that her reason for being here is her sunny disposition, her ability to make others feel good about themselves. I think the world is a better place, both for the disabled and the rest of us, because of her presence. I've learned a lot from Ellen. And she still surprises us with how much she can accomplish when given the chance."

Says Kathy Highhouse, one of Ellen's former teachers, "She's a wonderful kid. Everyone loves her. She paved the way for a lot of children."

Ellen isn't yet sure of her future plans. Currently, she's apprenticing in a local restaurant, "to get a feel for the workplace," she says. "I've also been promised a job at a supermarket. I'm still not sure what I want to do." ■

Where to Turn for Information

Down syndrome is the most commonly occurring genetic "accident" in humans. It's estimated that the condition affects some 300,000 Americans, and occurs in one in 800–1,000 live births. For more information or educational referral services, contact: • National Down Syndrome Society, 666 Broadway, New York, NY 10012. Phone: 800-221-4602; Fax: 212-979-2873; Web site: www.ndss.org or • The National Down Syndrome Congress, 7000 Peachtree-Dunwoody Road, N.E., Building 5, Suite 100, Atlanta, Georgia 30328. Phone: 800-232-NDSC or 770-604-9500; e-mail: NDSCCENTER@aol.com

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Good Morning. My name is Michelle Kirkpatrick. I am a Developmental Specialist with ARC-Allegheny. I serve families of children under three with special needs. I assist families in the care and education of their children with developmental delays in their homes and around their communities. I am not the parent of a child with special needs, but through my work over the past three years, I have come to know the impact of Early Intervention for children and their families. As an Early Intervention professional, I do have a stake in the proposed changes which are being discussed here today.

I was struck, first and foremost, by the language being proposed to describe the population which benefits from EI services. Regarding the county MH/MR program, I read that it is defined as an entity that "provides a continuum of care for the mentally disabled." It was the phrase *mentally disabled* that appalled me. When I relayed it to a number of the families with whom I work, there was equal surprise and upset. The phrase *mentally disabled* is just plain insensitive: it shows a total disregard for the national movement towards person-first language--that is, to put the person before the disability. In other words, *persons with mental retardation* instead of *the mentally disabled.* But besides being insensitive and offensive, the phrase is also confusing, since the infant and toddler population who may be eligible for EI services also includes children who are physically impaired or have sensory impairments; such a phrase may actually deter some families from asking for services. A more accurate and sensitive description would be *persons with disabilities.*

Next I would like to speak on the section regarding timelines. This draft includes the phrase from the federal regulations that services for an eligible child must start "as soon as possible after the IFSP meetings." The phrase *as soon as possible* is vague and open to broad interpretation. Families cannot wait until EI staff, with huge caseloads, get around to getting services underway. The only way to make sure that families are clear on their rights, and that counties are clear on their duties, is to set a deadline--14 days seems more than reasonable.

Finally, I would like to address the issue of requirements and qualifications for Early Intervention personnel. Based on the importance of the Service Coordinator and the broad scope of that person's duties, the qualifications suggested in this draft are grossly insufficient. According to the draft, a service coordinator could have an associate's degree in *any subject area* and three years' work or volunteer experience in management or supervision, to qualify. There is no requirement in the current draft that the service coordinator bring to the job academic training in the field of child development, much less experience in the field, and special training in the needs of families of children with special needs. At a MINIMUM, I would recommend that a service coordinator must have a Bachelor's Degree in a field related to Early Intervention, and at least two years experience working with children with special needs in Early Intervention or preschool programs. Further, the regulations should include a caseload maximum for service coordinators. These are the only ways to ensure that the families they serve are not just adequately, but fully, supported.

I am confused about the position of "Early Interventionist" which has been proposed in this draft. It is unclear how this service differs from that provided by the service coordinator and the special educator. And again, the requirements for this position are minimal: a two-year degree in *any subject* and three years volunteer work with children. So an individual with a two-year degree in diesel mechanics who baby-sat his nieces and nephews is qualified to do my job? I think not! With a Bachelor's Degree in Education and two years of teaching, coupled with countless hours of volunteer service with children with and without special needs, I felt my own knowledge base was insufficient; I am thus pursuing my Master's Degree in Early Intervention. This section of the draft is unneeded and should be removed. The requirements for the person delivering special instruction should be elevated to the level I mentioned earlier for service coordinators, with one addition: ongoing training in specific areas of disability which that person will encounter on the job.

Thank you for giving us the opportunity today to voice our concerns and our desires regarding the Early Intervention system in Pennsylvania. We know that you will take what we have said, from our hearts, under serious consideration. In conclusion, these are the faces of some of the children whom I have served in my practice as an EI professional. Each week, their families welcome me into their homes. They trust me; they look to me for guidance and support. They deserve the best we have to offer them. After all, the investments we make in our children today will ensure a better world for all of us tomorrow. Please help me, and all Early Intervention professionals, continue to do our work to serve these children and their families in the best manner possible.

Michelle Kirkpatrick

Michelle Kirkpatrick
Developmental Specialist
COMPRO/ARC-Allegheny
711 Bingham Street
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Good afternoon, my name is Brenda Alter and I am honored to be here today. I have a 2 1/2 year old daughter with Downs Syndrome. One of the symptoms of this genetic disorder is low muscle tone...I am still waiting for signs of that! Kali is very active, very intelligent, and very much in her "terrible 2's".I enrolled her in early intervention as a newborn and I thank God for that service. She walks, talks , knows sign language, and interacts with others very well. She is also very affectionate, and you might say to -know Kali is to love her. I owe a lot of that praise to her therapists. She had physical and developmental therapy as a newborn and at age 1, I requested a speech therapist. Kali's Service Coordinator has been very competent and helpful. She explained all of the services to us, making us aware of the best avenues for us to take with Kali. This can be very confusing and you need guidance of qualified personal. Information is no substitute for knowledge and experience. I spend a lot of time with my daughter and work very hard, however it is so helpful to have someone come in to work with Kali more experienced than myself. She needed someone to teach me things to do to build up her muscle tone and develop cognitive and speech abilities. Little things that these therapists are trained to do make the biggest difference. Several times in her therapy sessions I thought Kali was doing good ,but I needed someone there to say "she is doing good but let's do this and she will do even better." I think it's wonderful to have someone tracking her progress. There have been times I can be in denial or even consider some things normal because that's all I know or see. This enables me to be a better mom for Kali.

On the subject of medical coverage the coverage the rest of our family has would require me to get a referral for everything Kali needs. She has had several problems with her respiratory system. She gets croup quite often, and there is nothing scarier then waking up in the middle of the night to your baby gasping for air. Having the medical coverage she has is a true blessing. I can't imagine having her in an HMO where I have to worry about where or what is covered . I have other worries on my mind. It many cases it can be a matter of life or death. Kali has always had the best possible care from the service coordinator to the therapist to the individuals behind the scenes There is always a friendly ,experienced individual to assist with problems we are having. I have had many issues to worry about and knowing the financial part is taken care of is a tremendous help.

When asked to speak on how early intervention helped my family today I made a comparison. When a construction crew builds a new bridge, they get thee most experienced people. They have to so that it can support cars, trucks, and buses. The qualifications and experience of those workers must be very extensive. They have to build a solid foundation to withstand much abuse and be able to last a long time. I see that very much related to early intervention. Kali needs that solid foundation which as a team, her therapist's and myself can provide. She goes through milestones every day , but with her knowledge she can withstand them and if we keep pushing her it will last a lifetime. Statistics show that by age 5 children will have achieved more than half of their brain development; The basis on which they build their adult language, logic, and reasoning. Certainly we can't wait until a child enters 1st grade to begin teaching them. They won't wait that long to start learning. This is, of course, even more true with children with disabilities. My daughter's possibilities are endless, please don't burn her bridges, let her make all the choices. You may say you have nothing to do with her future, well let's start with her foundation.

Brenda Alter
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October 23, 2000

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

Dear Mr. Knowlton:

The Schreiber Pediatric Center has been providing service to children since 1936. Over the past years, we have had the honor to serve thousands of children with special needs. One of our success indicators was parent involvement. As such, we asked parents for their review of the regulations being proposal for Early Intervention Service by the Department of Welfare. As a service to them, we have compiled a listing of comments and/or suggestions on the proposed regulations as noted by families we serve. There may be duplication of information since several families wanted to contact the State directly.

The following is a section-by-section review of areas of concern or comment pertaining to the proposed regulations:

Section 4226.5 Defiinitions

(a) (vi) Item (L) Early Interventionists
Action: Delete term or expand definition of responsibilities
Rational: Currently not a recognized educational entity. Does not have defined educational requirement standards as other personnel listed under this Section.

(b) Family training, counseling and home visits
Action: Define each term separately
Rational: All three terms have different meaning in Early Intervention.

Section 4225.12 Waiver Funds

Action: Delete
Rational: This is another funding source limited to Department of Health and Human Resources approval cycles (3 years) – would fall under section 4226.14 Documentation of other Funding Sources.

Section 4226.14 Documentation of Other Funding Sources

Action: Define process to make families aware of various funding sources and their requirements, eligibility, etc. – Change title to "Documentation of Fund Sources."

Rational: Parents should be provides written details of advantages and limitations of various restrictions posed by each funding source, i.e., Infant & Toddler Waiver requires parents to certify child ICF eligible – high level of delay 50% in one or 33% delay in two of the development groups.

Section 4226.23 Waiver Eligibility

Action: Delete, include under Section 4226.14, new title "Documentation of Funding Sources."

Rational: Provide parents with information that is inclusive for them to give informal consent as to preferred funding stream.

Section 4226.37 Annual Training

Action: (1) Delete term "the service coordinator" and "early interventionist." Restate: "All personnel who work directly..."

Rational: No need to specify categories of professions required. If so, must list all individual categories.

Action: Define payor source of required 24 hours.

Rational: The funding of twenty-four hours of training would pose hardship on many non-profit service providers, as it removes staff from direct support, billable services.

Section 4226.55 Early Interventionist

Action: Define in item (2) what implementing the child's IFSP directly means.

Rational: Could be interpreted to mean delivery of services which requires skills of licensed personnel, i.e., physical therapist, etc.

Action: The term "supervising" the implementation of services provided by other early intervention personnel should be restated to "coordinate"

Rational: Standard implies that this individual would provide skills for monitoring, oversight of individuals licensed by State. This would exceed basic qualifications listed under 4226.56 Requirements and Qualifications.

Section 4226.62 MDE (A) (2)

Action: Insert State's current exception procedure.

Rational: Due to service availability in Pennsylvania, many counties will not be able to comply with standard requirements for independent service providers. In fact, State has had to develop exception procedure.

Section 4226.73 Participants in IFSP meetings and periodic review

Action: Heading should emphasize that process is "multidisciplinary" with parent and two or more disciplines or professionals.

Rational: Set the intent of meeting and provides objective level.

Section 4226.74 Content of IFSP, item (1) Natural Environment

Action: Due to confusion caused by current interpretation of IDEA, this section should be reworded to read:

> "*Natural environments – location of services.* In accordance with §303.341, the IFSP must – (i) Specify the natural environments (locations or settings) where each early intervention service will be provided; and (ii) Include a justification of the extend, if any, to which each service will not be provided in a natural environment."

Rational: Duplicates federal standards.

Thank you for the opportunity to express our point of view on these proposed regulations.

Sincerely,

William F. Jefferson
President

WFJ/smh