Original: 2122

TESTIMONY ON PROPOSED DEPARTMENT OF PUBLIC WELFARE EARLY INTERVENTION BIRTH TO THREE REGULATIONS

Submitted by:
Mary Mikus
Parent Chair
Philadelphia Interagency Coordinating Council
October 2, 2000

Introduction

My name is Mary Mikus. I am parent of a very recently turned three year old in early intervention, Parent Co-Chair of the Philadelphia Interagency Coordinating Council (PICC), Family Inclusion Coordinator at the Institute on Disabilities/University Affiliated Program at Temple University. In my role at the Institute on Disabilities, I coordinate and conduct Families First, a PICC sponsored day long family leadership training program and assist in the implementation of Competence and Confidence: Partners in Policymaking (C2P2), an eight session leadership training program for people with disabilities and parents of young children with disabilities. In this capacity I have come into contact with hundreds of families in the past two years who have shared their early intervention experiences, both good and bad, with me.

Thank you for the opportunity to present testimony. We are particularly appreciative of the Department's response to grant additional hearings and extend the comment period on the proposed regulations. The Philadelphia hearing scheduled in conjunction with the October PICC meeting is indicative of a positive partnership between the Department and the PICC.

I would like to start by saying that I personally, am very happy with the early intervention services my son is receiving. His services have made a significant positive difference and dramatic improvement in his life and the life of our family. His service provider, UCP, has brought to our family a team of individuals who are committed to his growth and development, who are sensitive to our family's needs and who support our vision for Sean – that his life be fully inclusive.

On the whole, we are lucky in Pennsylvania to have a system that from the top down strives to support families and provide quality services. Of course, there is room for improvement and opportunities for continued partnerships.

We are pleased that the Department has drafted long-awaited and much needed regulations. I will now comment on some of our concerns and recommendations. I will also outline some new proactive recommendations to enhance early intervention in PA and to strengthen the partnership between families, providers, program administrators and policy makers.

Personnel Qualifications

We are unclear about the role and responsibilities of certain positions outlined in the draft regulations and concerned about the required qualifications that are stated.

Service Coordinator

For families, the Service Coordinator plays one of the most essential roles in the early intervention system. The Service Coordinator is the person the family meets first. He or she creates a lasting impression about the system. He or she dispenses information as well as conveys attitudes about services, about children with disabilities, about the family's role and about requirements, rights and responsibilities. The Service Coordinator

is the gateway for children entering the system and the gatekeepers for families requesting services and information.

The draft regulations state that the minimum requirement is an associate's degree, which could be in any subject area and three year's experience in management and supervision. These qualifications are not adequate. It is essential that the Service Coordinator have experience and education in the early childhood development, particularly with children with disabilities and in working with families, particularly families of children with disabilities. We recommend that the regulations reflect a competency based approach, such as what was developed by Dr. Phillipa Campbell under contract to the Department in 1997.

Early Interventionist

First, it is very unclear as to what the job of the early interventionist is, particularly how this position relates to other disciplines. There is lack of clarity as to whether this position is service coordination or special instruction.

Second, the qualifications which are the same as for Service Coordinator, are inadequate. Again, it is crucial that early intervention personnel have adequate training and experience in working with children with disabilities and their families. We recommend a competency based approach. But before qualifications are developed a more detailed description of this position is required.

As a concluding comment about personnel qualifications, we request that the Department uphold the federal requirement that the state's personnel standards for early intervention be based on the "highest requirements of the state applicable to a specific profession of discipline." This standard must be reflected in the regulations.

Screening, Evaluation and Assessment

The Philadelphia Interagency Coordinating Council supports the current Multidisciplinary Evaluation (MDE) process and holds the position that the initial screening as outlined in the draft regulations may undermine the MDE process. We recommend that the initial screening process be removed. This process will result in too many children not receiving needed and appropriate services since they may be screened out of early intervention or may be misdirected because they have not been fully evaluated through an MDE. The MDE provides a more complete picture of the child, giving the family and service coordinator more information on which to establish needs. The MDE also allows for procedural safeguards for the family should a conflict arise.

It is also critical that the evaluation team be a team and not just one person. The cross-discipline approach helps ensure a well-rounded picture of the child. Further, we recommend that a specific discipline or 'expert' in the suspected area of the child's diagnosis be represented on the team. The presence of such a person will facilitate an appropriate service plan.

The regulations further do not support federal requirements about public awareness about early intervention programs. We recommend specificity in the regulations that direct counties to carry-out child-find activities and other efforts to identify at risk and in need children and to support their inclusion in early intervention programs in ways that are sensitive and supportive of the family's role in and understanding of their child's circumstances.

Timelines

There is a critical omission on specific timelines. There is no timeline for when services are to be initiated after the development of the IFSP. We recommend 14 days from IFSP completion. It is also not clear whether the initial 45-day period for IFSP development begins at the time of the referral or at the time of determination of eligibility.

IFSPs

We submit the following recommendations which will enhance the IFSP process and develop a stronger partnership among members of the IFSP team which are generally families, clinicians/providers and service coordinators.

Procedures for IFSP development

We would like the regulation addressing the review process to include a clause which states that IFSPs can be reviewed more frequently than every six months at the request of family. Only the exceptional family realizes that they can request an IFSP review at any time if they so desire.

We further recommend that this provision state that the service coordinator must have the authority to commit the County's resources or someone with that authority must attend. I am aware of a number of families, including mine, who have spent a great deal of effort preparing for IFSP meetings. These families have notified Service Coordinators in advance of potential controversial items for discussion or out of the ordinary requests that are anticipated to come up at the meeting. They then find out after lengthily discussion at the meeting that the meeting has to be reconvened so that the proper person in authority can attend and participate in a re-discussion.

We also recommend that families be informed by the Service Coordinator of those who will be attending the IFSP meeting in sufficient time prior to the meeting. It is only courteous that the family knows who will be entering their home. The IEP process provides this type of notification and serves as a good model. Conversely, it is good to know who is not coming to the meeting. At my first IFSP meeting, to my surprise, my Service Coordinator did not invite anyone on my team. I had assumed this was her job. My son's OT was present because I called him. No others in my team could fit it into their schedule at the last minute.

Interim IFSPs

We do not support the concept of an interim IFSP. It is our position that an IFSP can not be developed without a MDE.

Transition

The transition process is not clearly laid out in the regulations. Key elements in the federal regulations which are omitted in these draft regulations include guidelines for training and discussion with parents, steps to help the child adjust to a new environment and clarification about forwarding of records. Most critically lacking is the provision, known as pendency. that allows the IFSP to remain in place until services are provided by the MAWA. This clause is particularly important in serving as a procedural safeguard while disputes about services are being resolved. We strongly recommend the inclusion of these provisions.

In addition, there is a lack of clarity about whether a child can move to a center-based program during the transition year if the team views it as appropriate. It is our recommendation that there be more flexibility between these two systems particularly regarding a team recommendation for 'early' center based placement. For example, it is not in the best interest of the child and even impractical at times that the child has to wait until his or her third birthday. This is particularly true when at a transition meeting, or even sooner, the team determines that a child can best achieve his or her educational and developmental goals through a center based placement. This time lag between a team decision and placement particularly doesn't make a lot of sense when the child's third birthday is shortly after September and he or she has to wait and can't transition with many of his or her peers who move with the school cycle.

Further, a more streamlined transition needs to include more flexibility and overlap between development of the IFSP, transition to the 3-5 system and IEP development. For example, if the team understands and is aware of the child's needs, appreciates the families concerns and priorities and has worked collaboratively developing and achieving goals throughout the IFSP process, the process of developing a complete and separate IFSP and an IEP within a short time frame may be duplicative and not an effective use of resources.

This type of situation occurred with my son Sean. Because of timeframes, he was due for his IFSP and IEP at about the same time when he was almost three years old. We, his family, wanted to combine the IFSP/IEP meetings with a focus on his IEP. We wanted to do this since the team was pretty much the same, there was ongoing communication among family, clinicians and pre-school teachers and we had all talked and developed new goals focusing on his IEP. Instead, we ended up reviewing all his IFSP goals which seemed redundant and not having any time to address his IEP goals. We recommend that at the transition meeting, the team lay out the process of coordinating how both the IFSP and IEP be developed and coordinated smoothly and effectively during the transition year.

Eligible Services

We recommend that the clause 'included but not limited to' be added to the list of eligible services. This clause is in PA Act 212, but omitted from the draft regulations.

While the vast majority of services children receive are included on the list, there are occasions that a service deemed necessary by the team is not on the list. The regulations must allow for this flexibility in meeting a child's needs.

Conclusion

In conclusion, the regulations are very skeletal at best, somewhat unclear and as such have the potential to be damaging to the quality of services. Pennsylvania has been a pioneer in the education of children with disabilities. These regulations present an opportunity to continue to model best practice. We recommend that the state consider incorporating into the regulations the following recommendations. These innovations will strengthen LICCs and enhance partnerships between families and the early intervention system:

1. Parent training through the LICCs. Philadelphia is in its second year of Families First, our local PICC leadership training program. Over 100 families have been through this one-day program taught by parents. We are developing new trainings including one on Transition and one on the IFSP/IEP process. We are also collaborating with a neighboring county on initiating a similar training there.

2. Self-determination. The idea of individuals with disabilities deciding the course of their lives is a new concept which supports individual rights, equality and enhances a person's sense of responsibility. Pennsylvania has certainly been a leader in this area. This process must be further expanded to families through innovative programmatic approaches. One way to initiate such an approach would be to allow families to choose therapists or providers who meet state standards and are willing to accept rates set by the county.

3. Parent 'ombudspersons' LICCs could be funded through the state to hire ombudspersons to inform families about programs and their rights.

We are very lucky in comparison, let's draw on our strengths – the expertise that exists and the partnerships that have been developed to revise and adopt regulations that truly bring out our best.

Original: 2122

October 2, 1900
Patricia mcCole, M.Ed.,O.T.R./L.

Thank you for this opportunity to comment on the proposed infant/toddler regulations.

I 've worked in early intervention for some twenty-five years, in a variety of roles, and in two states. I began as a parent of an ADHD child, and am now the grandmother of a toddler with Down syndrome. I have directed programs and worked on local and state task forces and committees to develop and provide early intervention services. I am currently enjoying my role as community therapist for Family Support Services, part of a very dedicated and experienced team; most of us with Master's degrees. Yet we frequently need to turn to one another for information and suggestions.

I absolutely support the need for professionally trained personnel both as coordinators and providers of early intervention. A bachelor's degree is only the beginning when working with the most vulnerable of our children. It takes a great deal of knowledge to provide the very wide variety of interventions necessary when working with the various difficulties our children have. It takes skill to explain interventions to parents so that they can help their child.

As part of a MDE team, I strongly urge that there always be two evaluators present. We must listen carefully and compassionately to the parent's story while observing the child. We need to spend time interacting and playing with the child. We explain every step to the parent and then compose the report for both the parent and whoever is going to provide ongoing services. It takes two well-trained people one and one-half to two hours or more to accomplish this. It would be impossible to do this with just one evaluator. A knowledgeable, professional service coordinator makes an incredible difference in this process.

However my strongest plea is for those children with moderate to severe diagnoses whose parents are unable to find affordable child care when they must work. We are all aware that child care is often not what it should be. Many programs are fearful of caring for these children; parents are rightfully fearful of placing their child in many programs. The least trained child care staff are usually with the very youngest children as if keeping them safe, clean and fed is sufficient. It is difficult to provide services in programs when the caregivers are unable to spend time to listen or learn about the child. They are truly too distracted. An hour or two a week with a therapist or educator does not help an infant or toddler unless the families and caregivers are able to integrate this information in the child's day.

I'd like to tell you about three of these children that I have worked with this past year.

Ikey is a child with pervasive developmental delay. He has few words and, at two, functioned more like a fifteen month old. He was placed in a nice facility but in a classroom with the other two year olds. There were kindergarten-type materials in the class but few toys. The children sat at tables or in a circle while Ikey typically lay on the floor or ran wildly around the room. I could not work in his room because my materials were too attractive to the other children. I couldn't bring toys for the other children because the children would fight over them. Ikey received three hours a week of EI services from three different but frustrated staff. The child care staff cared about Ikey but were equally frustrated.. What he needed was a small group at his level with trained staff. He had to wait until he was three years old.

If we truly believe early intervention is effective, we need plan better for the most vulnerable of our children.

Kelly's MDE occurred when she was seven months old. Her mother, a teacher, asked if she was autistic. In time, it became quite clear that she was. Our Penn team worked with Kelly and her family for two and one-half years. Her father took a night job since there was no child care program available to provide the care she needed. He was always tired, fighting sleep until she napped, which was never predictable. She did make progress, but has made much more progress since entering a center-based EI program.

If we really believed in the effectiveness of early intervention, she wouldn't have had to wait all that time.

Ally has moderate cerebral palsy. She has been receiving EI services since she was four months old. Her mother quit her job as a legal secretary to go on welfare to take care of her. When she was two, she found a good day care, and then negotiated a job as an aide there in order to oversee her care and provide training to the staff. Ally turned three and is now in an Easter Seal's program for part of the week where a coordinated team can help her more intensively. She and her mother should not have had to wait that long.

Most EI children do well at home or in good-enough programs. Older children in child care usually have more competent staff, and the children are not as distracted by visitors in the room. It is usually possible to include several children in the child's intervention. This is not true of younger children. There is a small percentage of our youngest children who need small groups and experienced staff. It is important that we also plan for them, because we really do believe that early intervention works.

Thank you.

Patricia McCole
7411 Brockton Rd.
Phila., Pa. 19151

Original: 2122

Testimony

Early Intervention Proposed Rulemaking

October 2, 2000

Good afternoon. My name is Rosemary Karabinos and I am the director of Children Services at Special People In Northeast, in Philadelphia. Thank you for this opportunity to present testimony on the proposed DPW early intervention regulations.

I would first like to address the position of "early interventionist." It is unclear as to whether the early interventionist is the person we now refer to as a special instructor. If special instructor is a different position, then qualifications for this position have not been addressed. Given the responsibilities of the early interventionist, as indicated in the proposed regulations, and my assumption that the person in this position assumes the role of early intervention teacher or special instructor, then I believe that the qualifications are too low. I recommend that this position be clarified and that the minimum qualification be a bachelors degree in a field related to child development.

I also recommend, given the responsibilities of the service coordinator, that the minimum qualification for this position be a bachelor's degree in a field related to human services or child development.

Concerning annual training, I commend the department for its emphasis on training in order to have qualified, competent staff, however I have some concerns and a recommendation. The proposed regulations indicate an annual training requirement of 24 hours for all personnel who work directly with children. This appears to be in addition to annual training and re-certification in fire safety, emergency evacuation, first aid, and CPR. There is also a requirement of six credits hours, which one must assume are college credits, for the early interventionist. This seems to be excessive and expensive, especially in a unit cost reimbursement system where we need to maximize our direct service time. I recommend annual training of 24 hours, which would include the health and safety training items. Concerning the six credit hours for the early interventionist, I think they should be dropped. Unless the department is insistent on allowing non-degreed early interventionists to be hired, then a requirement for these people to obtain six college credits a year, until they graduate, would be reasonable, but not for all early interventionists to get six credit hours per year indefinitely.

Concerning initial screenings on children - if a child is determined to be not eligible for service based on a screening, it is my recommendation that parents be told that they have a right to a full evaluation if they are not comfortable with the results of the screening. Especially since the screening does not necessarily need to be a face to face encounter.

Concerning MDE's, I recommend that the MDE team have at least two professionals from different disciplines in addition to the service coordinator, and of course the parents. I do not believe that a service coordinator, who may have only 60 college credits that are not necessarily, even in a field related to child development, can be considered a "professional" on the team. And how can the MDE be considered "multi-disciplinary" with only one discipline represented on the team?

Concerning the IFSP, I recommend that the projected date for initiation of services say "as soon as possible after the IFSP, but not more than 14 days." With the shortage of staff and other pressures that early intervention providers have, "as soon as possible" could be a very long time, especially to the parents of an infant who needs intervention.

In the next area that I will address my opinion has changed just within the past month due to a personal experience. It concerns the provision of services before evaluation and assessment are completed. I would like to

see this section kept as it is written. My sister has four-month-old twins, one of whom was recently referred for early intervention in Bucks County due to the diagnosis of a physical disability. My sister received a visit from a service coordinator the day after her initial phone call, and because the baby has a physical condition that implied presumptive eligibility, services began before an evaluation was completed. This timeliness of service implementation is critical to help relieve anxiety in the parents and to assure the most positive outcomes. In my niece's case, early and consistent intervention can prevent the need for complicated surgery down the road.

My last suggestion is that the requirement of a child abuse clearance on all staff having contact with children be added, in addition to the criminal history check.

Thank you again for the opportunity to testify. I look forward to seeing that some of the recommendations presented today are incorporated into the final version of the regulations.

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My last suggestion is that the requirement of a child abuse clearance on all staff having contact with children be added, in addition to the criminal history check.

Thank you again for the opportunity to testify. I look forward to seeing that some of the recommendations presented today are incorporated into the final version of the regulations.

Original: 2122

Proposed Rule Making
Department of Public Welfare
Early Intervention Services - Chapter 4226

Parent Testimony - Philadelphia, 10/2/00

My name is Susan Davis. My daughter, Sara Jean Davis, was born on June 5, 1998 with Down Syndrome. We live in Montgomery County and Sara has been receiving early intervention services, first through MARC and now through UCP, since she was 3 months old. I am pleased to say that Sara is doing extremely well, and has benefitted greatly from the early intervention services she has received.

We have all read how critical the development of the brain is from birth to age three, setting up "connections" and patterns that will be with the individual their entire lifetime. It is just impossible to overestimate the value of building good strong foundations in all areas of development during this period. Sara is currently receiving speech-language therapy, occupational therapy, physical therapy, and special instruction. I participate in Sara's therapy as much as possible, and eagerly read each contact report. Since I also hold a full-time job, I usually go to two sessions a week, rotating among the various services. I have learned so much from Sara's therapists, and have continued to work on these exercises and developmental activities at home. I am disturbed by the minimum qualification standards for an "early interventionist" being set at a two-year degree with 3 years experience. I don't feel that two years is enough educational background to entrust a therapist with the development of my child. I personally have a four-year degree in accounting, and I learned so much more in the third and fourth year about the particular subject matter, that it is much more than "double" the educational value.

Sara's therapists all have 4-year degrees. Additionally, of her four therapists, 2 have completed masters programs and 1 is in pursuit of her Masters in Early Childhood Education. It is obvious when they work with Sara and in their comments about her growth and development that they are experts in their field, and additionally have a background that allows them to focus on the total child, and not just their own area of expertise.

I would like to see the minimum requirements replaced by a 4-year degree and 6-12 months of supervised work. While I understand that there may be a shortage of qualified early interventionists in certain less populated areas, I believe that these areas could be handled on an exception basis, rather than lowering the standards for the entire state.

Regarding IFSP's, we have had a full meeting at the six-month mark, as well as annually. All of Sara's therapists were in attendance, if possible. All of her therapists conducted an evaluation in preparation for the meeting. I believe that this is a critical step in

evaluating whether the plan is appropriate, or needs modification. A lot can happen in six months. Additionally, we were surprised, including her therapist to some degree, in one area that Sara had not scored a little higher, since she seemed to have made so much progress. While she had reached all of her goals during the last six months, we forgot that she started out pretty far behind her age group. This did have an impact on the level of service that was recommended for the next six month period.

4226.72 states that the six-month review may be carried out by a meeting or "another means", and that it would include "the degree to which progress toward achieving the outcomes is being made, and whether modification or revision of the outcomes or services is necessary." I would suggest that evaluations should be conducted as part of the six month review as well. It certainly made a difference in Sara's case. We really only have one chance to get it right. There is so little time to make such a big difference!

Additionally, I think services should be provided within 14 days of the development of the IFSP or interim review.

Transition from early intervention services - 4226.74 (9)(i)(B) states "Review the child's program options for the period from the child's 23rd birthday through the remainder of the school year. Does this mean from when the child is 23 *months* old? Additionally, while this is unclear, I believe that there should be some flexibility with respect to the exact dates that the child could transition, given that many preschool programs operate on a September-June or September-December time frame, which may not coincide with the child's birthday.

Finally, I am unclear with respect to certain provisions in the financial management section. What is meant by "private funding sources" in Section 4226.14 "Written documentation that all other private and public funding sources available to the child and family have been accessed and exhausted..." I certainly hope that Pennsylvania is not taking early intervention to a need-based program financially. Typically middle class children will suffer under a financial need-based program. I would certainly like to see that all children in Pennsylvania who require early intervention services receive them, regardless of socio-economic status. I could not afford to pay privately for all of Sara's therapy services in addition to the $500 a month I pay for day care. While it is a little early to tell, I certainly expect that Sara will be able to be a productive member of the community, hold a job and live semi-independently. I truly belive that resources spent in early intervention will pay dividends many times over as the child matures and becomes an adult.

Thank you for giving me the opportunity to speak before you.

Submitted by: Susan S. Davis
533 Bridle Rd
Glenside, PA 19038

Original: 2122

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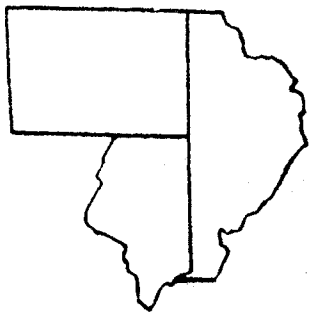

Lackawanna • Susquehanna • Wayne Counties

EARLY INTERVENTION INTERAGENCY COORDINATING COUNCIL

ADMINISTRATOR'S OFFICE
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October 2, 2000

Mel Knowlton
Office of M.R.
PO Box 2675
Harrisburg, Pa 17105-2675

Dear Mr. Knowlton,

Our local Early Intervention Interagency Coordinating Council recently met to discuss the proposed regulations for P.A.'s program for infants and toddlers (birth to age three). As a council, we would like to make the following comments or questions:

4226.37 Service Coordinators will need training in Infant CPR, First Aid, Emergency Evacuation and Fire Safely. How will these training's be made available and what is the reason for the requirement?

4226.56 The requirement for an early interventionist to have one year work or volunteer experience will present a problem in this geographical area given that it is already difficult to find early interventionists with the present requirements.

Regarding the six additional credit hours - does this mean college credits or continuing education credits?

4226.91 The Procedural Safeguards regarding the conflict resolution and mediation system are very confusing and should be clarified.

Thank you.

Sincerely,

Cindy Gillotti

Cindy Gillotti, M.A.
EI Co-Chair

child link

Original: 2122

October 2, 2000

Department of Public Welfare
Attn: Mr. Mel Knowlton
P.O. Box
Harrisburg, PA 17105-2975

Dear Mr. Knowlton:

Attached are the written comments from Erie County's Local Interagency Council, Child Link, regarding the draft regulations for Early Intervention.

We would like to thank the Department of Public Welfare for their part in extending the comment period, in order for us to obtain feedback from all interested parties.

Sincerely,

Ms. Mary Burrows

Ms. Mary Burrows
Parent Co-Chair Child Link

Matt Mandic

Mr. Matt Mandic
Professional Co-Chair Child Link

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Erie County Local Interagency Coordinating Council
Child Link

Comments of Early Intervention Regulations

RE: 4226.25-4226.28 Initial Screening

The definition as stated is unclear, wording should reflect the process of Initial Screening.

RE: 4226.26 Purpose of Initial Screening

Draft wording of purpose may lead people to believe that the service coordinator can "screen out" children from receiving a MDE. Rather it is a process to help the coordinator and family determine if further evaluation is necessary, and if so, who should be involved.

RE: 4226.37 Annual Training

As stated in draft, the wording "24 hours of training annually" seems vague, additional clarification should be provided.

RE: 4226.55 Early Interventionist

It is unclear what discipline or role this professional is. The roles and services previously included in early intervention bulletins offer comprehensive early intervention, therefore should this professional be added?

RE: Content of IFSP

Regarding dates; durations of services - the wording that initiation of services should be "as soon as possible after the IFSP meetings" could lead to varied interpretation of what as soon as possible. Perhaps a stated time frame or within a range of time should be included to eliminate ambiguity.

Original: 2122

Testimony
October 2, 2000

I would like to offer the following comments in response to the directive that the IFSP is not to be interrupted. There are certain elements within this generalized statement which I feel need further clarification. As a legal document, I realize that the services agreed upon, with set frequencies and duration, and thus verified through signature, are entered upon in good faith by all team participants.

At times, nonetheless, events do occur which threaten to temporarily interrupt these services. Currently, within our agency, if therapists must cancel an appointment with a family, because of a scheduling conflict, it is the responsibility of the therapist to coordinate time with the family to make up this service within the current month if at all possible. Likewise if a provider of services is ill, I believe make-up sessions should be scheduled within a timely manner.

My concern is for the following reasons for an occasional interruption:

The first instance being when the **family** cancels due to child or family illness or a commitment conflict, and attempts to make up services within that week is not possible; or even more significant, when a therapist or developmental specialist arrives to a home and no one is there during scheduled times.

Secondly, the times of vacation by the family. It is certainly the rights of the families to take vacations, as it is for our therapists. On this topic I would like to add that accrued vacation time is a legal right which full time employees have, and one should not be penalized for exercising this right. If provider employees are being paid for vacation hours taken, and then are asked to work overtime to make up missed therapy hours, should they not get paid for the overtime required after the vacation?

It is not reasonable either to assume that every unexpected cancellation will be addressed through addendum of services. With this recommendation, many common interruptions would be missed. The idea of having substitutes provide services as the remedy to guaranteeing continuation of the IFSP, has been proposed as a solution. As previously a developmental specialist, and now Program Supervisor, I am of the opinion that the rapport established between children, family members and therapists is unique and cannot easily be met by those unfamiliar with the child in question, no matter how skilled a professional. I fear that the substitute's time spent in the home would be counterproductive to the child's progress and to the IFSP purpose overall. It seems unnecessary to me to waste valuable therapy and family time for the sake of an occasional missed week, especially if the family has no problem with it.

My suggestion is to make clear in the final policies that if services are interrupted by family circumstances, attempts in good faith should be made to make up services where possible, but that this is not a legally binding directive. Interruptions by provider agency personnel (excluding vacations) should be made up at the request of the family. Please consider that the majority of families served are actively involved in the development of

their children and are capable of follow through in general, and in particular, on the occasion of missed sessions. As we continue to strive to promote what EI services are meant to be---the support of family efforts to care for their child--- let us consider the importance of the open relationship among family and other team members, and serve in a manner which is less dependent on rigid compliance at all cost, and more concerned about the comfort level of the families and children served.

Thank you for this consideration.

Submitted by,

Denise Braun

Denise Braun
Program Supervisor, BARC Early Intervention 0-3 Services

Testimony regarding the proposed DPW regulations—Infants and Toddlers with Disabilities Regulations

Given by: Donna Avolio, Director of Early Intervention, Pennsylvania School for the Deaf, Philadelphia, Pa.

I am here to discuss five proposed regulations that are part of the DPW regulations for infants and toddlers with disabilities . This would include Requirements and Qualifications of early interventionists, Initial MDE evaluations, Annual training, Transition at age three and Natural environments.

In the Requirements and qualifications section the minimal requirement of an associate degree is unacceptable. It appears that the law is vague when describing the necessary credentials and experience required for an "Early Interventionist". The very term "Early Interventionist" needs to be discussed to determine if it is a correct term to use .The proposed regulations do not appear to require that there has been coursework or practical experience with very young children with disabilities. It mentions experience with "children, families or people with disabilities". This is too broad and would allow someone with no experience with young children to be working directly with children and parents. In the field of education for young children with hearing loss, a low incidence disability, the recommended level of degree is a Masters with the acceptance of a bachelor's degree within the field if the undergraduate work was in deaf education and if the person is intending to continuing coursework towards a Master degree. There is a significant responsibility when providing young children and their families' quality early intervention service. Parents and children deserve a professional who has the knowledge and experience to respond to the children and their parents' needs. Initial identification and realization that a child has a disability is a critical point in the child's life. Parents need to have qualified professionals assist and support them. These professionals provide information that will help parents make critical decisions which will affect their child's development It is recommended that the base level of requirements is a bachelor's degree and one year of work with children with disabilities. Or at a minimum, a bachelor's degree only if the coursework is in teaching or the education of young children, parent infant education or in counseling.

In terms of the MDE, this provision requires an evaluation by someone other than a provider in all cases. It is true that it could be a conflict to have a provider in an evaluation if the fear is that the child may be determined to need only those services that the provider has. However, it has been my experience that there are MDE's that occur for children with a hearing loss, that do not address the fact that the child has a hearing loss. In fact there may only a brief statement that there is a suspected loss and in some cases it is not even mentioned. This occurs because no one on the evaluation team has experience or understanding of children with hearing loss and it's affect on the child's overall development, especially the area of communication which significantly impacts cognitive and social/emotional development as well.. If a provider of the service that the child may need cannot be included, then a qualified person, preferably a teacher of the hearing impaired or a speech therapist who works with children with hearing loss, needs

to be a part of the evaluation team. I believe that this would be difficult in a region of the state where it would be difficult to find a qualified person who is not also connected with a possible provider. In this case there should be an exception as long as there is another professional in the evaluation that is not from the same agency.

In terms of annual training, 24 hours per year of training seems to be directed at making up for what the person who is considered to be the "Early Interventionist" may not have. These weaknesses may be due to the initial lack of more specific training and experience that is not required in order to be in that position. If the professional is licensed and or certified in the discipline that he or she is providing then the 24 hours could be more focused and better used. It is true that all areas of training mentioned should be included in the training that an interventionist participates in one year. However 24 hours may not be necessary and may be burdensome if trying to provide timely consistent service to families. Training in CPR, fire safety and first aid should be required and documented but after those hours it should be required that 18 hours focusing on topics such as those mentioned in the regulations, especially procedural safeguards, policies and procedures and best practices in early intervention be required. In addition it is unclear whether the training is inservice, college training or CEU's. This should be outlined within this section of the regulations.

In the regulations covering transition. It is unclear what is acceptable in the regulations. For example, in a situation where a child may need to be in a preschool program some time before his or her third birthday the regulations are unclear. In cases where the IFSP outcomes and intervention plans developed by the IFSP team indicate and document that a preschool program would be the location that a child requires in order to achieve specific outcomes on the IFSP, would this be allowed? The regulations would need to specify under what conditions this would be allowed if at all. The criteria may require that a child be at least 2.6 years old. It should require that it has been specifically determined by all IFSP team members that the child can only achieve specific outcomes in this setting and why this location is appropriate even before the child is three. At this time the regulations regarding transition, give no guidance for these situations.
In addition, I believe that the regulations need to specify that the "legal entity" providing early intervention programs and the LEA be required to have certain persons included in the meeting to develop the transition plan. This would include the LEA representative, the parent, the service coordinator(0-3) and at least one person from the IFSP team (besides the parent). This is not currently specified.

Lastly, in discussion of how natural environments be addressed in the total provision of early intervention services, I wish to make specific comment. I have had first hand experience in situations where this part of the regulations has been misinterpreted when discussing outcomes for children with hearing loss. I have also heard from educators and parents with children who have low incidence disabilities, such as vision impairment in regards to how this part of the regulations are being interpreted. Although, I firmly believe in a family centered approach to the provision of early intervention services, it is sometimes indicated through the IFSP process that there is a need for the combination of

locations in which services are to be delivered. This is necessary due to the location's impact on the child's ability to achieve specific outcomes.

In trying to decipher the true intent of the law in describing the natural environment and how it is applied, I referred back to reading of the regulations that appeared to emphasize the IFSP process, the development of the plan and decisions made by the IFSP participants in determining if the outcomes could be achieved in a child's natural environment.

The basic theme inherent in the Part C regulations clearly puts emphasis on making individualized decisions based on the child's needs as identified in the IFSP process. The regulations do state "to the maximum extent appropriate" early intervention services are provided in the home, or in community settings in which children without disabilities participate. The word *appropriate* is key here. In the Federal Register dated September 5, 2000 (Volume 65, Number 172) the following is stated, "it appears that natural environments is being interpreted by some to mean that, without exception, early intervention services must be provided only in a child's home or community setting in which children without disabilities participate. Clearly, this limitation is not intended under the statue or these regulations."

I agree that the regulations must adequately address the misinterpretation of the understanding of natural environments by clarification in writing. As indicated in the Federal Register dated 9/30/00, I agree with the proposed changes to the writing of the regulations regarding natural environments, to make clear that the process of the IFSP determines the location and justification of the location for each service that a child needs that is not in a recognized "natural environment". I agree that a revised definition of "natural environments" in the regulations occur. It is clearly stated in the Federal Register that "the definition of the IFSP highlight the crucial role the IFSP team (including the parents) plays in implementing the natural environments provisions, but does so without imposing additional burden on the IFSP team."

Changes in the description of the IFSP will identify the responsibility of the IFSP team in determining and justifying service that will not occur in a recognized "natural environment".

The discussion of the proposed clarification and changes in how the regulations regarding natural environments will be written, as reported in the Federal Register, is extensive and thorough. I agree with the proposed clarification and in my opinion feel it is necessary due to the way natural environments is being interpreted at the present time.

Thank you for your time and consideration of this testimony.

Original: 2122

81

361 Colonial Crest Dr.
Lancaster, PA 17601

September 23, 2000

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

Dear Mr. Knowlton:

I have recently reviewed the proposed regulations for Early Intervention Services (55 PA Code CHS. 4225 & 4226) as drafted by the Department of Public Welfare. In light of these propositions, I would like to submit the following for consideration.

1) The term "Early Interventionist" is listed in Section 4226.5 Definitions, section (L), and appears in many subsequent sections of this document. This is a new term which has not been previously defined, and is not found in any classification indexes. In order to ensure that an "Early Interventionist" position is filled properly with a person genuinely qualified to meet the needs of those receiving services, this term must be better defined. This term is again found in Section 4226.36 Pre-service Training. Again, this is an undefined category of professional that is not recognized by any authority of education at this time. One's necessary skills and responsibilities are not formally listed in any document. In Sections 4226.55 Early Interventionist and 4226.56 Requirements and qualifications, an Early Interventionist is described very similarly to a service coordinator. If different than a service coordinator, what specifically is this person responsible for in implementing the IFSP? Is this person in any way distinct from other early intervention personnel? I must reiterate that this term should be either deleted, due to its ambiguity, or much more clearly defined.

2) Section 4226.62 MDE, Paragraph (2), states that an initial MDE must be conducted by personnel independent of service provision. The extent of this statement is unclear. For instance, is an examiner who provides the initial evaluation of a child for the MDE prohibited from providing direct service through another organization? Does it also mean that, if this examiner is employed by another organization, this organization as a whole can not be included as a provider of services to this child? This statement must be more clearly expressed so as to leave no room for misinterpretation by those administering the early intervention program.

3) Section 4226.32 Contacting Families, states that families must be contacted at least every 4 months while a child is within the tracking system. This sections should include guidelines of documentation requirements of these contacts. I have personally heard from several families for whom I provide services that are concerned because they are not contacted in any way by their service coordinator, with the exception of the Annual IFSP and 6-month Reviews. In order to truly meet the needs of these families, requirements for the documentation of follow-up contacts would greatly increase the probability that these contacts would actually occur.

I would like to express my gratitude to the you and your Department for allowing me this opportunity to provide my input and concerns regarding this document, which greatly impacts the children and families with whom I am privileged to work.

Sincerely,

Lori M. Martin, OTR/L

Original: 2122

September 22, 2000

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

RE: Public Hearings on Birth to Three Early Intervention Regulations on October 2, 2000

Dear Mr. Knowlton:

I will not be able to attend the public hearings on October 2,2000 regarding Early Intervention Regulations. However, I would like to make some comments, suggestions, and ask some questions to your itinerary:

College degrees for staff - I think college degrees should be encouraged, if not, definitely early childhood courses in intervention should be mandatory for staff.

Deadlines for services to start for children - I think the child should not be too old, so that learning new skills/behavior could me molded more easily.

Complete evaluations for referrals - Absolutely! Unless there is certainty that the child does/does not need a complete evaluation.

Specific Process for transition - Yes, I think there should be a specific process for transition to programs for children ages three to five; but this should not be "written in stone". Every child is different and may require more or less than another child at each transition phase.

Annual training for staff – Of course there should be annual training. Every day the medical world is advancing in technology. Scientists are finding different genes, which cause different ailments; and possibly the prevention/cure for these abnormalities will require additional training to the current training.

KEY ISSUES

Lowering qualifications for personnel - Nationwide every institution/corporation is lowering or re-directing duties, positions, and qualifications of their personnel. If this "lowering" does not impede or stagnate the progress of the child ...maybe it would be ok.

Lack of timelines - I think timelines should be within a reasonable period according to the child's condition.

Unclear transition process - I think everything should be clear regarding our beautiful children.

I also think that childcare intervention workers should be advocates for the children they serve. If they see what could possibly be a medical problem with the child, although they treat them psychologically, I think they should directly contact the child's physician and discuss the matter and stay on top of the issue until it is resolved, even if the physician does not agree with the intervention worker. The physician sees the child approximately every three months for about 15-30 minutes as opposed to the intervention worker seeing the child on a weekly basis from 30-45 minutes.

Case in point, we noticed that my grandson began hitting his head in a fit of anger after he fell off his bed when he was about 15 months old. He would hit his head so hard that he would bust his lip, and bruise his eye or face. It would seem to me that an MRI or the like should have been administered to rule out hematoma, etc. Sometimes he exhibits this behavior in front of his intervention worker or becomes very aggressive and combative. Yet still, these symptoms are considered "The terrible twos". We were told he had small capillaries, and the remedy was to give him more vegetables, which he does not like. The head banging has slowed down a bit, but the aggressive behavior has increased so much that his mother is yelling and spanking him too much because she becomes frustrated at him. Could it be possible that due to his small capillaries, he is not getting enough oxygen to his brain? He is very strong for two years old and has literally hurt people by hitting them with his hands or throwing objects at them.

As the grandmother, I'm getting deaf ears from the intervention worker, my daughter, and the physician. What is my next recourse Mr. Knowlton, to wait until he begins pre-school and be told that he needs that POISON Retlin? What is the intervention workers responsibility to the child! I know they are not physicians, but a blind person can see that this type of behavior is not going to gradually vanish with time. Something medically/psychologically is wrong and the tests I previously mentioned should not be ruled out.

Thank you for your time Mr. Knowlton. Please present this letter to the meeting. I will be looking forward to hearing from you shortly.

Sincerely,

Doreen Waller

Doreen Waller
1838 S. Cecil Street
Philadelphia, PA 19143
(H) 215-729-0433
(W) 215-7272161

Original: 2122

HEATHER S. GERLACH

305 East Hudson Ave.
Altoona, PA 16602
814-942-5762
LadyDarkKnite@cs.com

September 19, 2000

Dear Sir or Madam,

Hello, my name is Heather and I am writing in regard to the suggested changes proposed by the Pennsylvania State legislation concerning Early Intervention.

I would like to start by telling you a little bit about my son, Byron. He was born on December 25, 1998, three and a half months premature. Byron weighed two pounds one ounce at birth and dropped down to one pound fourteen ounces shortly thereafter. He was fed through a tube and kept alive by oxygen tubes connected to his nose. Approximately one week after his birth, he suffered from a brain and lung hemorrhage. This left him with part of his brain unable to function. He remained in the hospital until April 6, 1999. When Byron finally came home, he was attached to a lung monitor that would beep to let his father or I know if his heart rate became erratic (too slow or too fast). He was taken off this machine when he was around six months old. This past March, Byron underwent shunt surgery to help with his Hydrocephalus. Byron is now 20 months old and progressing well, although he is still behind most children in his age group. He has just recently begun to pull himself up to standing and he knows about 10 words.

The progress that Byron has made, in a great part, is due to his Early Intervention therapist and teacher. They visit him and show me different techniques to use to help him learn. They are wonderful people who are well qualified to help children with disabilities. They understand parent's concerns and they know how to help.

Some of my concerns about the proposed legislation are as follows:

(1) If the qualified personnel that now visit with the families of Early Intervention participants are replaced with volunteers (or other untrained personnel), will they know how to help our children? I worry that since there are many different disabilities, that untrained personnel will not understand the effects of those disabilities. I'm also concerned with the problems that volunteers might bring, such as how much time they will be able to devote to the children. Will these volunteers need to set up visits around their schedules (work, social occasions, etc.) and if so, where does the convenience for the families end up? Will different volunteers visit the child every week? If so, how will they learn the temperament, personality, and problems the child is facing? And will the volunteers put their hearts into their work, or will they volunteer simply to look good on a college or work resume? The teachers and therapists that are involved with Early Intervention at the present time are skilled and qualified personnel that know about the disabilities of special needs children. They understand the challenges the family's face. They are caring individuals who chose this field as a way to help others. They schedule appointments that meet the needs of a busy family. The same specialists visit the child so they understand about the child's personality and what they need to focus on in order to help that child learn.

(2) If the IFSP is written and it is not reviewed for two years, I feel that this will lead to problems.

Children develop at a much faster pace and within two years, the child will be well beyond the goals proposed in the original IFSP. For instance, one of Byron's goals was to learn how to sit, and within a six-month period of time, he was getting into, as well as getting out of sitting. If I were unable to review his IFSP for another eighteen months, what would his specialist do with him? Since he has already reached his goal? I believe that the system that is set up now for a review is much better than the proposed one because it meets the developmental timeliness of the children in a better manner.

(3) With no set time limit between the set-up of an IFSP and the start of services, children may be waiting for months before the services start. Do we want to keep our children, who need help, waiting?

(4) The screening process, if done by untrained professionals, may exclude children from receiving services that the child may need. If the coordinator is not trained enough to know the different disabilities and how they effect certain developmental stages, how will they know if a child does or does not need services?

(5) Another concern of mine is about children who are only disabled in one area may not receive services. Why should those children be left out? My son is behind in a few areas, however his only major delay is in his gross motor skills. He does not walk yet, at 20 months. So, would his services be taken away and leave him to fend for himself in this area? Maybe not walking until he is 3 or 4, or possibly never at all? Why exclude children who need help, even if it is only in one or two areas of development?

(6) There is no requirement for a written evaluation report. I feel that these reports are important to the families of the children as well as doctors and future specialists the child may see. These reports help families to see exactly what kind of progress their child is making as well as informing future therapists or teachers about where the child is at the present time.

In closing, I would like to say that Byron has come a long way with the help of Early Intervention therapists, teachers, and service coordinators. I feel that the changes being proposed will not only effect the progress of my son, but may harm the future children of Pennsylvania. Children are our future; we need to give them everything we've got. Changing the Early Intervention system, in my view, may be catastrophic to the development and learning of our special needs children. Please, think about what I have written and consider it when voting about this topic. Thank you for your time.

Sincerely,

Heather S. Gerlach
305 East Hudson Ave.
Altoona, PA 16602
814-942-5762

Original: 2122

50

9-17-00

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

Dear Mr. Knowlton,

I am writing about the importance of Early Intervention services that my daughter, Bailey, receives. She was born with Down Syndrome and is now 18 months old. Bailey is currently being seen by a developmentalist, occupational therapist, physical therapist, and speech therapist. They all come to our home and have provided so much guidance and support.

When Bailey was born, we were shocked and worried. We did not have the experience

and specific knowledge to help her with motor skills, verbal output, cognitive development, etc. Our service coordinator immediately explained Early Intervention and arranged for therapy. We have relied on their expertise on several occasions. Bailey's therapists are highly skilled and experienced professionals. We truely value their education and would hope to continue with their outstanding services.

We feel extremely lucky to be a part of Early Intervention and sincerly hope the program continues to employ educated, experienced, caring individuals.

Thank You,

Keri Heaton
11 High Ridge Ct
(412.795.7446) New Kensington PA 15068

Original: 2122

HEATHER S. GERLACH

305 East Hudson Ave.
Altoona, PA 16602
814-942-5762
LadyDarkKnite@cs.com

September 19, 2000

Dear Sir or Madam,

Hello, my name is Heather and I am writing in regard to the suggested changes proposed by the Pennsylvania State legislation concerning Early Intervention.

I would like to start by telling you a little bit about my son, Byron. He was born on December 25, 1998, three and a half months premature. Byron weighed two pounds one ounce at birth and dropped down to one pound fourteen ounces shortly thereafter. He was fed through a tube and kept alive by oxygen tubes connected to his nose. Approximately one week after his birth, he suffered from a brain and lung hemorrhage. This left him with part of his brain unable to function. He remained in the hospital until April 6, 1999. When Byron finally came home, he was attached to a lung monitor that would beep to let his father or I know if his heart rate became erratic (too slow or too fast). He was taken off this machine when he was around six months old. This past March, Byron underwent shunt surgery to help with his Hydrocephalus. Byron is now 20 months old and progressing well, although he is still behind most children in his age group. He has just recently begun to pull himself up to standing and he knows about 10 words.

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Some of my concerns about the proposed legislation are as follows:

(1) If the qualified personnel that now visit with the families of Early Intervention participants are replaced with volunteers (or other untrained personnel), will they know how to help our children? I worry that since there are many different disabilities, that untrained personnel will not understand the effects of those disabilities. I'm also concerned with the problems that volunteers might bring, such as how much time they will be able to devote to the children. Will these volunteers need to set up visits around their schedules (work, social occasions, etc.) and if so, where does the convenience for the families end up? Will different volunteers visit the child every week? If so, how will they learn the temperament, personality, and problems the child is facing? And will the volunteers put their hearts into their work, or will they volunteer simply to look good on a college or work resume? The teachers and therapists that are involved with Early Intervention at the present time are skilled and qualified personnel that know about the disabilities of special needs children. They understand the challenges the family's face. They are caring individuals who chose this field as a way to help others. They schedule appointments that meet the needs of a busy family. The same specialists visit the child so they understand about the child's personality and what they need to focus on in order to help that child learn.

(2) If the IFSP is written and it is not reviewed for two years, I feel that this will lead to problems.

Children develop at a much faster pace and within two years, the child will be well beyond the goals proposed in the original IFSP. For instance, one of Byron's goals was to learn how to sit, and within a six-month period of time, he was getting into, as well as getting out of sitting. If I were unable to review his IFSP for another eighteen months, what would his specialist do with him? Since he has already reached his goal? I believe that the system that is set up now for a review is much better than the proposed one because it meets the developmental timeliness of the children in a better manner.

(3) With no set time limit between the set-up of an IFSP and the start of services, children may be waiting for months before the services start. Do we want to keep our children, who need help, waiting?

(4) The screening process, if done by untrained professionals, may exclude children from receiving services that the child may need. If the coordinator is not trained enough to know the different disabilities and how they effect certain developmental stages, how will they know if a child does or does not need services?

(5) Another concern of mine is about children who are only disabled in one area may not receive services. Why should those children be left out? My son is behind in a few areas, however his only major delay is in his gross motor skills. He does not walk yet, at 20 months. So, would his services be taken away and leave him to fend for himself in this area? Maybe not walking until he is 3 or 4, or possibly never at all? Why exclude children who need help, even if it is only in one or two areas of development?

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In closing, I would like to say that Byron has come a long way with the help of Early Intervention therapists, teachers, and service coordinators. I feel that the changes being proposed will not only effect the progress of my son, but may harm the future children of Pennsylvania. Children are our future; we need to give them everything we've got. Changing the Early Intervention system, in my view, may be catastrophic to the development and learning of our special needs children. Please, think about what I have written and consider it when voting about this topic. Thank you for your time.

Sincerely,

Heather S. Gerlach
305 East Hudson Ave.
Altoona, PA 16602
814-942-5762

48

Original; 2122

September 16, 2000

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

Dear Mr. Knowlton,

Recently I had the chance to review the proposed regulations for the Early Intervention Services as formulated by the Department of Public Welfare. After reviewing the new regulations, I feel as a provider of early intervention service that more definition needs to put towards sections 4226.5, and 4226.55.

My concern is when reading the highlighted sections that there truly is no real definition of what or who an early interventionist can be. I have search under the reference index still to find no true definition. I have serviced children with special needs for nine years now as an occupational therapist. I have been confident in knowing what my role is and how to fulfill it, but the newly introduced term of early interventionist brings confusion to my role. I am requesting that a more defined definition of that person qualifications, duties, and role in EI be outlined in a more concise format.

I truly enjoy my job in providing quality service and care to the pediatric setting. I feel Early Intervention is a gift to parents and their child being served, however, I also believe families deserve to be given the best service they can receive for their child.

Thank you for taking time to read this letter. Any response would be greatly appreciated.

Sincerely,

Angela Rice, COTA/L

Original: 2122
Original 2144

407 Weldon Drive
York, PA 17404

September 15, 2000

Mr. Mel Knowlton
Office of Mental Retardation
P.O.Box 2675
Harrisburg, PA 17101

Re: Proposed changes in State Special Education Services and Programs, and Early Intervention regulations

Dear Mr. Knowlton:

I have been a speech/language pathologist serving youngsters, primarily birth to school age, for 28 years. I have particular expertise in the field of hearing loss. I have been privileged to be employed by two long standing non-profit agencies, who came into existence for the sole purpose of enabling disabled youngsters and their families, well before government mandates concerning services to these children were enacted. In order to be in compliance as regulations currently stand, I have had to decrease the quality of my service to these families. I worry to think what erosion the proposed new standards will cause. Parents of infants in trouble are in crisis. They do not have the luxury of hoping what is recommended to them is in actuality the "best practice" for their child.

In Lancaster County, where I am currently employed, the service coordinators are trained, not educated. They tell parents that any speech therapist is equally capable. All good therapists find a niche in which their expertise is greater than other areas of the field. Therapy domains are too vast for any one person to be expert in all areas. Currently children are assigned to providers not on the basis of therapist skills but on geographical accessibility. (I formerly worked in York County where the service coordinators routinely took an active approach in matching particular therapists to particular families. I continue to receive phone calls from York/Adams SCs asking pertinent information in order to make a good placement.)

Our current contract with MH/MR prohibits the therapist from sharing her expertise with a family without running it by the service coordinator first. This is cumbersome and keeps the therapist from giving information when the family needs to hear it. We are frequently not consulted with regard to frequency and duration of service. This sometimes puts me at odds with my ASHA ethical standards. Duration and frequency can be longer or shorter than necessary. I am the department head at my agency. One of may staff followed proper channels, and requested that the SC discuss reducing duration with the child's mother. The service coordinator then chastised the therapist for not doing the job correctly. She was sure that my staff could not be doing the job right in less time. The government pays for this lack of efficiency.

I have sat in an IFSP meeting where only positive things are said about a child (We are not allowed to report how the child is actually functioning) only to have the SC announce that the child qualifies for waiver funding. The SC was totally unable to explain how anything called a "waiver" could be beneficial to the family. She also couldn't explain how if the child was doing so well, she suddenly had a 50% delay.

Currently SCs are trying to encourage one therapist to be the child's generalist therapist, handling ST, OT, PT, Special Instruction, etc. Most of us, who have been in practice for a while, have vast experience working with other domains, but we are not PTs and OTs. Parents have no idea that they are not receiving adequate service, because they are told that this is "best practice". By the time they figure it out, the child is exiting one funding stream for another set of regulations by another government department. The undefined concept of "early interventionist" scares me to death.

I know excellent speech therapists who don't know diddlysquat about hearing loss because it is a low incidence disability. How could an early interventionist hope to help a family dealing with a deaf baby? The ill conceived independent evaluation team also places a family dealing with a low incidence disability at risk for receiving inadequate or wrong information at a time when they are in crisis and need good information the most. Someone knowledgeable about the particular disorder should evaluate a child. The independent team is usually made up of qualified therapists, who give general information to a family, at a time when the family needs specifics.

Families are also in crisis when they leave the touchy-feely world of the IFSP and have their first intermediate unit MDE. Suddenly, all of those areas of deficit, which could not be mentioned in the only positive reports for MH/MR, are revealed. Parents are frequently shell shocked, and feel betrayed, not by the SC, but by the therapist who was in their home every week, and didn't (was allowed by contract) give them complete information. The child's strengths are paramount in the therapy process, but weakness must to allowed to be identified.

To meet the needs of travel time, we have hired several new staff, frequently right out of training. They have no idea that they will be stranded in homes. Because center-based services have been demonized by EITA, these new clinicians have decreased opportunity to be mentored. It is difficult to provide good consultative and family directed therapy if you have never had the opportunity to acquire a "bag of tricks" by learning from more seasoned mentors.

I highly resent the tone of most EITA "trainings". I always made the family part of therapy – long before the government came up with this "best practice" idea. I never left a parent alone in a lobby, while I stole their child away for therapy. (The lobby was a wonderful, natural place for families having similar needs to share ideas and give each other support, however.)

The proposed changes to early intervention are worrisome because of the apparently purposeful lack of definitions. We currently function at the whim of "Bulletins" that indicates how certain vague parts of the current law are being interpreted. I have worked on both sides of the Susquehanna River. The difference in interpretation between the two counties is unbelievable.

Thank you for the opportunity to share my concerns. I am available for further comment if asked. We assume no reprisals will come to those who voice their concern. My agency already bends to the whim of MH/MR with regard to referrals, no matter how high our quality of service and reputation.

Very truly yours,

Dorlas L. Riley, MS CCC/SLP

Cc: Robert Nyse
Independent Regulatory Review Commission
333 Market Street
Harrisburg, PA 17101

Original; 2122

Sept 15, 2000

Mr Mel Knowlton,
Office of Mental Retardation
PO Box 2675
Harrisburg PA 17105-2675

Dear Mr. Knowlton:

I have reviewed the proposed regulations for EI and have some questions & concerns. I have been proving physical therapy services in Lancaster County for seven years. The families & children that I work with vary with their needs & resources. I provide services for children from birth to age 21 years, although currently my oldest client is 10 years of age.

Under section 4226.5 the term early interventionist is used. The title is not defined. I did read that the minimum standards would be a 2 year degree & 3 years experience. It is stated that an early interventionist could provide direct implementation of a child's IFSP. I was unsure as to what portion of the IFSP this person would be responsible for implementing. My question is what are the duties/responsabilities for this provider?

Regarding the section under evaluation & assessment, I believe it should include at least two professionals. It is very difficult to evaluate a child's fine motor, gross motor, speech & cognitive skills & assess a family's needs with one person in a short period of time. The child & family would not always receive quality service with one professional completing the evaluation.

I enjoy working with & assisting families & children in Lancaster County. I am concerned that we (the providers) may be moving away from providing quality services that truly benefit the children & families.

Sincerely,
Dinisha Kline PT

45

Original: 2122

407 Weldon Drive
York, PA 17404

September 15, 2000

Mr. Mel Knowlton
Office of Mental Retardation
P.O.Box 2675
Harrisburg, PA 17101

Re: Proposed changes in State Special Education Services and Programs, and Early Intervention regulations

Dear Mr. Knowlton:

I have been a speech/language pathologist serving youngsters, primarily birth to school age, for 28 years. I have particular expertise in the field of hearing loss. I have been privileged to be employed by two long standing non-profit agencies, who came into existence for the sole purpose of enabling disabled youngsters and their families, well before government mandates concerning services to these children were enacted. In order to be in compliance as regulations currently stand, I have had to decrease the quality of my service to these families. I worry to think what erosion the proposed new standards will cause. Parents of infants in trouble are in crisis. They do not have the luxury of hoping what is recommended to them is in actuality the "best practice" for their child.

In Lancaster County, where I am currently employed, the service coordinators are trained, not educated. They tell parents that any speech therapist is equally capable. All good therapists find a niche in which their expertise is greater than other areas of the field. Therapy domains are too vast for any one person to be expert in all areas. Currently children are assigned to providers not on the basis of therapist skills but on geographical accessibility. (I formerly worked in York County where the service coordinators routinely took an active approach in matching particular therapists to particular families. I continue to receive phone calls from York/Adams SCs asking pertinent information in order to make a good placement.)

Our current contract with MH/MR prohibits the therapist from sharing her expertise with a family without running it by the service coordinator first. This is cumbersome and keeps the therapist from giving information when the family needs to hear it. We are frequently not consulted with regard to frequency and duration of service. This sometimes puts me at odds with my ASHA ethical standards. Duration and frequency can be longer or shorter than necessary. I am the department head at my agency. One of may staff followed proper channels, and requested that the SC discuss reducing duration with the child's mother. The service coordinator then chastised the therapist for not doing the job correctly. She was sure that my staff could not be doing the job right in less time. The government pays for this lack of efficiency.

I have sat in an IFSP meeting where only positive things are said about a child (We are not allowed to report how the child is actually functioning) only to have the SC announce that the child qualifies for waiver funding. The SC was totally unable to explain how anything called a "waiver" could be beneficial to the family. She also couldn't explain how if the child was doing so well, she suddenly had a 50% delay.

Currently SCs are trying to encourage one therapist to be the child's generalist therapist, handling ST, OT, PT, Special Instruction, etc. Most of us, who have been in practice for a while, have vast experience working with other domains, but we are not PTs and OTs. Parents have no idea that they are not receiving adequate service, because they are told that this is "best practice". By the time they figure it out, the child is exiting one funding stream for another set of regulations by another government department. The undefined concept of "early interventionist" scares me to death.

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To meet the needs of travel time, we have hired several new staff, frequently right out of training. They have no idea that they will be stranded in homes. Because center-based services have been demonized by EITA, these new clinicians have decreased opportunity to be mentored. It is difficult to provide good consultative and family directed therapy if you have never had the opportunity to acquire a "bag of tricks" by learning from more seasoned mentors.

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The proposed changes to early intervention are worrisome because of the apparently purposeful lack of definitions. We currently function at the whim of "Bulletins" that indicates how certain vague parts of the current law are being interpreted. I have worked on both sides of the Susquehanna River. The difference in interpretation between the two counties is unbelievable.

Thank you for the opportunity to share my concerns. I am available for further comment if asked. We assume no reprisals will come to those who voice their concern. My agency already bends to the whim of MH/MR with regard to referrals, no matter how high our quality of service and reputation.

Very truly yours,

Dorlas L Riley MS CCC/SLP

Dorlas L. Riley, MS CCC/SLP

Cc: Robert Nyse
Independent Regulatory Review Commission
333 Market Street
Harrisburg, PA 17101

44

Original: 2122

Schreiber Pediatric Rehab Center of Lancaster County

625 Community Way
Lancaster, PA 17603
(717) 393-0425
Fax (717) 392-7107
TDD: (717) 393-1503

A not-for-profit United Way Agency

September 14, 2000

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

Dear Mr. Mel Knowlton,

As a physical therapist, who works with pediatric patients ages 0 to 21 years, I am very concerned with the proposed regulations for Early Intervention Services (55 PA Code CHS. 4225 & 4226) as formulated by the Department of Public Welfare. After reviewing the proposed regulations, Section 4226.5 and Section 4226.55 especially, I would like to submit the following for your consideration.

Section 4226.5 Definitions-Early Interventionist : The "Early Interventionist" title remains an undefined term and is not found in the index section of the proposal. Since this is a relatively new term, it would benefit all involved in the provision of Early Intervention if it were more completely defined.

Section 4226.55 Early Interventionist : This section seems to fit the job description of those who currently are called "Service Coordinators." Because of this fact, is there a way that this "Early Interventionist" title could be deleted or re-defined to specify exactly what portions of the IFSP would be implemented by this person(s).

The non-specific degree requirement for the "Early Interventionist" presents a serious issue and concern. This person would have direct contact with families. The extremely limited knowledge base and limited background of the "Early Interventionists" as defined in your proposal would present a problem when fielding the wealth of questions that parents propose to those involved in the care of their children. The involved child with special needs is a very complicated and delicate subject. Parents of children with special needs deserve an intermediary that is well-versed and well represented in the health care field to serve as a liaison to the many medical professionals involved in the child's total care.

Thank you for the opportunity to express my concern in regards to these regulations that would directly affect the children that I work with on a daily basis.

Sincerely,

Jennifer L. Gorman, MSPT

Jennifer L. Gorman, MSPT
Physical Therapist

51

Original: 2122

Beth P. Shelley, OTR/L
427 West Newport Road
Lititz PA 17543

September 13, 2000

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

Dear Mr. Knowlton:

I am an occupational therapist with 18 years of experience in the field of pediatrics. I have reviewed the proposed changes for early intervention services (Title 55) and have several concerns I would like to address.

The need for early intervention in children has been documented and supported. The effectiveness of intervention is affected by the service provider's knowledge and expertise. The new term "early interventionist" needs to be better defined. A person with an early childhood degree does not have the neurophysiological knowledge that an occupational or physical therapist does. Occupational and physical therapists don't have the knowledge of cognitive skills that teachers do, and so on. Although some broad aspects of development can be taught to an individual, the child receiving services by this individual would definitely not be of the same quality and effectiveness of specialists (occupational therapists, physical therapists, speech and language pathologists, etc.). Considering the importance of early intervention, it would be neglectful to not provide children with the services they would benefit from. Therefore, the role and qualifications of an early interventionist needs to be clearly defined.

Thank you for your consideration of my input regarding these important regulations.

Sincerely,

Beth P. Shelley, OTR/L

Beth P. Shelley, OTR/L

Original: 2122

Schreiber Pediatric Rehab Center of Lancaster County

625 Community Way
Lancaster, PA 17603
(717) 393-0425
Fax (717) 392-7107
TDD: (717) 393-1503

A not-for-profit United Way Agency

September 5, 2000

Robert Nyce
Independent Regulatory Review Commission
333 Market Street
Harrisburg, PA 17101

Dear Mr. Nyce:

I am a licensed Speech-Language Pathologist in Lancaster County specializing in pediatrics. I work for a rehabilitation center that services children birth to twenty-one. Our center has contracts with several institutions that provide service to these youngsters in which the governments proposed regulations will affect dramatically. I have seen and experienced these regulations over the past year and a half and I'm appalled, not only as a professional but also as a taxpayer. As a professional, I'm a strong advocate for my families and most of all my children. These regulations have taken away my power to help insure that these children and families will survive. As a tax- payer, I see the amount of wasted money in Early Intervention and it jeopardizes my ethics and morals everyday. If citizen knew how the regulations and system truly worked, I can guarantee they would stand up and ask the government to explain. My purpose for writing this letter, is to share with you some concerns and experiences that have occurred in which the regulations have not allowed me to service my families and children with appropriate cause. Mr. Nyce, I was raised to respect and honor my good fortunes in which this country allows. I do not respect the fact that my colleagues and I have to work everyday under regulations that hinder our professional opinion and ability to care for those most important to us, families and children.

In Lancaster County, children needing service are funded by Mental Health and Mental Retardation. It is the official's interpretation of the regulations, which frighten me. Over the last year and a half, I have become so frustrated with the system it makes me ill. I have a child on caseload with obvious fine motor and sensory delays that should be receiving Occupational Therapy. When the service coordinator was contacted she set up an evaluation, which revealed my suspicions and a recommendation for Occupational Therapy was made. The service coordinator discussed the situation with mom. I got a

phone call two days later and was told " Mom said it was not a priority and she did not want the service." I stated to the service coordinator that this child's issues are affecting all areas of treatment. Her response, "I must say again, Mom said she did not feel it was a priority." In this new system of Early Intervention, if a parent does not see an area of concern, it is not addressed. Therapists have lost the right to state their clinical opinion. I went to college and received a Master's Degree, Mr. Nyce, and I am angry that if a parent does not see a delayed area as a priority, it is an open and shut case on the part of MH/MR, and I am not allowed to indicate to the families that these delayed skills are affecting their child's progress and must be addressed. I believe in allowing the parent to make decisions but not allowing the therapist to indicate what repercussions will follow is wrong. Beginning services at early ages is much more beneficial to the child and more cost effective than waiting until the parent feels it's a priority and the damage is done. Service Coordinators usually have a Bachelor's Degree in Social Work not in a specific therapy. They are not qualified to help families make clinical decisions or answer questions to specific therapies. I also noted while reading the proposed regulations the term "early interventionist." I realize the bottom line is money and trying to create a profession that can treat all three therapies. This is rather disturbing that the government would want to place the care of child with special needs in the hands of an individual who has less than a Bachelor's Degree. Some of these children are medically fragile. Do you really think these individuals are trained to handle them? I have been handling children clinically for ten years and still find some of my cases challenging. The fact that government is considering this as an option for discussion is sad.

Another concern is the fact that Early Intervention uses the term " Team Approach." The system is not a "Team Approach" when it is the parent and the service coordinator making the decisions about services to receive, environment, and goals at an IFSP. I have gotten several cases where parents have stated that the team was a service coordinator and them. Again, if the child would qualify for 2 services but parents only states one as their priority, the other is not addressed. Mr. Nyce, do you realize the affects on these children if areas are not serviced when recommended? We see children who have multiple disabilities. If their delayed skills are identified early and treated accordingly, the easier it is for them to interact with their environment and become a functional part of society. If therapists are not part of that initial team and allowed to state their clinical opinion, areas of delay go untreated until parents notice that their child is not doing a skill and then when they question the therapist they get upset because the therapist did not say anything. Parents are integral to the Early Intervention system just as much as therapists. I believe that government does not agree. These interpretations of the regulations also limit the environments that we may see children in. In our center, any child that is birth to three is seen home based. Parents are not given their options for service delivery at the time of the initial IFSP. They are told their services are to be done only home-based. Many of my parents have stated that it is an interference of their home activities to have 2-4 therapists coming into their home a week. Parents should be allowed to have a choice, not choices made for them. I have a couple whose child has Pervasive Developmental Disorder and was funded by Early Intervention a year ago. During the time of MH/MR funding, this couple had a difficult time dealing with their son's diagnosis and felt that they were the only family with a child like this. They spent

twenty-four hours a day, seven days a week trying to make sense of their child's tantrums, inability to talk and self-stimulation/self-injurious behaviors. Mom broke down with me one day and said," I can't get away and I have no one to talk to. My family and friends don't understand. They like to give advice but it is not appropriate for a PDD child." I feel that the regulations of requiring natural environment is actually reversed mainstreaming. Three years ago the system allowed children birth to three to come center-based. Parents were able to get out of their homes and meet parents of children with disabilities. These families have enough stress to deal with and not allowing them a choice of where to receive services is absurd.

Mr. Nyce, I feel I am good at what I do. I truly resent the fact that the government is demeaning my skills as a professional, in which I worked six long hard years to obtain my degree and went into debt to the state of Pennsylvania in order to become what I feel I was destined to be, with these proposed regulations. I feel that my families and children will suffer terribly as well. Thank-you for taking the time to read this letter.

Sincerely,

Jodi L. Baker MS CCC/SLP

43

Original: 2122

Schreiber Pediatric Rehab Center of Lancaster County

625 Community Way
Lancaster, PA 17603
(717) 393-0425
Fax (717) 392-7107
TDD: (717) 393-1503

A not-for-profit United Way Agency

September 5, 2000

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

Dear Mr. Knowlton:

I am a licensed Speech-Language Pathologist in Lancaster County specializing in pediatrics. I work for a rehabilitation center that services children birth to twenty-one. Our center has contracts with several institutions that provide service to these youngsters in which the governments proposed regulations will affect dramatically. I have seen and experienced these regulations over the past year and a half and I'm appalled, not only as a professional but also as a taxpayer. As a professional, I'm a strong advocate for my families and most of all my children. These regulations have taken away my power to help insure that these children and families will survive. As a tax- payer, I see the amount of wasted money in Early Intervention and it jeopardizes my ethics and morals everyday. If citizen knew how the regulations and system truly worked, I can guarantee they would stand up and ask the government to explain. My purpose for writing this letter, is to share with you some concerns and experiences that have occurred in which the regulations have not allowed me to service my families and children with appropriate cause. Mr. Knownlton, I was raised to respect and honor my good fortunes in which this country allows. I do not respect the fact that my colleagues and I have to work everyday under regulations that hinder our professional opinion and ability to care for those most important to, families and children.

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twenty-four hours a day, seven days a week trying to make sense of their child's tantrums, inability to talk and self-stimulation/self-injurious behaviors. Mom broke down with me one day and said," I can't get away and I have no one to talk to. My family and friends don't understand. They like to give advice but it is not appropriate for a PDD child." I feel that the regulations of requiring natural environment is actually reversed mainstreaming. Three years ago the system allowed children birth to three to come center-based. Parents were able to get out of their homes and meet parents of children with disabilities. These families have enough stress to deal with and not allowing them a choice of where to receive services is absurd.

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Sincerely,

Jodi L. Baker MS CCC/SLP

Original: 2122

September 4, 2000

78

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

Dear Mr. Knowlton:

I am writing this letter, as a parent of a child with Down Syndrome, to all concerned parties regarding the impending proposed Early Intervention regulations published June 2, 2000.

There are numerous issues that are of immediate and grave concern to me, my daughter, and future generations. It is incomprehensible that there is the possibility of receiving an incomplete evaluation at the outset when these children (and these are human beings we are talking about) are already beginning life behind the eight ball.

Equally as horrifying is the thought that our children will be placed in the hands of totally unqualified and therefore unknowledgeable service coordinators. Aside from the occasional parents who know before hand of their child's diagnosis, you are dealing with shell-shocked parents who don't have all or maybe any idea of what services are available to them. They rely on the professional guidance of their service coordinator to guide them and inform them of all the opportunities for therapy in order to start these children out on the correct foot.

It should be an absolute requirement that each therapist, special education teacher, vision/hearing specialist, day-care teacher and any other professional that has worked with the child, be at the table for any IFSP to hear first-hand the progress and therefore future needs for any child. This is where a child's future is decided! Every piece of information from each professional is vital. This information most definitely needs to be in writing and it should be the authority of the IFSP team (OT, PT, Speech, etc.) to decide the appropriate future services and the correct environment since they have the direct contact under the right circumstances for their sessions with each child.

The timeliness for scheduling and implementation of every IFSP is critical! As every parent knows, time flies, and before one knows it, the child is three and transitioning into the IU. Any services missed, even for a few weeks, could drastically affect any child's progress and future placement in a chronologically appropriate class.

The system, as it presently exists, has enough pitfalls due to high turnover rates of coordinators who have an overabundance of cases, that any other short-changing of qualifications or unduly withholding of services due to untimely implementation of the IFSP, etc. will only disastrously affect each and every child needing these services.

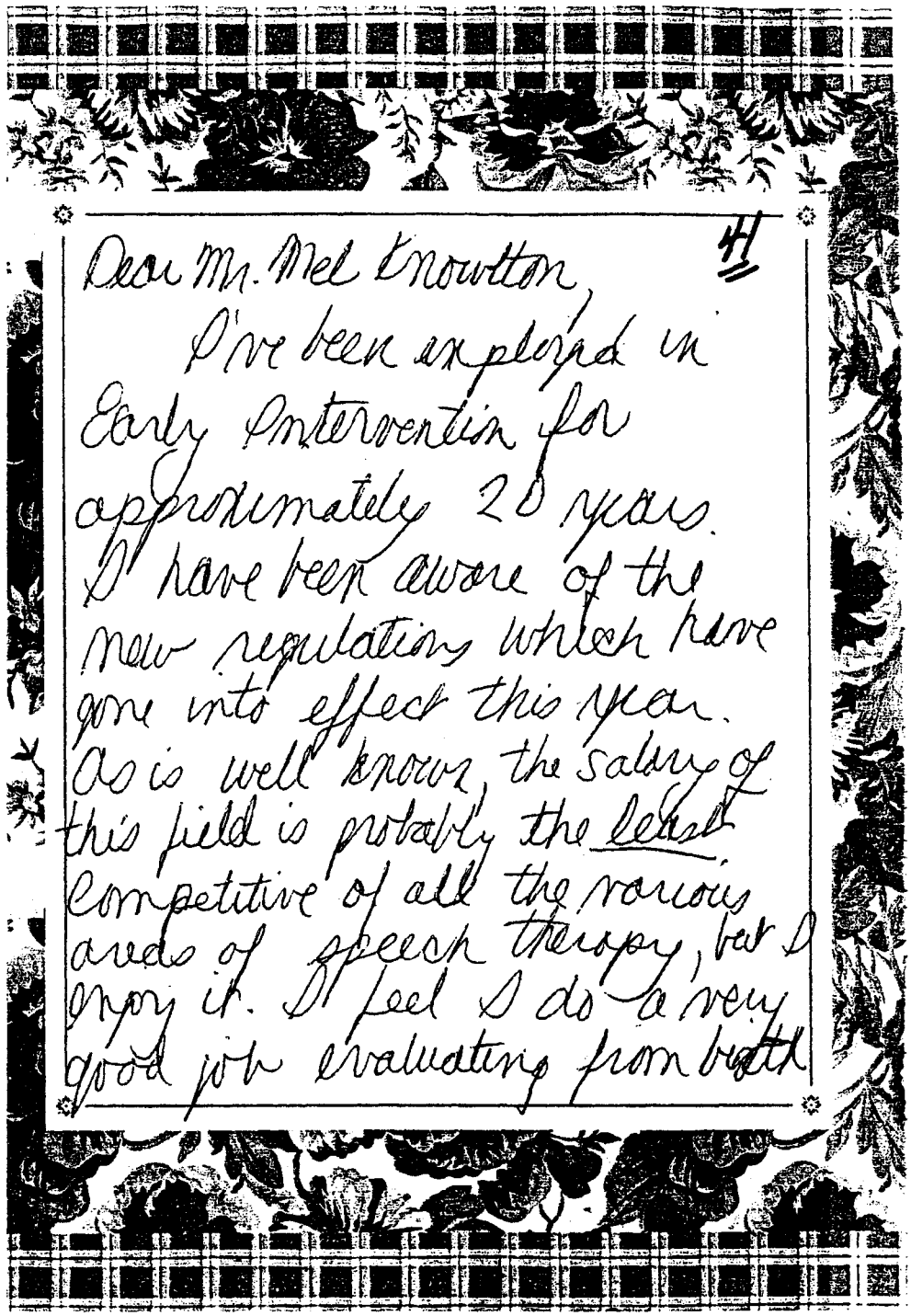
All of these children, and the families providing their care, deserve all the services possible as suggested by the most knowledgeable and professional person possible. Please prevent any further breakdown of a delicate system by not allowing any of these regulations to pass.

Thank you for your consideration.

Sincerely,

Anne L-Wenner

Original: 2122



4/

Dear Mr. Mel Knowlton,

I've been employed in Early Intervention for approximately 20 years. I have been aware of the new regulations which have gone into effect this year. As is well known, the salary of this field is probably the least competitive of all the various areas of speech therapy, but I enjoy it. I feel I do a very good job evaluating from both

to 3, but I recognize there is always room for improvement. Since I am an independent contractor, I would have to go to this mandated training on my own time. I feel that if you want this training to cover everyone, you must be willing to compensate people for their time. I am more than willing to pay for courses that increase my understanding of the various facets of speech therapy. I am not willing to take 24 hours of training when it is mandatory! Because of this, I will be stopping my evaluations of children under 3. Early Intervention has lost an dependable, competent speech therapist who offered a high standard.

Margie Abrem

42

TRI-COUNTY HUMAN SERVICES CENTER, INC.
185 Fallbrook Street
Original: 2122 P.O. Box 514
Carbondale, Pennsylvania 18407-0514

Area Code 570-282-1732—876-4731
Fax - 282-6529

SUSQUEHANNA COUNTY OFFICE
P.O. Box 285
61 Church Street
Montrose, PA 18801-0285
570-278-3393
Fax 570-278-1716

WAYNE COUNTY OFFICE
614 Church Street
Honesdale, PA 18431-1821
570-253-0321
Fax 570-253-5990

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

8/25/00

Dear Mr. Knowlton,

Attached please find comments / questions regarding the proposed Early Intervention regulations. Your consideration and clarification of this information is appreciated.

Sincerely,

Donna P. Gaudenzi, M.S.
M.R. Services Director

COMMENTS ON PROPOSED E.I. SERVICE REGULATIONS
55 PA. CODE CHS. 4225 AND 4226

4226.35 currently no formal Pre-Training requirements/ will a format be developed by OMR?

24 hours for service coordinators in areas of early childhood and health areas: where will this training be made available will there be specific format, content etc.?

4226.37 how will this be made available?
Since Service Coordinators do not provide "hands-on" services, what is the rationale behind training in Infant CPR, First Aid, Emergency Evacuation and Fire Safety? And are the latter 2 in regards to the child's home?

4226.51 Are current personnel grandfathered for Act 33?

42267.5 What is included in Assistive Technology? How is this funded if not covered by insurance, private or other?

Re: Personally Identifiable Information- what is included and where is it listed in the child's record?

What is included in transportation and other related costs?

4226.24 Is this a separate function from Service Coordination and if so, what position is responsible for this?
How are we to know who is NOT receiving services?
Is there a specific referral / child find procedure recommended?

42226.28 Is a letter the only acceptable document?

4226.32 Currently [and there is no additional staff to do this] we do this every 4 months to 24 months and then every 6 months until the child's 3rd birthday. Will additional personnel be provided for this and the child-find process?

4226.36 What is the annual certification referenced here and who is responsible for doing this?

PERSONNEL

4226.51 [5] Who are recommended advocates for these individuals?
[6] What is meant by "coordinating medical services"?

4226.56 Who pays for the annual 6 credit hours for E.Interventionists? How will this affect Provider's ability to recruit personnel?

4226.61 Will OMR be developing a Family Assessment format and provide training its utilization?

4226.62

MDE:
Timeline-
[ii] There has been some indication that interim IFSPs were not recommended. Will there be a form issued by OMR and a way to enter this data to EIRS?

4226.74 A. Frequency and Intensity: clarification on correct way to document this?

What is meant by "group"?

[9] Transition:
[c] doesn't this unduly label a child?
[what is considered a reasonable effort?]
[3] Please clarify how "23rd birthday" is supposed to read.

4226.94 Mediation:
[1] who is qualified to be used in this capacity?

4226.96 What is the definition of an "individual child complaint"
4226.100 by parents?

Original: 2122

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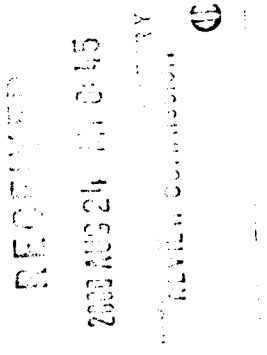
Testimony presented on Early Intervention Regulations

August 21, 2000



Submitted by:

Sharon Mahar Potter,Deputy Director
Pennsylvania Protection and Advocacy, Inc.

Independent Regulatory Review Commission
14th Floor, Harristown 2
333 Market Street
Harrisburg, Pennsylvania 17101

Testimony on Early Intervention Proposed Regulations

Pennsylvania Protection & Advocacy, Inc. is the Federally funded, non-profit agency responsibility for providing protection and advocacy to people with disabilities. Included in this population are our youngest citizens, children under five who are receiving early Intervention services.

Eleven years ago, I was hired as the Early Intervention Project Coordinator. I had the opportunity to work side by side with families, advocates, service providers, staff from Pennsylvania's Department's of Education, the Department of Welfare's Office of Mental Retardation and the State Legislature. Together we learned from each other and put a system together that provided supports and services to children with special needs and their families.

As you know the youngest children in Early Intervention are infants and toddlers. Services available to children and their families fall under the purview of the Department of Welfare. I am not the parent of a child with a 'special need', however I do know that while most families are trying to figure out what they need and where to get that need met. The Early Intervention system is the answer and it should be as simple and accessible as possible. Therein lies the problem and the reason for my comments:

I am pleased that the Department scheduled three Public Hearings, however July and August are absolutely the worst possible months for families. It is the time when most families get away and relax. It is my understanding that the deadline for submitting comments has been extended which does appear to acknowledge the importance of family input.

Under 'Definitions':

A statement reads" "County MH/MR program is defined as an entity that

'provides a continuum of care for the mentally disabled". Aside from political correctiveness, the term is inaccurate since many children who receive early intervention services are mentally alert and their eligibility is based on their physical disability or sensory impairments. "A person with a disability' might be more appropriate.

The definition of "Parent' is of great concern. Although many children in foster care do have involved biological parents, many do not. When a foster parent clearly has a long-term parental relationship, parental rights have been relinquished and there is no conflict of interest - the foster parent should be considered the parent of the child under their care.

Financial management:

Although I believe it is appropriate to use both private and public funds to every extent possible, parents must consent to participate in the Waiver, they cannot be required to apply for Medicaid, and they are not required to use their private insurance. Parents may indeed volunteer to use their private insurance but specific information on the impact of using that insurance is critical. Specifically, is there a deductible or is there a decrease in yearly or lifetime benefits? If the answer to these questions is yes, the future medical care of their child may be compromised.

General Requirements:

There is no reference to a 'Public Awareness program". As I mentioned earlier, a family new to the Early Intervention system is trying to figure out where to go for help. We have a responsibility to them to keep it as simple as possible by distributing clear, concise, culturally diverse information to the general public.

The IFSP,(Individual Family Service Plan), is the most important document a child and family have. It determines what services and supports will be provided, when they will be provided, how often and by whom. It is critical. In the proposed regulations it states: "the IFSP must be developed within 45 days of referral" Does this mean that the child is evaluated within 45 days or does it mean that a child's IFSP is in place and the child can begin receiving services? The proposed regulations may be out of compliance with the Federal regulations when it is suggested that the MDE could be bypassed

altogether in favor of a plan for further assessment and tracking.

Personnel:

The qualifications of the 'Service Coordinator' are of concern. There are individuals in the Early Intervention system who are competent to provide services and it is important that we make efforts to keep those individuals in the system. However, we must guarantee that the qualifications reflect the competencies of the individuals working with our most vulnerable citizens. There should be a specific time period for them to get credentialed and in fact, if this is not done the state may be a violation of the Federal law.

When the Early Intervention program was in it's infancy, we suggested a maximum caseload of 35 children for service coordinators. The proposed regulation do not address this issue.

What exactly is an Early Interventionist? What do they do? Are they supervising, coordinating services or actually providing services? The position and the responsibilities of this position are much too vague. Please clarify.

Evaluation and Assessment:

There are two issues of concern related to the evaluation process. First, it is important for a child to have an independent evaluation. Unfortunately, when an evaluation is done by the same agency that will serve the child, the recommendations could reflect what the agency has to offer rather than what the child needs. Second, if a child needs a particular type of evaluation and no independent evaluator is available the evaluation may fall back on the provider however, one possible solution to this might be using the expertise of the Regional Office in these cases.

The MDE report should be shared with the family before the IFSP meeting is scheduled since the information contained in the MDE is critical to the discussion and decision making at the IFSP. Parents should also be informed that they can bring another person with them to MDE and IFSP meetings.

There is no reference to the Federal law that IFSP's should be reviewed every 6 months. Surely, this is an oversight.

Although the proposed regulations refer to the list of personnel required by federal regulations it does not give anyone the authority to commit county resources which means that a successful IFSP meeting may have occurred but implementation could stopped at a higher level.

The phrase "services must start as soon as possible" isn't specific enough. Every day is critical in the life of an infant or toddler. There needs to be a specific time line in the regulations. We suggest 14 days.

The issue of pendency during transition is addressed in a current Bulletin. It should be included in the regulations as well. It is also important for the child that their program and placement remain the same during transition year unless there are specific programmatic reasons for the change.

Procedural Safeguards:

Most parents have no idea what the Early Intervention system is let alone how to file a complaint, identify time lines, request evaluations, and understand the impact of MDEs, IFSPs, pendency and transition. The state has an obligation under the federal regulations of "widely disseminating to parents and other interested individuals, including parent training centers, protection and advocacy agencies, independent living centers, and other appropriate entities, the State's [complaint management] procedures"

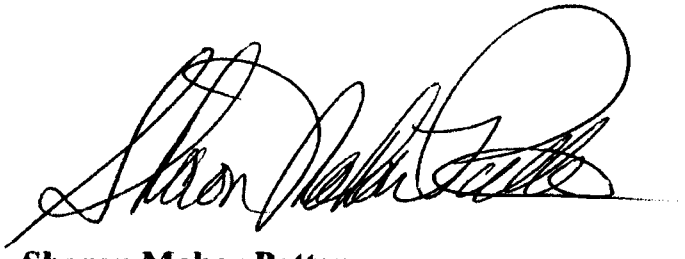
In addition, families should have the right to examine their child's records at no cost, should receive information in a language that is understandable to the public and have the right to use the services of an expert, including an attorney at administrative hearings.

Families come in many forms. For children living in foster families, the foster parent is often the best person to make decisions for that child. In the 1997 Draft there was a statement which I believe should be restored in this final document. It read 'A foster parent is eligible to serve as a surrogate if all requirements for surrogate are met".

These regulations are a long time coming. I commend the work of the Department and the diligence of the parents of infants and toddlers in this system.

Thank you for the opportunity to comment.

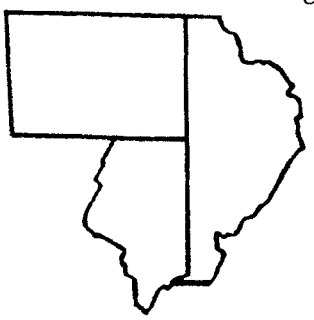
Submitted by :



Sharon Mahar Potter
Deputy Director
Pennsylvania Protection & Advocacy, Inc

40

Original: 2122



Lackawanna • Susquehanna • Wayne Counties

MENTAL HEALTH & MENTAL RETARDATION PROGRAM

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August 17, 2000

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

Re: Early Intervention Regulations

Dear Mel:

This correspondence is written in response to the proposed Early Intervention Regulations published in the Pennsylvania Bulletin. Thank you for the opportunity to share our comments.

We are hopeful that the promulgation of regulations will provide clarity for County Programs in the day to day administration of Early Intervention services. We would suggest that interpretive guidelines, similar to the Inspection Instrument for Community Homes, be developed. These series of questions and explanations add clarity to the interpretation of a specific regulation.

The regulations, as written, incorporate many facets which will enhance the quality of Early Intervention services. Pre-service training, annual training, and personnel requirements, as written, should enhance the skills of personnel. However, these same sections will seriously hamper our ability to provide Early Intervention services. Consideration should be given to the relevancy of the pre-service training for all workers. For example, emergency evacuation is appropriate for staff working in center-based programs, however, I do not understand the relevance of this specific training for a service coordinator.

The requirement for service coordinators and early interventionists to have one year experience will seriously hamper our ability to recruit staff. Requiring one year experience with a bachelor's degree is excessive. In addition, the requirement for credit hours annually for early interventionists will become a fiscal, as well as a staff recruitment problem. Although the intent is honorable, the fiscal impact of these regulations should be measured.

I would suggest that the current Early Intervention rates cannot support the additional costs for training, let alone the increase in salary structure for experienced workers.

We would appreciate clarification for section 4226.62(d2), Timeliness. "For exceptional circumstances that make it impossible to complete the evaluation and assessment" within 45 days, the County must document those situations AND develop an interim IFSP. How can an interim IFSP be developed if we do not yet know if the child is eligible for services?

A smooth transition for toddlers receiving Early Intervention services to pre-school or other appropriate services is utmost in the minds of all stakeholders. I would agree that it is our responsibility to notify the local educational agency that the child will shortly reach the age of eligibility for pre-school services. However, it is the local educational agency which schedules and coordinates these conferences. Often times we cannot influence the timeliness of these meetings.

In the case where a child may not be eligible for pre-school services, it is necessary for service coordinators to coordinate services on behalf of that child, however, the formality of a conference is not necessary.

Again, thank you for the opportunity to comment on these regulations. We look forward to a final product which is reasonable and manageable for all Early Intervention stakeholders.

Sincerely,

Stephen Arnone
Administrator

SA:km

Public Comment 34

Original: 2122

PCCY
Philadelphia Citizens for Children and Youth
Seven Benjamin Franklin Parkway Philadelphia, PA 19103
FAX # (215)-563-9442
(215)-563-5848

August 2, 2000

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

Dear Mr. Knowlton:

PCCY is writing to comment on the proposed regulations for the early intervention program for children under three with developmental delays. We appreciate the opportunity to comment, and have organized our response under the general categories that we, and other advocates, believe are essential to change before these regulations are issued.

Comment Period

We were concerned to learn a number of weeks ago that public hearings on these regulations would be held only during July and August, the prime family vacation months. As these regulations have taken over two years to develop, we are convinced that an extension in the hearing schedule would not unduly prolong the process. It is very important that families and other stakeholders participate in the public debate on this issue; we are deeply concerned that they will be shortchanged because of the scheduling decision made by the Department.

Financial Management

We urge you to clarify that a child's early intervention services should not be delayed in order to secure public or private funding sources, no should services in a child's IFSP be adjusted to reflect available funding sources.

General Requirements and Personnel

We are concerned that the regulations do not include any reference to the federal requirements that there be a public awareness program, in addition to the child find system. Public awareness is essential, as there are many children in the state who might benefit from these services, but whose parents are not aware of them.

With respect to personnel, we note that the service coordinator's proposed qualifications do not include any training in child development, the needs of children with disabilities and their families, or other related subject areas. We support the "competency based" approach recommended by the Education Law Center and others, and urge you to value this function sufficiently to ensure that the professionals who fill it are qualified to meet the needs of children with disabilities.

Similarly, the "early interventionist" is described in only very general terms, and again, only minimal educational requirements and experience are mandated. We would appreciate another look at this clearly key position in the new service structure, and an analysis of the function and the specific qualifications needed to fulfill this function. The input of parents and professionals in the field of child development and disabilities is essential here.

IFSPs

We are concerned about timely implementation of IFSPs. In Philadelphia, this situation has led to litigation; in Montgomery County, the regional office has ordered corrective action. We concur with the recommendation of the Education Law Center that a deadline be set, probably no longer than 14 days. Without this kind of clarity, many children will be denied needed services.

Procedural Safeguards

The regulations make no mention of the complaint management system that is federally required. Parents often do not know that this system exists or how to use it. We recommend that the state insert the appropriate language here to match the federal language, and that some provision on accessibility of this information to parents be included. In addition, it is important, as a procedural safeguard, that parents have access to copies of their child's records without cost. We are also concerned about the limitations on foster parents serving as surrogate parents, which we are convinced can result in unnecessary delays in needed services for children. Providing services to children in foster care is very difficult; improving the surrogate parent process would help some children to access services without delays.

Conclusion

We appreciate the opportunity to comment, but once again urge you to extend this comment and hearing period beyond the summer schedule. We know that the process would benefit from the input of both parents and agencies who are unable to respond to a July or August hearing schedule. We look forward to your consideration in this matter.

Sincerely,

Shelly D. Yanoff
Executive Director

Public Comment 37

Original: 2122

Pennsylvania Occupational Therapy Association Inc.
IN AFFILIATION WITH THE AMERICAN OCCUPATIONAL THERAPY ASSOCIATION
1-800-UR1-POTA

August 2, 2000

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

Re: Proposed Rulemaking, Early Intervention Services (30 Pa.B. 2785)

Dear Mr. Knowlton:

I am the President of the Pennsylvania Occupational Therapy Association ("POTA"), a statewide association representing the interests of over 6,000 licensed occupational therapists. Please accept the following comments of POTA concerning the proposed Early Intervention Services regulations published in the *Pennsylvania Bulletin* on June 3, 2000.

First, Subsection (i)(C) of the definition of "nutrition services" includes: "Feeding skills and feeding problems." While dieticians and related professionals address nutritional issues and deficiencies, they do not address the mechanics of self-feeding or swallowing. Self-feeding is an activity of daily living, and as such, licensed occupational therapists are the appropriate professionals to provide therapy in this area. Swallowing examinations and therapies, on the other hand, are provided by licensed speech language pathologists. Therefore, we propose that Subsection (i)(C) of the definition of "nutritional services" be deleted.

Second, the inclusion of the term "perceptual...development" in the definition of "physical therapy" in Section 4226.5 is inappropriate. Therapy concerning perception is not a matter of physical functioning within the scope of practice of physical therapists. Licensed occupational therapists provide this type of service in Pennsylvania. We believe that the term "motor development" used in this definition accurately reflects the type of services that physical therapists provide. Therefore, we propose that the term "perceptual" be deleted from the definition of "physical therapy" in Section 4226.5.

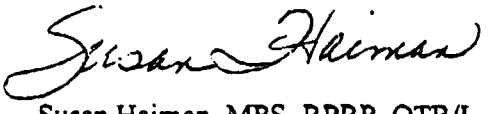
Lastly, the definition of "occupational therapy" in Section 4226.5 does not reflect the family concerns, priorities, and resources that are essential to the development of a child. Therefore, in light of the foregoing comments and in light of the need to recognize the role of family in occupational therapy, we propose the following definition for "occupational therapy":

> Occupational therapy–An array of services to address the functional needs of a child related to adaptive development (including self-care and feeding skills), adaptive behavior and play, social development, and sensory, perceptual, motor and postural development, which are designed to improve the child's functional ability within daily routines while addressing families' concerns and priorities, and includes the following:
>
> (i) Identification, assessment and intervention.
>
> (ii) Adaptation of the environment, and selection, design, and fabrication of assistive and orthotic devices to facilitate development and promote the acquisition of functional skills.
>
> (iii) Provision of services for habilitation or rehabilitation of delays in development or loss of functional ability and prevention or minimization of the impact of initial or future impairment.[1]

We would like to thank the Department of Public Welfare for its efforts in drafting these proposed regulations. We, like the Department, are committed to providing high quality services to children whose ability to develop to their full potential depends upon professional and compassionate early intervention services.

Thank you for considering our suggestions for revisions.

Respectfully submitted,



Susan Haiman, MPS, RPRP, OTR/L, FAOTA
President
(215) 951-2593

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[1] We offer slightly different language for this Subsection in the interest of clarity.

Public Comment #27

Original: 2122

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

From: Kelli O. Thompson
Director of Childhood Programs
UCP of the Capital Area
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Camp Hill, PA 17011

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WRITTEN TESTIMONY
PROPOSED EI REGULATIONS

GENERAL PROVISIONS

4226.5 Definitions

(i) We are concerned when the Department refers to the professional requirements as the "highest requirements". Typically entry level requirements are based on the minimal requirements in a profession or discipline. We would recommend that the Department change the wording to "lowest requirements".

Natural environments-We completely support the definition included in the proposed EI regulations however, in light of our recent correspondence with the county and the Department, others may need a more clear definition of what a natural environment truly is. The goal should be a clear definition with no misunderstood interpretations regarding natural environments.

FINANCIAL MANAGEMENT

4226.14 Documentation of other funding sources

(a) Our agency feels that the statement in this section is unclear as to *who* shall exhaust all of their funding sources. Also, it is unclear as to what "all other private and public funding sources available to the child and family" refers to.

GENERAL REQUIREMENTS

4226.22 Eligibility for Early Intervention services

(1v) There is not a definition anywhere in the proposed regulations for adaptive development. We are assuming that this term is referring to self-help skills that include feeding, toileting, dressing and hygiene. We would recommend that a definition for adaptive development be included in the Definitions section (4226.5).

4226.23 Waiver eligibility

(3iiE,F,G) Our agency feels strongly that the three "major life activities" - Self-direction, Capacity for independent living and Economic self-sufficiency – could not possibly be referring to the life of a child age birth through two. It is our recommendation that these three areas be

removed completely from the proposed regulations as well as from the Waiver eligibility requirements.

4226.36 Preservice training
Our agency is in full support of requiring trainings however; to require such a vast number of trainings prior to working with children or families will limit the availability of much needed staff. Also, such requirements may deter interested persons from obtaining a job in the Early Intervention field.
(9) We question as to why personnel will need fire safety and emergency evacuation training when the majority of services now occur in private homes and community childcare sites. Should there be a distinction made between Preservice trainings required for home/community based services and facility based services?

4226.37 Annual Training
(a) Again, our agency agrees that annual training is absolutely imperative. The concern lies in the *amount* of required annual training. The requirement of 24 hours annually will limit the availability of staff as well as impose a financial hardship on the agency. We would like to know if there will be any type of reimbursement for these mandated training hours.

4226.41 Traditionally underserved groups
(2) There is not a definition anywhere in the proposed regulations for "culturally competent services". We are not sure what the Department means by culturally competent services and we recommend a definition for culturally competent services be included in the Definitions section (4226.5).

PERSONNEL
4226.55 Early Interventionist
We are not sure whom this position is meant to describe. The definition of who this individual is needs to be clearly defined somewhere in the regulations. Is this person a special educator, a service coordinator, a developmental therapist or other professional therapist, a teacher or someone entirely new?

4226.56 Requirements and Qualifications
(a) The level of expertise of the early interventionist is of great importance. Our agency feels that the current requirements are too broad. The requirements need to relate directly back to a related field including Early Child Development, Education, Human Development and Family Studies or Special Education.
(b) Our agency is greatly concerned with the annual requirement of 6 credit hours. It is unclear how these 6 credit hours relate to the 24 annual hours of training (4226.37). Requiring 6 credit hours annually is excessive and will create a financial hardship for individuals and programs. Another point to consider is the fact that a variety of relevant coursework either does not exist or is not available for most persons working in the Early Intervention field.

EVALUATION AND ASSESSMENT

4226.62 MDE

(2) We would like further clarification as to what is meant by "...personnel independent of service provision." We would also recommend an exception process for areas where resources are limited. Such limitations could include low incidence disabilities, lack of therapists, etc.

4226.96 Opportunity to examine records

Our agency feels that "...and any other records about the child and the child's family" is a broad statement. We would recommend adding a disclaimer that would read "when appropriate" or "the providing agency has a right to maintain confidentiality when dealing with situations of abuse or other touchy situations". It is our feelings that the agency also has a right to confidentiality. We feel that by making such a broad statement, the Department may be limiting what is actually kept in files or may actually limit intervention when dealing with situations where personnel wish to remain confidential when reporting (i.e. Child abuse, neglect, etc.).

We would also like to take this opportunity to say that we fully support the oral testimony presented on July 24, 2000 by Terry Casey, Executive Director of Pennsylvania Child Care Association. The testimony was titled "Child Care: The Natural Environment & Comments on Proposed Regulation Amendments for Early Intervention Services".

We appreciate having been given the opportunity to provide input on the proposed Early Intervention regulations. Our agency recognizes all of the time, hard work and effort that the Department has put into Early Intervention Regulations. We are committed to providing Early Intervention services and feel that together we can work towards successfully meeting the needs of infants and toddlers with special needs and their families. Thank you!

Kelli A. Thompson