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ABSTRACT

This report presents testimony and statements concerning the reauthorization of the early intervention and preschool programs under the Individuals with Disabilities Education Act. Among the presenting testimony were: Carol Ann Baglin of the Maryland Infants and Toddlers Program; Dr. Robert Davila, of the Office of Special Education and Rehabilitative Services; Dr. James Gallagher, of the Carolina Institute for Child and Family Policy; Dr. Mary Beth Bruder, representing the Consortium for Citizens with Disabilities; Dr. Brian McNutly, of the National Association of State Directors of Special Education; Thomas Trish, parent, from the Laguana/Otoe Missiouria Tribes; Elizabeth Williams, parent, of the Mississippi Band of Choctaw Indians; and Jane Wiechel, Ph.D., of the Ohio Department of Education, Division of Early Childhood Education. Additionally, numerous prepared statements from these and other witnesses are included. (DB)

INTERVENTION AND PRESCHOOL PROGRAMS UNDER THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

HEARINGS

BEFORE THE

SUBCOMMITTEE ON SELECT EDUCATION

OF THE

COMMITTEE ON EDUCATION AND LABOR
HOUSE OF REPRESENTATIVES

ONE HUNDRED SECOND CONGRESS

FIRST SESSION

HEARINGS HELD IN WASHINGTON, DC, APRIL 11 AND 12, 1991

Serial No. 102–6

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HEARING ON REAUTHORIZATION OF THE EARLY INTERVENTION AND PRESCHOOL PROGRAMS UNDER THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

THURSDAY, APRIL 11, 1991

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON SELECT EDUCATION,
COMMITTEE ON EDUCATION AND LABOR,
Washington, DC.

The subcommittee met, pursuant to notice, at 11 a.m., Room 2257, Rayburn House Office Building, Hon. Major R. Owens, [Chairman] presiding.

Members present: Representatives Owens, Payne, Serrano, Jefferson, Ballenger, and Klug.

Staff present: Wanser Green, Pat Laird, Laurence Peters, Maureen Crawford, and Sally Lovejoy.

Chairman OWENS. Would everybody please take a seat.

The Subcommittee on Select Education is now in session Before we hear from our first distinguished witnesses I would like to read an opening statement.

There is a war raging for world economic dominance, and the key weapon is the human component. Education is the tool and the process we must use to upgrade this invaluable human factor. An under-educated populace has far-reaching, adverse implications for our Nation's effectiveness in the global economic competition. The education of children with disabilities must not be left out of this equation.

School readiness, high school graduation, and student competency are the first three national education goals set forth by the President and the governors two years ago. The first of these is the most critical. If our children are not ready to learn, the other goals are meaningless. For children with disabilities, the provision of early intervention services and preschool programs is the first step toward readiness.

It is clear that an investment in early childhood education is critical to the prevention of later educational failure. According to the 12th Annual Report of the Office of Special Education Programs, of the total number of students with disabilities, about 65,395 or 27 percent, ages 14 and older, dropped out of high school. As a result, unemployment has reached a high of 70 percent, while underemployment has been charted at 20 percent for this particular population.

Given these circumstances, it is incomprehensible that a majority of States are not making adequate and appropriate early intervention services for low-income and minority families a priority. This is particularly troublesome given the increasing cultural diversity of our population.

By the year 2010, it is projected that nearly one quarter of all children in the U.S. will be children of color. While poverty is on the rise among all children, minority children are more likely to live in poverty.

Additionally, we will have to provide services for the escalating number of children born to crack- or other drug-addicted women and to the 1 in 5 children who have a developmental or behavioral disorder. We must ensure that our commitment to early intervention is inclusive. We can no longer accept the fact that among children with special needs, only 29 percent are diagnosed before age 5.

The Education of the Handicapped Act, which has now been renamed the Individuals with Disabilities Education Act, was heralded as the cornerstone of Federal policy for special education and related services to provide equal education opportunities for children with disabilities. In 1986, Congress committed itself to making this population ready for school by authorizing the preschool and early intervention programs. We now have the opportunity to reinforce that commitment. The hearings over the next two days will assist us in making decisions which will strengthen this much needed legislation.

[The prepared statement of Hon. Major R. Owens follows:]

Statement of Hon. Major R. Owens, a Representative in Congress from the State of New York

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Chairman OWENS. I yield to the ranking member, Mr. Ballenger, for an opening statement.

Mr. BALLENGER. Thank you, Mr. Chairman.

I am proud to say that North Carolina is one of those States that has made the commitment and is willing to work with you in any way we can.

I am happy to welcome Congressman Mike Espy. He and I came in together in the 100th Congress. I am glad to see you are here, Mike.

I would also like to recognize the folks out in the audience that will be on a later panel, the Underdown family, from Hickory, North Carolina, my hometown. Both Steve and Gayle are here and their son, Matthew, who is four years old and a Down Syndrome child.

Also, I would like to recognize from North Carolina, Robin McWilliam, a research associate from the Frank Porter Graham Child Development Center at the University of North Carolina in Chapel Hill, NC. He has worked with my wife who is on the State Day Care Commission. We have been involved with children there for quite some long time.

Also James Gallagher, a research associate at the Carolina Policy Study Program at Chapel Hill. The Carolina Policy Study Program has a grant from the Department of Education to study the implementation of Part H which is the early intervention program.

Later, we'll welcome Dr. Davila who is the Assistant Secretary on Special Education and Rehabilitation Services representing the Administration.

This is the first hearing of the 102nd Congress by the subcommittee focusing on disability issues. I would like to say, just as an individual, that during my 12 years in the State Legislature in North Carolina I worked on the Human Resources Budget Committee which gave me a great deal of knowledge as far as this program is concerned at the State level. Also, the Western Division of the North Carolina School for the Deaf is in Morganton, North Carolina, which is right next to my hometown.

I also have a nephew who presently lives in a group home in Alexander County, which is right next to the city of Hickory, who has Down Syndrome and is very happy and successful in his life in this group home.

I commend you, Mr. Chairman, for calling this hearing. I personally, as you might gather, have an interest in it and I think that we can look forward to a very educational hearing.

Chairman OWENS. Thank you, Mr. Ballenger. Mr. Klug.

Mr. KLUG. Sir, I want to commend you, if I can, for having this series of hearings.

As a father of two boys, one who is 2 and one who is 6, it is clear to me that if you're not involved with your children's education early on, in many cases it is too late to get them fully plugged into the system later.

My six-year-old, who just started kindergarten, fortunately has parents who've spent time with him on a nightly basis learning to read and learning to study. Unfortunately, many other kids with whom he is in kindergarten in Madison, Wisconsin do not even know their alphabet at this point.

If you look at the broad spectrum of children who enter the world of disabilities, it is an even tougher road. I think we need to figure out a way to get services to those kids. Unfortunately, this legislation comes at a time, and this will be an issue to talk about later on, when many States in this country are having major fights on budget problems at the State front. How can we combine the interest of helping children at a time when we've got fewer dollars is a task that is going to consume a great deal of our time. Frankly, I know it is a time consuming process in my State capitol of Madison.

The State of Wisconsin has had a long history of doing fairly progressive legislation in these matters, but right now my State, unlike North Carolina and like some other States, is having a hard time coming up with the money. I can tell you personally that I am committed to the idea. But at the same time I think we have to realize that finding the dollars for these kids will not be easy. That's the dilema we face in the next two days of hearings.

Chairman Owens. Thank you. We are honored and pleased to welcome our distinguished colleague from the State of Mississippi, the Honorable Mike Espy.

Congressman Espy.

STATEMENT OF HONORABLE MIKE ESPY, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MISSISSIPPI

Mr. Espy. Mr. Chairman, my thanks to you, my good friend, Cass Ballenger, and to other members of this subcommittee, for allowing me the opportunity to appear before you this morning to.

Mr. Chairman, I have a written statement; it is very brief. Also, if you would allow me to include the statement in its entirety along with certain extraneous materials I have, if I could have your permission to have that included as part of the record, I would appreciate it.

Chairman Owens. Without objection, your entire statement will be included in the record.

Mr. Espy. Thank you, Mr. Chairman.

Also, I have with me a young woman named Katherine Nodel who is on loan for a year to my office from the American Psychological Association. She is very familiar with this program and how it operates in Mississippi. I have her with me, so she can answer any questions should you have any at the conclusion of my opening statement.

Mr. Chairman and members of the subcommittee, I have several areas of concern about Part H of the Individuals with Disabilities Education Act. They include: (1) the concept of differential funding, (2) the Interagency Coordinating Council, (3) entitlement to services, (4) lead agency authority, (5) long-term funding and program cost, and (6) parental consent for services.

As you know Mr. Chairman, we in Mississippi have tremendous problems associated with our high rate of poverty. Our rates of low birth weight babies and infant mortality rival the rates of Third World countries.

In Humphries County in the Delta, in my District for example, 30 out of every 1,000 babies born will never live to blow out the candle of their first birthday cake. Humphries County in Mississippi socially and economically is listed, unfortunately, as the second poorest county in the United States. The first poorest county is a county called Tunica, also within my congressional District.

In Humphries County again, Mr. Chairman, I say to you and this committee, that out of every 1000 babies born, 30 of them won't live beyond their first year of life in America in 1991, which certainly associates with the statement you made at the opening of this hearing.

For many of those babies that do survive, there are risks of malnutrition, developmental disabilities, physical handicaps and learning problems.

Part H of Public Law 99-457 offers Mississippi the opportunity to address some of these problems in a systematic and coordinated interagency effort by providing funding for early intervention services. The Mississippi State Department of Health is the lead agency for the Part H effort in our State. While planning for statewide implementation, we have operated two pilot programs, one of which is in my Congressional district.

Mr. Chairman, we have served 457 children and their families since the pilots began about two years ago. But we have now approximately 6400 children, or 5 percent of our youngsters in the birth to 36 months age range that are still in need of such services. We know that early intervention services are critical if the devastating effects of physical, mental, and medical problems are to be prevented or lessened. And we know that the crippling effects of poverty are the most evident in the youngest and most helpless of our children. These children and their families need basic support and coordination of services if they are to have any hope of reaching their true potential.

Mississippi desperately needs a coordinated early intervention system if the effects of poverty and disability are to be really mitigated. For us to put in place an effective system, we need to continue the planning efforts under Public Law 99-457. More specifically, Mississippi needs two more planning years. And those planning years, fiscal year 1992 and 1993, need to be federally funded at an allocation of not less than the current annual planning funding level.

Funding barriers and an acute shortage of personnel trained to provide early intervention services stand in the way of full implementation by October 1, 1991. If Mississippi, like some other States, already had a statewide early intervention program in place prior to the enactment Public Law 99-457, we probably would have been able to comply with the implementation and funding guidelines in this program. But, however, we were not one of those States.

So this morning, I am proposing that Public Law 99-457 be amended. States, such as Mississippi, that are making a good faith effort to comply should continue to receive the Federal funding as they move forward toward true statewide implementation.

As it now stands, Mississippi must be able to assure the Federal Office of Special Education Programs that we will provide statewide case management and evaluation services to all eligible children no later than October 1, 1991. As it stands now, if we are not able to meet that deadline, we will lose our Federal funds and without those funds we simply cannot supply and support this vital program.

As we all know, that deadline is only six months away and we have only two pilot programs in place funded entirely through Part H monies. Furthermore, meeting this deadline would require expansion of State funding by at least $1.7 million at a time when fiscal restraints are calling for agency cutbacks. In fact, Mr. Chairman, our State Department of Health may have its Fiscal Year 1992 budget for existing services cut by $7 million. In fact, that is true. Our legislation has already adjourned and this, in fact, is the case.

So if a "differential funding" provision were placed in the legislation, then States such as Mississippi could continue to strengthen and coordinate interagency efforts while working to obtain the needed State funding for full implementation.

This program provides a much needed service in Mississippi. For a State where the needs are so great, Federal initiatives must be flexible enough to reward effort and progress toward a goal when immediate full implementation is precluded by the lack of adequate resources. We are making every effort to solve all these problems. We are making progress. We must be allowed the chance to go forward; not be "flunked out" due to fiscal issues beyond our control.

Mr. Chairman, our children did not create our budget problems. They should not be the ones to pay for them. This program was authorized and reauthorized by State legislation but ironically, they included zero funding for this very needed program in Mississippi. So Mr. Chairman, we are asking that of this subcommittee this morning. We appreciate the opportunity to appear before you and would ask for any questions at this time should you have any.

[The prepared statement of Hon. Mike Espy follows:]

STATEMENT OF HON. MIKE ESPY, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MISSISSIPPI

Mr. Chairman and members of the subcommittee, I appreciate the opportunity to speak before you this morning on behalf of infants and toddlers with developmental disabilities and their family members in Mississippi and in support of the reauthorization of Part H of the Individuals with Disabilities Education Act.

I have several areas of concern however about the implementation of this program at the State level. They include: (1) the concept of differential funding, (2) the Interagency Coordinating Council, (3) entitlement to services, (4) lead agency authority, (5) long-term funding and program cost, and (6) parental consent for services.

However, in my oral testimony this morning I will address only issues related to start-up funding for this program. My recommendations regarding the aforementioned areas are attached and I would request that they be inserted into the record.

As you know, we in Mississippi have tremendous problems associated with our high rate of poverty. Our rates of low birth weight babies and infant mortality rival the rates in Third World countries. In Humphries County in the Delta, for example, 30 of every 1,000 children born never live to blow out the candle on their first birthday cake. For many of those babies who do survive, there are risks of malnutrition, developmental disabilities, physical handicaps and learning problems.

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Mississippi desperately needs a coordinated early intervention system if the effects of poverty and disability are to be mitigated. For us to put in place an effective system, we need to continue the planning efforts under Public Law 99-457. More specifically, Mississippi needs two more planning years. And those planning years, fiscal year 1992 and 1993, need to be federally funded at an allocation not less than the current annual planning funding level. Funding barriers and an acute shortage of personnel trained to provide early intervention services stand in the way of full implementation by the October 1, 1991 deadline. If Mississippi, like some other States, already had a statewide early intervention program in place prior to Public Law 99-457, we probably would have been able to comply with the implementation and funding guidelines in this program. But, we were not one of those States.

I am proposing that Public Law 99-457 be amended. States such as Mississippi that are making a good faith effort to comply should continue to receive Federal funding as they move forward toward statewide implementation. As it now stands, Mississippi must be able to assure the Federal Office of Special Education Programs that we will provide statewide case management and evaluation services to all eligible children no later than October 1, 1991. If we are not able to meet that deadline, we will lose our Federal funds and without those funds we simply cannot support this vital program.

The deadline is only six months away and we have only two pilot programs in place funded entirely through Part H monies. Furthermore, meeting this deadline would require expansion of State funding by at least $1.7 million at a time when fiscal restraints are calling for agency cutbacks. In fact, our State Department of Health may have its Fiscal Year 1992 budget for existing services cut by $7 million.

If a "differential funding" provision were placed in the legislation, then States such as Mississippi could continue to strengthen and coordinate interagency efforts while working to obtain the needed State funding for full implementation.

This program provides a much needed service in Mississippi. For a State where the needs are so great, Federal initiatives must be flexible enough to reward effort and progress toward a goal when immediate full implementation is precluded by the lack of adequate resources. We are making every effort to solve all these problems. We are making progress. We must be allowed the chance to go forward not be "flunked out" due to fiscal issues beyond our control. Our children did not create our budget problems. They should not be the ones to pay for them. Thank you Mr. Chairman.

Chairman OWENS. Mr. Congressman, I think your message is very clear and direct. I do not have any questions, but I'll ask my colleague, Mr. Ballenger.

Mr. Ballenger.

Mr. BALLENGER. Mike, I think we pretty well understood the situation.

Congressman Klug has the same problem you have, except I am quite sure that Wisconsin doesn't have the birth death rate problem.

I just got back from Nicaragua and I am not sure what the death rate of new born babies is there, but we've got to do something to help you out. The one real important thing that I found out when I was down there is everybody—everybody in Nicaragua, El Salvador was worried because of the cholera epidemic in Peru. It has already moved into Columbia and it is supposedly heading up the coastline into Central America. The problem is that there is a need for dehydration salt.

I have been doing this for 15–20 years, and everybody there has always complained about the water systems. I was wondering, in those 2 counties that you mentioned, is their water supply clean? I know all of the babies in Central America that die seem to die from drinking bad water, diarrhea, that sort of situation. I was just wondering how the water system was in Mississippi.

Mr. ESPY. We have done some work and some investigation in this area as well, Cass. I'll just say to you, I don't know about El Salvador, but in Nicaragua, in Cuba and Costa Rica and some of the nations on the continent Africa, have infant mortality rates much better than those that exist in Mississippi at this time.

The water supply is abundant and generally pretty clean. The access, though, to that supply still represents a problem in my State. There was a situation recently in a community in the Southern part of my district what was found in a community of 60 families, half black, half white, was still without running water in their homes. Some residents in that community had deep water wells; some had culverts to catch rain water when it rained. But the majority of the residents of that community had to still haul water from a rusty bucket from a stream. So that still exists in America.

The Farmers Home Administration recognizes this problem and they have been working with our office to resolve this.

I will say in general the water supply is adequate. It is pretty clean, but its just a matter of education and access to get to that supply.

Mr. BALLENGER. Education, I think, is what this whole program is about.

I thank you, Mr. Chairman.

Chairman OWENS. Mr. Klug

Mr. KLUG. No questions.

Chairman OWENS. Mr. Jefferson

Mr. JEFFERSON. I don't have any questions, Mr. Chairman.

Chairman OWENS. There are no further questions.

Congressman, we have your testimony and we will take into consideration your request. Thank you very much for appearing before us.

Mr. ESPY. Thank you Mr. Chairman.

Chairman OWENS. Our next set of witnesses will consist of parents: Ms. Liz Williams, Ms. Trish Thomas, Ms. Gayle Underdown.

Ms. Williams is a parent from the Mississippi band of Choctaw Indians, accompanied by Pam Dalme, Special Education Director.

Ms. Trish Thomas is a parent from Laguna/Otoe-Missiouria Tribe, Laguna Pueblo, New Mexico. Ms. Gayle Underdown is a parent from Hickory, North Carolina.

Welcome. We have copies of your written testimony which will be entered in its entirety into the record. I would like you to take this time to elaborate on any particular part of your testimony at this point.

Why don't we begin with Ms. Liz Williams.

STATEMENT OF ELIZABETH WILLIAMS, PARENT, MISSISSIPPI BAND OF CHOCTAW INDIANS, PHILADELPHIA, MISSISSIPPI

Ms. WILLIAMS. I appreciate the opportunity to testify here in support of the continuation of early intervention and preschool handicapped programs on Indian reservations. Both my child, Magaline, and I, as well as other Choctaw children are being served in ways which were impossible before the establishment of these programs.

I am a member of the Mississippi Band of Choctaw Indians. My child, Magaline, came to me as a foster child when she was seven months old. She suffered a post traumatic head injury and suffers from visual, physical impairments. Magaline has always been a happy child despite the impairments she has endured in her short life time. She did not begin to walk until she was one year old. She did not begin talk until she was two years old. Her growth compared to average children her age was delayed.

When Magaline was one year old, Choctaw Social Services recommended that I contact Choctaw Special Education Program and the program for young handicapped children. With the help of these programs, Magaline was determined eligible for Social Security income, Children's Medical Program Services, was referred to medical specialists and completed a physical therapy screening. She began receiving physical therapy when she was one year old. The physical therapist provided her with varying methods of teaching her to walk; such as walking cane, infant walker and brace for her leg. The therapist informed us of techniques that could be done at home to reinforce her progress.

Now Magaline is in the Choctaw preschool at Choctaw Day Care Center. She has continued her physical therapy services through a preschool special education program. Transportation has been provided for her to each physical therapy session. Her exercises have centered around her right wrist and her toe walking. The weekly visits to physical therapist have helped her gain better use of her wrist and have helped improve her walking.

Magaline was screened by a Choctaw preschool special education program for other possible disabilities. She was determined to have a visual impairment which was diagnosed by an ophthalmologist. The preschool program has begun getting materials, such as visual aids and establishing teacher awareness of her problem before she begins kindergarten next school term, as well as providing assistance needed by the Choctaw Day Care Center she now attends.

Every time I have a call or needed special help, the program has always been there for me. They have provided us moral support and strength. With the help of these two programs, I have watched Magaline grow into a child that will be able to adapt to any new situation regardless of her impairments. I rely heavily on special services that Magaline continues to receive in order for her to make it in this world.

I know that there are other children and parents, such as my family, on the reservation who benefit from these programs. We will need such services to continue and I recommend that the Congress continue the program and, if possible, enlarge it for Indian tribes.

[The prepared statement of Elizabeth Williams follows:]

STATEMENT OF ELIZABETH WILLIAMS, PARENT, MISSISSIPPI BAND OF CHOCTAW INDIANS, PHILADELPHIA, MISSISSIPPI

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Chairman OWENS. Thank you.

Ms. Dalme, did you want to make a statement?

STATEMENT OF MS. PAM DALME, DIRECTOR OF CHOCTAW SPECIAL EDUCATION

Ms. DALME. Yes. Thank you very much.

I, too, am grateful for being able to be here to talk to the committee about the great benefits that Part B and Part H programs have brought to the Choctaw Indian Reservation in Mississippi.

We are currently serving 53 children between the ages of 0 to 5 years old and their families. I would like to use a little bit of this time to talk to you about some of the problems that we're having and some of the recommendations that we have.

Unfortunately, I need to report that we are seeing a dramatic increase in serious handicapping conditions on the Reservation. It is largely due to the great growth in Indian population. Twenty percent of the Choctaw population of 5,000 is under the age of six. That was done in a recent Census Survey. The increase we are seeing is also due to physical defects which accompany gestational diabetes.

We are basically having two problems in delivery of services. First of all, it is the lack of funds to adequately serve all of the tribes with the Bureau of Indian Affairs in the Department of Interior and the lack of coordinating services to fill the resource gaps, especially for health care.

I have submitted written testimony outlining the problems in obtaining the special health care through Indian Health Services and Contact Medical Care. At Choctaw particularly, Indian Health Services has a contract for deliveries with the University Medical Center in Jackson, which is 75 miles away from the Reservation. Choctaw mothers, for the most part of their pregnancies, receive their prenatal care at local hospitals on the Reservation. Then when it comes time to deliver, they are transported to Jackson.

Contact Health Services can only pay for surgery or emergency care that is needed to protect the child's life when a handicapped child is born. For any needs beyond this category, you have to go to other areas or other places to obtain services.

As the lead agency in the Bureau of Indian Affairs, this special education program is the lead agency for Part H. This makes us have to go out and beg and borrow services from other agencies. Sometimes we succeed and sometimes we fail. For many cases, had it not been for our Part H funds for staff that we have had, we would not have had the human resources that we need to provide the support for the child and, at the same time, persist in the efforts to secure the services from the providers.

The second problem we are experiencing is with the Department of Interior. Its difficulties are due to limited funds to carry out its responsibilities as a State, per se, for Part H.

It is my understanding that the Department of Interior is interested in transferring their responsibility from the office of Indian Education programs to Indian Health Services, with set-aside funds being used to assist the State in becoming the lead agency for Indian children for purposes of Part H. I would like to say that the Mississippi Band of Choctaw Indians would vigorously oppose this move.

Most States can not or will not serve these children for several reasons. Number one being there is simply a lack of State funds at the State and local level to adequately serve the non-Indian infant and toddler population.

Second, the State agencies have great difficulty in accessing the reservation populations due to either geographic location, issues of jurisdiction or of greatest importance, the difference in the tribal culture and language.

Third, there is often a reluctance by States to diligently reach out to Indian population because of their attitudes that Indians are a Federal, not a State, responsibility.

On the basis of our experience, the tribe respectfully makes the following recommendations for your consideration.

First of all, we would like to recommend that the Indian set-aside be increased to a minimum of 2.25 percent for these reasons.

First, there is a higher incidence of handicapped infants and toddlers due to the population increases.

Second, there is a higher incidence of handicapped infants and toddlers due to health conditions which include alcohol-related disabilities. I would like you to note that Indian Health Services, in their Fiscal Year 1992 budget submission, estimated that the national incidence of fetal alcohol syndrome is two for every 1,000 live births. They also show that for specific Indian populations, that number goes up to 15.6 for every 1,000 live births.

More resources will be needed if these children are to receive the critical early intervention services that they need.

The third thing is lack of resources. There are not within the State, and certainly not within Mississippi, resources that are needed to adequately serve Indian children. Similarly, unless the Congress appropriates additional funds for the Bureau of Indian Affairs or for Indian Health Services, there will not be an adequate funding level for either of these agencies.

The second recommendation we have is in the reauthorization, if possible, to address the limitation by the Indian Health Service to contract health care. In particular, we recommend that Indian Health Services not limit their Priority I health care and extend it to handicapped children.

Finally, we thirdly recommend, and strongly recommend, that the Department of Interior, Office of Indian Education Programs, remain the lead agency for serving Indian children who live on the reservations and we strongly oppose any efforts by the Department or Interior to relinquish this responsibility to either the States or to Indian Health Services.

While we understand many of the obstacles that the Department of Interior is facing in carrying out their responsibilities, many of which are associated with a reluctance to request additional funding, we do not feel that young Indian children will be better served by simply transferring this responsibility.

Instead, the Department of Interior should be strongly urged to accept its responsibility for all infants and toddlers on reservations—not simply those with BIA funded or operated schools and to prepare budget requests, initiate service programs and continue to coordinate their efforts accordingly.

On behalf of the Mississippi Band of Choctaw Indians and the families like Ms. Williams and the children who have received direct payments from Part B and Part H funds, thank you for your consideration.

[The prepared statement of Pam Dalme follows:]

Statement by Pam Dalme, director of Choctaw Special Education

I, too, am grateful to be able to tell the Committee of the immense benefits the Part B and Part H programs are bringing to Choctaw children and their families who, prior to their onset, received at best only routine health care services. I want to use my time to focus on the Part H program, outline problems with implementation and make some recommendations.

Unfortunately, I must report that we are seeing dramatic increases in serious handicapping conditions, largely due to great population growth -- 20 per cent of the Choctaw population of 5,000 is under age six -- as well as due to the physical defects which accompany gestational diabetes. The tribal rate for open spine disorder, for example, is twice the national average and there is an unusually high incidence of cleft palates. (The tribe has the second highest diabetes rate among all Indian tribes. American Indians have the highest diabetes rate of all population groups in the country.)

The problems of implementation are those primarily of (1) lack of funds to adequately serve all tribes and the lack of coordinating services to fill in the resource gaps, especially for health care and (2) Department of the Interior difficulties, due to limited funds, in carrying out its full responsibility as the 'state' for Part H.

1. Lack of Funds and Services

Indian tribes, unlike states and units of local government which have the capacity to acquire financial resources through taxation, have only those funds for educational and health care services which are requested in the administration's budget each year and are appropriated by the Congress.

Many of the most urgent needs of children at this age are those for specialized and often expensive health care services. Part H anticipates that the Indian Health Service would be a primary provider in this area. Such is not the case and an explanation of how IHS funds may be expended will clarify this.

Most tribes have either a small hospital or field clinic in their communities. Most often the hospitals, such as that on the Choctaw Reservation, do not have surgical or obstetrics units. The larger tribes have full service hospitals equipped for both surgery and obstetrics and in some parts of the country -- primarily the southwest and Oklahoma -- there are large regional IHS facilities which offer a range of services.

Any medical or specialty services, including those services of psychologists and psychiatrists, which can not be performed in the reservation facility fall into a category called contract health, that is, all care which must be purchased from non-IHS providers. The Indian Health Service, in determining which services to fund, follows a priority system. CHS funds have been so short for nearly ten years now, that only those CHS cases which fall into the Priority I category -- cases considered urgent and emergent -- have been approved for payment. All other services are deferred.

This system results in a health care process, beginning with pregnancy and delivery, which increases the likelihood that disabling conditions will be untreated. At Choctaw, for example, the hospital has a contract with the University Medical Center in Jackson, some 75 miles one way, from the reservation for deliveries. Choctaw mothers, for most of their pregnancy, receive prenatal care at the local hospital and are then transported by ambulance to Jackson for delivery. If the child is born with disabling conditions, CHS can pay for services/surgery deemed as 'emergency or necessary to protect the life of the child.' Any needs beyond that category must be paid for from other sources.

This forces us to beg and borrow services from other agencies. Sometimes we succeed and sometimes we fail. An example involves orthodontic care for a cleft palate child, who was born with a severely disabling and disfiguring cleft palate. Several reconstructive surgeries were required and orthodontic appliances were needed the straighten the teeth following the operations. It took several months of work and bickering back and forth with service agencies before we were successful in obtaining the necessary funds. Had we not had the Part H funds for staff, we would not have had the staff resources needed to provide support to the child and, at the same time, persist in efforts to cajole the services from providers.

(2) DOI Reluctance to Assume Responsibility

It is my understanding that the Department of the Interior is interested in transferring its responsibility to the Indian Health Service, with the set-aside funds to be used to assist states in becoming the lead agency for Indian children for purposes of Part H. The Mississippi Band of Choctaw Indians would vigorously oppose such a move.

Quite simply, most states can not or will not serve these children for several reasons: first, there is simply a lack of funds at the state and local level to adequately serve the non-Indian infant and toddler population; second, state agencies have great difficulty in accessing reservation populations due to geographic isolation, issues of jurisdiction, and, of greatest importance, lack of knowledge of tribal culture and language. Gaining access to a handicapped infant and its family for services requires local familiarity. Third, there is often a reluctance by the states to diligently reach out to the Indian population because of entrenched attitudes that Indians are a federal, not a state, responsibility.

RECOMMENDATIONS

On the basis of our experience, the tribe respectfully makes the following recommendations for your consideration:

1. We recommend that the Indian set-aside be increased to, at a minimum, 2.25 percent for three reasons:

a. Higher incidence of handicapped infants and toddlers due to population increases

The American Indian population is growing rapidly. This trend alone will result in more children who need early intervention services.

b. Higher incidence of handicapped infants and toddlers due to health conditions which include alcohol-related disabilities

The onset of diabetes during pregnancy is contributing larger numbers each year of children born with congenital defects. More resources will be needed if these children are to receive critical early intervention services.

The growing incidence of fetal alcohol syndrome is also resulting in larger numbers of disabled and at risk infants and toddlers. While the Mississippi Choctaws are fortunate to have avoided, in large part, this damaging condition, others have not and the needs of their children must be considered during reauthorization. The Indian Health Service, in its FY 1992 budget submission, estimates that the national incidence rate of FAS is generally thought to be around 2/1,000 live births reports FAS incidence rates among specific Indian populations which reach 15.6/1,000 live births.

c. Lack of Other Resources

There are not within states, certainly not within Mississippi which has great budget shortfalls and the lowest per capita income of all states, the resources which will be needed to adequately serve Indian children. Similarly, unless the Congress appropriates additional funds for the Bureau of Indian Affairs or the Indian Health Service, there will not be adequate funding levels from either of these agencies.

2. We recommend that the reauthorization, if possible, address the limitation by Indian Health Service of contract health service (CHS) payments for care for handicapped children. In particular, we recommend that the IHS not limit its CHS services to Priority I care in the case of handicapped children.

3. We strongly recommend that the Department of the Interior remain the lead agency for serving Indian children who live on reservations and we strongly oppose any efforts by the DOI to relinquish this responsibility to either the states or the IHS. While we understand many of the obstacles which the DOI is facing in carrying out its responsibilities here -- many of which are associated with a reluctance to request additional funds, we do not feel that young Indian children will be better served by simply transferring the responsibility. Instead, the Department

of the Interior should be strongly urged to accept its responsibility for all infants and toddlers on reservations -- not simply those with BIA funded or operated schools -- and to prepare budget requests, initiate service programs, and coordinate efforts accordingly. Thank you.

Chairman OWENS. Thank you.

Ms. Trish Thomas.

STATEMENT OF TRISH THOMAS, PARENT, LAGUNA/OTOE-MISSIOURIA TRIBES, LAGUNA PUEBLO, NEW MEXICO

Ms. THOMAS. Good morning. Chairman Owens and committee members, my name is Trish Thomas. I am of the Laguna and Otoe-Missiouria tribes. I reside on the Laguna Indian Reservation in New Mexico.

I am here today to share some of my thoughts about the needs of Indian families with young children with disabilities. These are based on my own experience as a recipient of early intervention services that have been both positive and negative for myself and my family.

I would like to begin by telling you about my two children. First, my daughter, Kori, who was considered normal at birth, but at age four months showed signs of respiratory distress. She was found to have numerous allergies to foods and other substances. She also has asthma and seizures. Kori began postural drainage therapy at age four months every four hours for six months.

Two years later, I gave birth to my son, Travis. When Travis was born he was put into a Newborn Intensive Care Unit because of an irregular heart beat. He was kept in there for three days and released with a clean bill of health.

When I left the hospital, I knew something was wrong with him, so I continued to take him to the Indian Health Service to have him evaluated. Every time they would tell me he was okay. I soon got labeled as an over-reactive mother. It wasn't until 2.5 years later that my feelings and concerns were validated and he was finally diagnosed as having a bilateral hearing loss that was in the severe to profound range.

It was a long, hard and painful struggle to obtain the services that we, as an Indian family, were comfortable with. Our services were what they called individualized. Though in the beginning we were put into a system and made to fit into the services and time frames that really met the professionals needs and not ours, it wasn't until we told them that we, as Indians, sometimes function in a different manner when it comes to the special needs of Indian children. Only then did our early intervention program change and become more family-centered and culturally responsive.

In the past, you have heard compelling testimony affirming the family as the primary learning environment for children under six years of age. This points out the critical need for parents and professionals to function in a collaborative fashion.

One would think that now, five years later after the passage of Public Law 99-457, Part H, that we would be further along. Unfortunately, I must advise you today that Indian infants and toddlers are still getting lost in that bureaucratic shuffle. Today, many parents still experience the same problems that I experienced in obtaining services for my children.

These problems result from poor coordination of services between various Federal and State programs which are supposed to serve Indian children and their families. We still have to deal with our

State and private agencies, along with the Bureau of Indian Affairs, Indian Health Services and our own tribal agencies.

Interagency collaboration and coordination is crucial if families are to successfully get help for their special needs infants and toddlers. There is still a pressing need for agreement among Federal and State agencies that provide services for our special needs Indian infants and toddlers; we still have not seen these agreements being developed and implemented.

Let me share an example. In 1989 several concerned Indian parents and professionals got together and wrote up comments to the BIA about its proposed Memorandum of Agreement with IHS to implement Part H services to Indian infants and toddlers. We spent hours on a letter that outlined our suggestions for improving services on Indian reservations. We never saw any result of our effort. To my knowledge, this agreement was never completed nor did we receive an answer to our correspondence or to our telephone calls to the BIA.

To me it only makes sense that since IHS is the first agency to have contact with Indian infants and toddlers that they should be a key piece to the Part H program, receiving assistance from the BIA and the tribes. A way must be found to ensure that the BIA works more collaboratively with IHS and the States.

I am also a parent member of the New Mexico Part H Procedural Safeguards Committee. In this capacity, I have participated in work groups to help make our State's Part H policies and system responsive to Indian infants and their families.

We have struggled with the numerous Federal requirements of Part H, such as the eligibility criteria, IFSP time-frames, and procedural safeguards. Many of these Federal regulations seem inflexible. The system will not meet the needs of Indian infants and toddlers and their families.

For example, the Part H time-frames for referral, evaluation, and the IFSP development do not allow for Indian parents to spend time consulting with their extended family. While this may not be true of all families, it is particularly critical for traditional Indian families who require extended family input into this decision-making process. If they are not allowed to do this, they will lose their trust in their service agency and may not proceed with early intervention services.

Indian families need to be given options of other services available that address their children's developmental needs. We need to be allowed to perform traditional Indian ceremonies before professional services for our children with special needs are sought by requests from child care providers. This process will only enhance western services for our special needs children.

The Federal Part H requirements and regulations should allow States—in fact, encourage them, to fashion a system of early intervention that works for all its citizens by recognizing the differences in the way families from culturally different ethnic groups live and care for our children.

Mr. Chairman, committee members, thank you for hearing my thoughts on improving Part H services.

[The prepared statement of Trish Thomas follows:]

STATEMENT OF TRISH THOMAS, PARENT, LAGUNA/OTOE-MISSIOURIA TRIBES, LAGUNA PUEBLO, NEW MEXICO

Chairman Owens and committee members, my name is Trish Thomas. I am of the Laguna and Otoe-Missiouria tribes. I reside on the Laguna Indian reservation in New Mexico. I am here today to share some thoughts about the needs of Indian families with young children who have disabilities. These are based on my own experience as a recipient of early intervention services that have been both positive and negative for myself and my family. I would like to begin by telling you about my two children. First my daughter, Kori, who was considered normal at birth, but at age four months showed signs of respiratory distress. She was found to have numerous allergies to foods and other substances. She also has asthma and seizures. Kori began postural drainage therapy at age 4 months every four hours on the hour for six months. Two years later I gave birth to my son, Travis. When Travis was born he was put into a Newborn Intensive Care Unit because he was experiencing an irregular heart beat. He was kept in for three days and released with a clean bill of health. Although when leaving the hospital I still felt that something was not right. I continued to be concerned about my son's development, so I continued to seek medical help only to be told he was alright. My concerns and feelings were not validated until 2½ years later when Travis was finally diagnosed as having a bilateral hearing loss that was in the severe to profound range.

It was a long, hard, and painful struggle to obtain the services that we as an Indian family were comfortable with. Our services were to be what they called individualized. Though in the beginning we were put into a system and made to fit with the services and time-frames that really met the professionals needs, not our needs. It wasn't, we told them, that we as Indians sometimes function in a different manner when it comes to our special needs Indian children. Only then did our early intervention program change and become more family-centered and culturally responsive.

In the past, you have heard compelling testimony affirming the family as the primary learning environment for children under six years of age. This points out the critical need for parents and professionals to function in a collaborative fashion. One would think that now, five years after the passage of Public Law 99-457, Part H, we would be further along. Unfortunately, I must advise you today, that Indian infants and toddlers are still "getting lost in the bureaucratic shuffle." Today, many parents still experience the same problems I experienced in obtaining services for my children.

These problems result from poor coordination of services between various Federal and State programs which are supposed to serve Indian children and their families. We still have to deal with our State and private agencies, along with the Bureau of Indian Affairs (BIA), Indian Health Services (IHS), and our own tribal agencies. Interagency coordination is crucial if families are to successfully get help for their children. There is still a pressing need for agreements among Federal and State agencies that provide services for our special needs Indian infants and toddlers. Yet, we still have not seen these agreements being developed and implemented.

Let me share an example. In 1989 several concerned Indian parents and professionals got together and wrote up comments to the BIA about its proposed Memorandum of Agreement with IHS to implement Part H services to Indian infants and toddlers. We spent hours working on a letter that outlined our suggestions for improving services on Indian reservations. We never saw any result of this effort. To my knowledge, this agreement was never completed, nor did we receive an answer to our correspondence or to our telephone calls to the BIA.

To me it only makes sense that since IHS is the first agency to have contact with Indian infants and toddlers that they should be a key piece of the Part H program, receiving assistance from the BIA and the tribes. A way must be found to ensure that the BIA works more collaboratively with IHS and the States.

I am also a parent member of the New Mexico Part H Procedural Safeguards Committee. In this capacity, I have participated in work groups to help make our State's Part H policies and system responsive to Indian infants and their families. We have struggled with the numerous Federal requirements of Part H, such as the eligibility criteria, IFSP time-frames, and procedural safeguards. Many of these Federal regulations seem inflexible. The system will not meet the needs of Indian infants and toddlers and their families. For example, the Part H time-frames for referral, evaluation, and IFSP development do not allow for Indian parents to spend time consulting with their extended family. While this may not be true of all families, it is particularly critical for traditional Indian families who require extended family input into decision-making. If they are not allowed to do this they may lose any trust in their service agency and may not proceed with early intervention services.

Indian families need to be given options of other services available hat address their children's developmental needs. We need to be allowed to perform traditional ceremonies before pursuing professional services for our children with special needs. This process will enhance western services for our special needs children.

The Federal Part H requirements and regulations should allow States, in fact encourage them, to fashion a system of early intervention that works for all its citizens by recognizing the differences in the way families from diverse ethnic groups and cultures live and care for their children.

Mr. Chairman, committee members, thank you for hearing my thoughts on improving Part H services.

Chairman OWENS. Thank you.

I have Ms. Gayle Underdown on the witness list, but I understand we have other representatives of the family. Will the representatives of the Underdown family proceed?

STATEMENT OF GAYLE AND STEVE UNDERDOWN, PARENTS

Mr. UNDERDOWN. Good morning.

We are Steve and Gayle Underdown, parents of three children, Andrew, Matthew and Christiana. We appreciate the time you have given us to talk about our experiences with early intervention.

Our State's ICC logo is one of the family under the rainbow. To us it signifies the promise of protection, affirmation and inclusion of the family at all levels.

We would like to relate the events that formed our family's rainbow to you. Like a rainbow, the storm and the clouds had to come first.

In 1986 we were blessed with the event of our second of three children. Thirty-one hours after an extremely difficult and exhausting labor, Matthew Steven Underdown arrived at 7 lbs 8 oz. with a completely black, bruised face due to a facial presentation and he had grand mal seizure.

On the third day of his life, an intern at the hospital informed me, away from my wife, that Matthew probably had Down Syndrome. I was devastated. Where was my son who was just in the hospital for a seizure? Now he was being diagnosed as mentally disabled. The joy I felt at his birth had turned into feelings of guilt, disbelief, fear of the unknown and anger.

A family is the most vulnerable and broken when their dreams are shattered no matter what their socio-economic status is. The support and the empowerment they receive at that critical time will carry them through many years to come.

Early intervention gave us something tangible to do that couldn't be done later. It helped us impose some control on a seemingly uncontrollable situation.

Early intervention has provided the basis for Matthew's developmental pyramid and has started us on a road to empowerment and advocacy.

We hope that Matthew will continue to be an integral part of the community and mainstreamed when he reaches public school. We hope that Matthew will have caring, well-trained public school teachers who will not see him as a label, but take him where he is and enthusiastically work with him and his friends so they can learn from each other.

We hope Matthew will be able to graduate from his neighborhood high school and not from a self-contained school for the disabled. We hope that Matthew will be able, should he wish, to attend a college of his choice and pursue a career in order to live independently and become a taxpayer.

You see, early intervention will be meaningful and successful only when normal children are themselves mainstreamed at birth with their peers who have disabilities. Many of these children will go on and earn educational degrees and will have had valuable experiences to teach in their own classrooms. It is our dream that Matthew and other children with disabilities will reach their own full potential and will help educate our world.

Ms. UNDERDOWN. Our family has been involved in over 44 different services during the past four years of Matthew's life and we have some general observations to share with you.

First, in affirming and empowering the family when they are the most fragile is crucial and the services should adopt philosophies to accomplish that goal.

Second, labeling a child who is young and just in those early tender years is dehumanizing. Our children are not disabilities; they are people. We look forward to the day when a label is not the ticket to services.

Third, an array of accessible services are needed to meet the family's unique and changing priorities. Time may be of assistance then, but it is an enemy to families and when services are unavailable due to inaccessibility or waiting lists, precious time is lost and families are frustrated. States who have adhered to the time lines should be rewarded.

We hope for a flexible system focused on informal and existing community resources, such as preschool, churches, day cares and volunteer advocacy and parent organizations. Service coordinators need to be fully informed of these services to share with their parents.

Fourth, it is imperative for families to be empowered in leadership roles in order to continually shape policies focused on quality, family and friendly services. Parents should also be in such higher positions as service coordinator and resource referral. As a rainbow's colors are combined and one blends into another, so should our service system so that all parts are represented and all parts are of equal importance.

I would like to tell you some of the specific services that have been especially helpful to our family. We felt significant support from advocacy groups such as ARC. Non-traditional therapies have been especially responsive to us. Volunteer swimming and horseback riding programs have enhanced Matthew's physical development.

Our mainstream experiences have probably been our most value and this has been Matthew's best year yet in a Suzuki preschool receiving related services from the preschool program and our Family Infant Preschool program. The coordination between these seven individuals and three organizations have been fabulous. Respite has also been excellent and FIPPS has been an excellent source of information and empowerment.

The Exact English Sign Language that we taught Matthew before he was able to talk himself has significantly enhanced his communication.

We would like to have seen some cross communication between service providers especially within the medical community. We would have also like to seen better quality of services and personnel in traditional handicapped services. Programs are only as good as the people who are in them and who are teaching and adequate funding is essential to make this goal to be realized.

We would have also liked to have had more integrated therapies treating Matthew in his natural learning environment.

Finally we would have liked to have referrals to parent networks to empower us and to gain from their positive and negative experiences.

At the end of next month, Matthew will have completed his most optimal developmental years. We are confident that he is well prepared, but we don't hold that assumption for all children with disabilities.

Please make sure that States implement this law for children with disabilities and their families. With all the negative events that are happening in the world, you all can be really proud of your involvement in this law that surely does make a positive difference in our world.

As for the Underdowns, instead of living in a far away land over the rainbow, we find ourselves a whole family in North Carolina, under the rainbow protected by it's promise and it's support.

[The prepared statement of Gayle and Steve Underdown follows:]

TESTIMONY OF GAYLE AND STEVE UNDERDOWN

TO THE
UNITED STATES' HOUSE OF REPRESENTATIVES
SUBCOMMITTEE ON SELECT EDUCATION

WITH RESPECT TO
REAUTHORIZATION OF PART H
AND
PART B, SECTION 619
OF THE
INDIVIDUALS WITH DISABILITIES EDUCATION ACT

APRIL 11, 1991

TESTIMONY OF GAYLE AND STEVE UNDERDOWN

STEVE'S TESTIMONY:

Good morning. We are Steve and Gayle Underdown, parents of three children, Andrew, Matthew and Christiana and appreciate the time you have given us to talk about our experiences with early intervention. Since Matthew was born around the same time as PL99-457, we felt a strong tie to it and have seen the parallels between Matthew's development and the law's development. Our state's ICC logo is one of the family under the rainbow and it signifies the promise of protection, affirmation, and inclusion of the family at all levels. It is also significant bacause sometimes it feels like the only place PL99-457 will be realized is somewhere over the rainbow. We would like to relate the events that formed our families rainbow to you. Like a rainbow, the storm and the clouds had to come first.

In 1986 we were blessed with the event of our second of three children. We were prepared for the birth in the usual way of an expected and welcowed pregnancy - the nursery, showers, breathing techniques, names, exercises, birth announcements, and preparations for our older son who was not quite two. The big day arrived May 27 at 8a.m. with the first contractions. We had an exciting and joyous ride in the car together remembering the birth of Andrew and how this was even better because we knew the joy that awaited us which we hadn't known the first time around.

Thirty one (31) hours after an extremely difficult and exhausting labor, Matthew Steven Underdown arrived and 7 lbs. 8 oz. with a completely black, bruised face due to a facial presentation, and had a grand mal seizure. Arrangements were made for Matthew to be transferred to another hospital because of the seizure. I went ahead and my wife followed with her mother. They were delayed by a farm vehicle that allowed them to witness a beautiful double rainbow that so often follows an unexpected and hard summer thunderstorm. (In S.C. summer is definitely underway in May.) This one sign would have tremendous significance to us in the days and years to come.

On the third day of his life, an intern at the hospital informed me, away from my wife, that Matthew probably had Down Syndrome. I was devastated. Where was my son who was just in the hospital for a seizure? Now he was being diagnosed as mentally disabled! The joy I felt at his birth had turned into feelings of guilt, disbelief, fear of the unknown and anger. I had already felt so connected with love to Matthew because it was obvious his birth was painful, and I had barely left his side throughout. Now I felt Matthew must also be hurting inside if he had Down Syndrome. Gayle was also devastated and felt like she would never smile or laugh again and that our lives were over even though we were only 25 and 27. I suppressed as much natural emotion as I could and focused only on positive feelings. This suppression contributed to later problems. After an intense and unexpected emotional roller coaster we took Matthew home. In all our preparations, we never planned for this event.

Although our feelings have significantly charged, simply recalling those days brings back that deep pain as if it is happening right now, and this story is not for pity but to show you the depths of despair one can fall to when reality is so far away from expectations and the norm. Had we been left alone in that place, we never would have smiled or laughed again, and our lives would have been over - especially Matthew and Andrew's. For a family is the most vulnerable and broken when their dreams are shattered no matter what their socio-economic status is, and the support and empowerment they receive at that critical time will carry them through many years to come.

Fortunately, we were not left in despair. We found out about early intervention from our birth attendant, and this was the first ray of light that shone through our stormy clouds to form our rainbow. Early interventions gave us something tangible to do that couldn't be done later. It helped us impose some control on a seemingly uncontrollable situation.

GAYLE'S TESTIMONY:

Our family has been involved in numerous programs and services and have some insight as to what we see as helpful. First, families are very vulnerable and fragile at the point of receiving the news and caring well trained professionals can make the difference between remembering the event as a horror story or a nurturing experience.

Second, labeling a young child is crushing for families. We refused services from the DMR because we felt is was not worth the price of labeling Matthew. We felt Matthew would lose his identity if we labeled him mentally retarded. We fully support the change in the law from handicapped child to child with a disability. Our children are people first.

Third, an array of services need to be available to meet the family's unique and changing priorities, and the services must fit the family instead of vice versa. For our family, the services provided by the state did not seem aggressive enough to stimulate our son's naturally suppressed senses due to his Down Syndrome. We found private programs in other states that provided the intensity we felt our family needed in order to maximize the window of opportunity we had been given in these first five years. We were setting the foundation for Matthew's eventual intelligence, and we needed something more tangible than "kitchen talk". The state supported day program was unacceptable to us, and the private early intervention program was not, at that time, a program we considered to be of quality. Within the year, they had a change of staff and location, and we enrolled Matthew in the program, but were put on an 18 month waiting list. Time is not a family's friend, and there is great frustration when time slips away while on a waiting list. Hopefully waiting lists will cease to be an issue with the implementation on PL99-457, and the states who have adhered to the timelines should be rewarded. While we waited, we contracted our own related services and therapies and started an infant stimulation program in our house with other families on waiting lists. Over the past four years, Matthew's and our needs have changed as he has grown. We firmly believe that each family is unique and best able to identify their needs. What worked for us will not necessarily work for anyone else. We would advocate a system that is flexible and comprehensive that includes all community resources in their information network - especially the nontraditional resources such as churches, day cares, private preschool and volunteer organizations. It is through these resources that our family has found the most valuable services.

Fourth, in order for this system to be comprehensive, it is imperative for families to be decision makers not only in their own plan but in the local, state and federal plans. Families have more roles to play than just "emotional storyteller" and "fund raiser" for programs and states, and they must be recognized in decision making roles on all levels. As a rainbow is formed and one color blends into the next, so it should be in our delivery system of early intervention so that no part is missing and all parts are of equal importance.

We would like to tell you some of the services that were especially helpful. The nontraditional therapies fit into our idea of what early intervention means. In terms of physical development, the volunteer programs of swimming, horseback riding and playful parenting gymnastics were most useful. Matthew's integration in the community through a mainstreamed preschool in S.C. and his current Suzuki School of the Arts have been the best experiences we have had! Matthew has shown the greatest amount of improvement in these nurturing environments where he can learn from his peers and can teach others the lessons he has to offer. Both programs have commented on what an asset he is to the class and how much more complete everyone's learning is. For our family, the respite offered by our county Mental Health has been excellent! Our other children are included, it is done in our home, and the workers are top notch! In terms of interagency collaboration, this year we have seven individual professionals in three separate organizations all working together and an affirming system of communication between all of them. The Family Infant Preschool Program has been an excellent source of information, support, empowerment and programming. All three of our children look forward to their sibling workshop days in the fall and spring. Before Matthew could talk, we bought a sign language dictionary and taught him Exact English in sign. We believe this significantly enhanced his communication skills and understanding of language.

Some of the things that would have been helpful to us are cross communication of service providers - expecially within the medical community with us receiving copies of all communication. This coordination has been extremely frustrating and lacking a family focus. We would also have liked to see better quality of services and professionals in the mainline of handicapped services. Energetic, creative and well trained professionals truly make a difference, and a program is only as good as the people working there. We would have liked to be treated as an entire unit instead of Matthew as a separate entity. Often the therapists we contracted during the first two years treated him out of context of his natural learning environment and were unwelcoming to our other children. It would have been a blessing if we could have been given phone numbers and names of parents to call to talk about their experiences. This would have helped empowered us as parents and enabled us to pull from their experiences, both positive and negative, in order to make intelligent decisions. We would have liked to been offered complete information about all available options - traditional and nontraditional- in the community, state and nation and to be served without the dehumanizing indignity of labeling our child.

Early intervention has provided the base of Matthew's developmental pyramid and has started us on the road to empowerment and advocacy. Our hopes for Matthew are many. First, we hope that Matthew will continue to be an integral part of the community and mainstreamed when he reaches public school, receiving individual services which he may require to help his education parallel his friends who do not have disabilities. We hope that Matthew will have caring, well-trained public school teachers who will not see him as a label, but take him where he is and enthusiastically work with him and his friends so they can learn from each other. We hope Matthew will be able to graduate from his neighborhood high school and not from a self contained school for the disabled. We hope Matthew will be able, should he wish, to attend a college of his choice and pursue a career in order to live independently and become a taxpayer. For you see, early intervention will be meaningful and successful only when 'normal' children are themselves mainstreamed at birth with their peers who have disabilities. Many of these children will go on and earn educational degrees and will have had valuable experience to teach in their own classrooms. That is our dream, that Matthew and other children with disabilities will reach their own full potential and will help educate our world.

We've shared our initial feelings regarding our reaction to becoming parents of a child with disabilities, and those are very risky to share because most people want parents to say how the disability didn't ever matter to them. It's helpful for you to see where we started in order to appreciate how very far we've come. Matthew has been every bit the joy that our other two children have been to us; but more than that, he has added to much to our family. These are lessons we never would have learned without this opportunity. We see him as one of our unique children who loves the beach, playing the box violin, Vilvaldi's Four Seasons, Sesame Street, his Paw-Paw's boat, pretending to be a bus driver and playing outside. We have gotten to know the person who came to be part of our family instead of the problem that accompanied him. It's scary to think of the joys we might have missed if we hadn't seized hope and put it on wheels. I'm sure we were able to do that because we knew we were providing the best start in life for Matthew.

At the end of next month, 80% of Matthew's intelligence will be determined. Our family has made wise investments for Matthew during these years, and we are confident he will grow to be the best person he can, making significant contributions to society. Unfortunately that's only because he was lucky to have a family of economic resources, and a child's development should not be left as a privilege for children of income and educated parents. As for the Underdowns, instead of living in a far away land somewhere over the rainbow, we find ourselves a whole family living in North Carolina, somewhere under the rainbow, protected by it's promise.

Ms. **Underdown**. This is Matthew Steven Underdown.

Chairman **Owens**. Welcome to the panel, Matthew.

Thank you very much.

Ms. **Underdown**. This is what Public Law 99-457 is all about.

Chairman **Owens**. Thank you very much.

We are certainly pleased to hear from all you in affirmation of what Public Law 99-457 has begun to do. I think you have made quite a number of recommendations in your statements.

Let me just pause for my colleague who has just arrived. Some of the witnesses have people accompanying them and we were not able to put them all on Panel I, so we have made three panels. This is a panel of three sets of parents. So we are going to stop at this point and if you have any questions for these three sets of parents, we will take those questions.

I have just one quick question: Did you have any problems learning about the intervention programs from the beginning? Was information available to you immediately or did you have to go searching to find out that the programs existed?

Ms. **Thomas**. Chairperson Owens, we were not directed to any type of early intervention program. When our son was diagnosed, we were just left hanging. We went out and sought services on our own and questioned IHS as to what was available. They did have the equipment at the time to test him and we were not told that they had the ability to contract for us to go outside. But once he was diagnosed, we were just left hanging and no one really told us what direction as to where we could have looked for service.

Chairman **Owens**. Is it safe to say that the system was not very friendly to you?

Ms. **Thomas**. No, it was not.

Chairman **Owens**. Any other comments?

Ms. **Underdown**. We had similar comments to Ms. Thomas. We also searched for our own intervention. When we received information about early intervention and when we went to look at it, we were faced with long waiting lists. Matthew has been on several waiting lists, one of which lasted over 18 months

Mr. **Underdown**. This was in his first two years of life.

Chairman **Owens**. Any other comments?

Ms. **Williams**. In my case, the special education program was there and the staff there. When they learned about Magaline, they were there for me, so I didn't have any problems as these two families did.

Chairman **Owens**. You were steered through the system to the proper people by the social workers?

Ms. **Williams**. Yes

Chairman **Owens**. Any questions from any members of the panel this point?

Mr. **Ballenger**. Yes, if I may. Mr. Chairman, I was just wondering if an the Indian reservations, and I should probably ask Pam this: Is there a fair amount of prenatal care offered in the system? Because when you mention the number of birth defects and so, I was just wondering if the lack of prenatal care might have caused low birth rate and that sort of thing

Ms. **Dalme**. Possibly, yes. There are programs there, however, some people don't seek the help of those programs. Some do and some don't. There are various problems. I think everyone would be a little bit different.

The distance. The Indian Health Services on the Choctaw Reservation, the only service we have, is basic medical care. There are no specialty doctors there, so anytime there is any type of problem, if the mother does have diabetes or if she has seizures or any special kind of problem, we have to transport them to Jackson, which is 75 miles away, to a medical center that is basically a training medical center, to assist us.

Chairman OWENS. Mr. Payne.

Mr. PAYNE. I just wanted to say with regard to the question about WIC and programs for early prenatal and infant care, I am just pleased to see that on yesterday the Budget Committee approved $2-$3 million in additional funding for 1992 and that will increase the WIC funding to the tune of about $300 million over the next four to five years to finally get to full funding for WIC.

I could appreciate the fact that only a small portion of eligible persons for the WIC program are being served because the Federal Government has not fully funded WIC. So I think that is a step in the right direction. I think the only way we were able to win this battle for full funding for WIC is because we were able to convince corporate leaders—and there were five top corporate leaders who appeared before the Budget Committee about a month ago, Bob Winter from Prudential Insurance Company in my district and the CEO of AT&T and others—who said we needed full funding for WIC.

We have to really start before school, even before a child is delivered. So, hopefully, we can see increased services all around in particular areas which are traditionally underserved.

Chairman OWENS. Mr. Jefferson

Mr. JEFFERSON. I wanted to ask a question with respect to the services to your Indian children. Do you know that in addition to dealing with the pertinent agency that provides the service would the person you are talking about happen to be with the Bureau of Indian Affairs, Indian Health Services and tribal agencies? You call for greater interagency coordination.

Do you have any specific recommendations as to how that ought to be addressed or attempted to be addressed by this committee?

Ms. THOMAS. Major Owens, Representative Jefferson, I think a starting point would be going through the tribes for their input, because I think right now a lot of the tribes would like to have input into the system.

They are willing to offer their assistance. They may not be willing to offer it financially but they have ways of working it because they know the system. They know how we, as Indians, work with our special needs children.

I think that you can get some really good insight from working with that local level, like the local BIA. The local BIA school has really done a lot. I think I have seen tremendous improvement in them working towards Part B out at Laguna.

Once again, I think they still need a lot of assistance literally, in pulling them all together. I don't know if my recommendation would be to work with the tribes and the Indian Health Services, because like I said, there are initial ones we need right now. We kind of have a little more trust in the Indian Health Services. Because of the historical interaction with the Bureau of Indian Affairs, that poses a barrier. I think if the Indian Health Service was maybe to initiate that, it might flow a little better.

Chairman OWENS. Thank you.

Mr. Serrano.

Mr. SERRANO. Yes. Thank you Mr. Chairman.

First of all, Mr. Chairman, let me thank you for your initiative on this hearing, and secondly apologize for being late. I was at a WHIPS meeting where we were dealing with votes on the budget.

I hope my question has not been covered during the testimony. If it has, I apologize to you.

Seeing all of you here together from so many different parts of our Country makes me wonder if there are agencies or organizations throughout the Country, or that you may know of, that do try to bring parents together to share not only their experiences, but their needs.

I was wondering if any of you could comment on whether there is outreach that you may be aware of that would involve you. Of course, I am going to be totally surprised when I find out that this is an organization.

Ms. UNDERDOWN. In the State of North Carolina, we have parent-to-parent centers that reach out to families. We also do our central directory, the family support network. That is another way of tying families together. Advocacy groups such as the Association for Retarded Citizens is another consumer group.

Our State ICC has taken a stand to really involve parents in the decision-making process whereby we have parents and professional co-chairs of the council and all of our standing committees. North Carolina is taking strides to network parents together.

Chairman OWENS. Thank you.

Ms. THOMAS. Chairman Owens, Representative Serrano, in New Mexico we have an EPICS program which stands for the Education of Parents of Indian Children with Special Needs. That is a parent training organization that is national and they work specifically with native American families who have children with special needs.

We also have Pro Parents Teaching which is another parent organization and we do have Protection and Advocacy which is another group there in New Mexico.

But because I think, as Indians, our needs are a little different and the way our communication interaction styles differ, I think the EPICS project has really been instrumental in getting and assisting native American parents, of special needs children in acquiring services and getting them to them.

Mr. SERRANO. So you feel that because your needs are different an effort has been made to reach out to you and try to bring it together.

Ms. THOMAS. Yes. They do utilize other Indian parents who have gone through the service system so that we can relate.

Mr. SERRANO. I know the Chairman obviously has and will continue to make this observation, but I would like to join him in saying that it is really good for us to have parents come before the Congressional subcommittees and help us in our deliberations.

One last comment on Matthew. I noticed that amongst the many things that I am sure you can say are very encouraging about Matthew's development, is that the minute you held him up, he looked at the camera. In my profession, that is a very good sign. What we need to teach him now is to look at the commercial cameras at the same time because that is for the six o'clock news.

Thank you.

Chairman OWENS. I want to thank all of you. I would like to proudly state that we have federally funded Parent Training Information Centers under the discretionary part of the same Act. They are asking for an increase in funding to provide an early intervention program. We would appreciate any information you have about how those Parent Training Centers work in your particular area or whether you know about them, et cetera. You may submit that information or any other comments or recommendations, in writing within the next ten days for the record.

Thank you again for agreeing to testify.

Our next panel includes officials and program personnel. Ms. Deborah Booth, Special Projects Manager, East Coast Migrant Head Start Center, Head Start Project, Chapel Hill, North Carolina; Ms. Carol Ann Baglin, Director, Infants and Toddlers Program, Baltimore, Maryland; Dr. Jane Wiechel, Director, Division of Early Childhood Education, Ohio State Department of Health, Columbus, Ohio.

We have copies of the written testimony which will be entered into the record in its entirety. I would like for you to elaborate on any particular points you would like to make or discuss anything that you might not have included in your written testimony.

You may proceed, Ms. Booth.

STATEMENT OF DEBORAH BOOTH, SPECIAL PROJECTS MANAGER, EAST COAST MIGRANT HEAD START PROJECT, ARLINGTON, VIRGINIA

Ms. BOOTH. Good Morning. I am Deborah Booth, Special Projects Manager with East Coast Migrant Head Start Project, whose administrative offices are in Arlington, Virginia.

I am pleased to be able to testify today on behalf of the East Coast Migrant Head Start Project and Migrant Children and Families.

Our project has been providing continuity of Head Start services since 1974 for children from birth to five years of age in 12 States along the East coast of the United States from Maine to Florida. Services are provided by contracting with agencies in local communities. We presently have 21 contractual arrangements with delegate agencies and the East Coast Migrant Head Start Project, Florida Branch.

Children qualify for this program if their families meet the Head Start income guidelines and if their families have travelled in the past twelve months for the purposes of agricultural work. Currently, we are annually serving 5,600 children; two-thirds of these children are younger than the age of three.

In the program year 1989–90, East Coast Migrant Head Start Project served 227 infants and toddlers and 203 preschool age children diagnosed with disabilities, according to the Head Start diagnostic criteria.

We are eager that Part H of Public Law 99-457 be reauthorized. One of the primary strengths of the Law is the requirement for parental involvement. Migrant families have frequently not been recognized as essential participants in the development of their children as it relates to the child's disability, diagnosis and treatment.

Mobility, isolated living conditions, language and diverse cultures establish barriers that are not easily overcome without the support of a law mandating their parents participation. It is especially crucial for our families since they must secure sources in different places in different systems, that they become empowered and independent to assure continuity of the services for their children.

We are most concerned about how States will assure access to appropriate services for migrant infants and toddlers and their families. Part H planning by States needs to systematically address the barriers created by migrant families' mobility, poverty, isolated living conditions and language and cultural differences. Concerns related to the reauthorization of Part H are as follows:

Our first concern is the State definition of "developmentally delayed" and "at risk." Under the current legislation, States may develop their own definitions. This sets up the potential for a migrant child to qualify for services in Florida, but be unable to secure services in, for instance, North Carolina. In this situation, the child could possibly be without services from March until November of each year while the family was in North Carolina.

Virginia, a three-year-old attending one of our Florida centers, has ataxia which causes her severe balance problems and gross motor delays. Virginia's family moves to Georgia, North and South Carolina during the summers to do short crop work. Virginia's mother is currently having to drive back to Florida throughout the summer to secure services for her child.

We recommend that an amendment to the law needs to be developed that would provide basic standard definitions for "developmentally delayed" and "at risk."

We also would recommend that financial incentives be incorporated to assist States in serving children at risk.

Our second area of concern is meeting the needs of culturally diverse children and their families. The children in our project are represented by a various and wide range of different cultures. This poses several problems for the families in securing appropriate services.

There is a severe shortage of bilingual and culturally sensitive diagnosticians, therapists and service providers. The Child Find and public awareness activities are not reaching the migrant population. Announcements and materials are usually in English and at a high literacy level. Many community agencies are not only not actively seeking to search out migrant children, but some are even refusing to do so.

Our primary recommendations in this area are that migrant families and advocates be included on all levels at the Federal, State and local levels of the Interagency Coordinating Councils and that migrant families be included at all levels of Part H planning.

We also would recommend that incentives are provided in the personnel preparation and demonstration grants to recruit people from the cultural groups represented by the migrant population.

Our final concern is the timely delivery of services. Because of the mobility of the migrant families, the timely delivery of services is crucial. There are several factors involved in this issue.

It is not unusual for families to have to wait three to six months for appointments for diagnostic evaluations. This means that the family will probably have left the area before an appointment can be scheduled. As the family moves from place to place, this problem may be repeated again and again. A child may go for over a twelve-month period without ever having received an evaluation or services.

Migrant children are not given priority because they will not be in the area for long-term follow-up care. It is easier for agencies to assume that the children and families can receive services elsewhere. It is easier to let it become someone else's problem.

An example of what currently happens to migrant children is Jose, an eight-month-old with developmental delays in all areas of development. He was referred for diagnostic evaluation on February 19th.

The evaluation was scheduled for March 7th. On March 6th, the evaluation center contacted the center's staff and the family to inform them that they were canceling the evaluation. The reason that they gave the family and staff was that since Jose's family was moving to Texas in April, he could just wait and get the evaluation there or they could wait until they returned back to the area in the Fall.

Our primary recommendations in this area are that in order to ensure that migrant children and their families receive services in a timely manner, we urge that the requirements for referral within two days of identification and completion of the diagnostic evaluation and the IFSP process within the forty-five days time limit being maintained in the legislation. States should have to develop and implement a plan for enforcing these time lines.

In conclusion, I would like to say that the East Coast Migrant Head Start Project values highly the results of early intervention. We urge that not only Part H of Public Law 99-457 be reauthorized, but that these recommendations be incorporated into the law. This will enable the needs of the migrant children with disabilities and their families to be met, as they move working in agriculture, providing food for our tables.

On behalf of East Coast Migrant Head Start Project and migrant children and families, I wish to thank you for your concern for children with special needs and thank you for the opportunity to testify today.

[The prepared statement of Deborah Booth follows:]

COMMITTEE ON EDUCATION & LABOR
U.S. HOUSE OF REPRESENTATIVES

Subcommittee on Select Education
Hearing Reauthorization of
Part H of PL 99-457

Submitted by:

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SUBCOMMITTEE ON SELECT EDUCATION

HEARING ON REAUTHORIZATION OF PART II OF PL 99-457

April 11, 1991

Testimony of East Coast Migrant Head Start Project

I am Deborah Booth, Special Projects Manager at East Coast Migrant Head Start Project in Arlington, Virginia. I am pleased to have this opportunity to testify on behalf of East Coast Migrant Head Start Project and migrant children and families.

East Coast Migrant Head Start Project has been providing continuity of Head Start services to migrant children, ages birth to five years, and their families since 1974 in twelve states on the east coast of the United States from Florida to Maine. Services are provided by contracting with agencies in local communities who have the capability, interest and dedication to provide quality Head Start services to migrant children and their families. There are presently twenty-one contractual agreements with these local agencies and the ECMHSP Florida Branch. Children qualify for the program if their families meet the Head Start income guidelines and if they have travelled during the past twelve months for the purposes of agricultural work. At the present time approximately 5,600 children are served annually; two thirds of those children are younger than three years of age.

In the program year 1989/90, ECMHSP served 227 infants and toddlers and 203 preschool age children diagnosed with disabilities, according to the Head Start diagnostic criteria:

Diagnostic Category	Numbers of Children
Blind	1
Visually Impaired	19
Deaf	1
Hearing Impaired	39
Physically Impaired	64
Speech Impaired	48
Health Impaired Includes: * developmentally delayed (prematurity failure to thrive) * epilepsy * severe asthma/chronic upper respiratory infections * blood disorders (ie. sickle cell, leukemia) * cancer * Neurological disorders * severe cardiac conditions * autism * renal failure/kidney conditions	220
Mental Retardation	11
Serious Emotional Disturbance	20
Learning Disabled	7

ECMHSP is eager that Part H of Public Law 99-457 be reauthorized. One of the primary strengths of the Law is the requirement for parental involvement. In Part H, the required focus on the use of the family's resources, priorities and concerns for the development of the child's Individualized Family Service Plan (IFSP), the requirements for parental involvement at all stages of service delivery and decision-making, and the requirements for parent training and counseling as allowable costs are all of primary importance. Migrant families have frequently not been recognized as essential participants in the development of their children as it relates to the child's disability, diagnosis and treatment. Mobility, isolated living conditions, language and diverse cultures establish barriers that are not easily overcome without the support of a law mandating their participation. It is especially crucial for our families since they must secure services in different places, with different systems, that they become empowered and independent to assure continuity of care and services for their children.

The experience of East Coast Migrant Head Start Project reveals that early intervention with diagnosis and care in those first three years, together with active participation of the family in the process, significantly improves the child's potential development and develops understanding and cooperation of the family. The family then becomes the advocate and a prime source for accessing the delivery of services.

The Part H early intervention program represents a new federal focus and commitment to infants and toddlers with disabilities. It is also requiring that states develop family-driven service delivery systems.

East Coast Migrant Head Start Project is most concerned about how states will assure access to appropriate services for migrant infants and toddlers and their families. Part H planning by states needs to systematically address the barriers created by migrant families' mobility, poverty, geographic isolation, and language and cultural differences. Concerns related to the reauthorization of Part H are as follows:

A. State definitions of "developmentally delayed" and "at risk". Under the current legislation, states may develop their own definitions for "developmentally delayed" and "at risk". Therefore, migrant children may qualify in one state, then when the family relocates to a different geographic area to work in the crops, the child may not qualify. A child may be diagnosed in Florida, move to North Carolina and need follow-up care. If the child does not meet North Carolina's definitions, then the child could go without services from March until November, when the child returns to Florida. This would clearly be detrimental to the child's developmental progress and an untenable position for the parents.

Virginia, a three year old attending one of our Florida centers, has ataxia which causes her severe balance problems and gross motor delays. She has broken the same arm twice due to falls. Virginia's family moves to Georgia, South and North Carolina during the summers to do short crop work. Virginia's mother has to drive back to Florida for follow-up appointments throughout the summer or wait until they return to Florida in the fall in order to secure services for Virginia.

<u>Recommendations</u>

1. An amendment to the law needs to be developed that would provide basic standard definitions for "developmentally delayed" and "at risk".

2. Incorporate financial incentives to the states to exercise their option to serve "at risk" infants and toddlers, which would also include environmental and biological risk factors.

B. <u>Meeting the needs of culturally diverse children and families.</u> There are several issues of major concern in this area. The children in our project are from diverse cultural backgrounds: Mexican, Haitian, Guatemalan, Puerto Rican, Afro-American, etc. This poses several problems for the families in securing appropriate services.

1. There is a severe shortage of bilingual diagnosticians, therapists and service providers. Non-discriminatory assessment and culturally sensitive service delivery is extremely difficult to achieve.

2. Agencies frequently will not provide translators and sometimes refuse to see the child and family unless the family can bring an translator with them. Families have reported that they have been unable to secure services because of this.

3. There is widespread unavailability of culturally sensitive service providers. For example, Andre, a one year old Guatemalan child, cannot sit or crawl independently. His pediatrician told his mother that the reason he was not sitting or crawling was because he was lazy since she had carried him around in a back pouch. He refused to refer the child for services or further diagnostic evaluation.

4. Migrant parents are not included in the planning of Part H services at the federal, state or local levels.

5. Child Find and public awareness activities are not reaching the migrant population. Announcements and materials are usually in English and require a high level of literacy. Many community agencies not only are not actively seeking out the migrant children with disabilities, but some refuse or put off serving the children. The family then moves to another location and begins the battle to secure services for their child again.

Recommendations

1. Include in the Statement of Assurances that the states will include migrant parents and migrant service providers and advocates in Part H planning.

2. Include in the policies and practices:

    a. Agencies should recruit and hire bilingual staff.

    b. Interpreters should be provided by the service agency at no cost to the family.

    c. Assessment tools should be evaluated before they are used for cultural appropriateness.

    d. States should include training in cultural issues in their personnel preparation and Part H training.

    e. Child Find agencies should actively seek to serve migrant children and should include migrant parents and advocates in their planning of strategies to identify and serve migrant children.

    f. Interagency Coordinating Councils at the federal, state and local level should include migrant parents and advocates.

3. Provide incentives in the personnel preparation and demonstration grants to recruit people from the cultural groups represented in the migrant population and include migrant parents and advocates on advisory and planning boards.

C. Timely delivery of services. Because of the mobility of migrant children and their families, the timely delivery of services is crucial. There are several factors involved in this issue.

1. It is not unusual for families to have to wait three to six months for appointments for diagnostic evaluation. This means that the families will probably have left the area before an appointment is available. As the family moves, this situation can be repeated again and again; a twelve month period can pass without a diagnosis or service plan for the child. The reasons given for this delay are a lack of enough diagnosticians experienced in infant and toddler assessment and too few diagnosticians for overloaded systems.

2. Migrant children are not given priority because they will not be in the area for long-term follow-up. It is easier for agencies to assume the child can receive services elsewhere. It becomes "someone else's problem".

   An example of what currently happens to migrant children is as follows. Jose, an eight month old infant with developmental delays in all areas of development, was referred for diagnostic evaluation on February 19, 1991. The evaluation center did an intake interview with the parents and center staff on March 4. Jose was approved for evaluation at this time. His evaluation was scheduled for March 7. On March 6, the evaluation center notified the parents and staff that they were cancelling the evaluation appointment. The reason given was that since Jose's family was migrating in April, they would not evaluate him. The parents were told to have the child evaluated in Texas or wait until the fall when they would return to the area. It will be months before Jose receives any services. His parents will have to continue to bear the worry and concern of not knowing why Jose is not developing normally and will not be provided with training in how to assist him develop.

3. Due to agencies' high caseloads and lack of staff, it may take several months to obtain reports and recommendations from diagnosticians and other service providers.

<u>**Recommendations**</u>

1. In order to ensure that migrant children and their families receive services in a timely manner, we urge that the requirements for referral within two days of identification and completion of diagnostic evaluations and IFSP development within forty-five days of the referral be kept in the legislation. States should have to develop and implement a plan for enforcing these timelines.

2. To address the severe shortages of appropriately trained diagnosticians and service providers, states should be monetarily and programmatically facilitated to develop comprehensive, culturally sensitive in-service and pre-service training programs for professionals and paraprofessionals at the local and state levels. University personnel preparation programs should be adequately funded.

In addition to the issues and recommendations presented here related to migrant children and their families, East Coast Migrant Head Start Project supports the recommendations of The International Division for Early Childhood of the Council for Exceptional Children.

In conclusion, I would like to say that we at East Coast Migrant Head Start Project value highly the results of early intervention. We urge that not only Part H of Public Law 99-457 be reauthorized, but that these recommendations be incorporated into the law. This will enable the needs of migrant children with disabilities and their families to be met, as they move working in agriculture, providing food for our tables.

On behalf of East Coast Migrant Head Start Project and our migrant families, I thank you for your commitment to children with special needs and for the opportunity to share our concerns. We will be pleased to provide any further information or assistance on this or future issues.

Chairman OWENS. Thank you.
Ms. Carol Ann Baglin.

STATEMENT OF CAROL ANN BAGLIN, DIRECTOR, MARYLAND INFANTS AND TODDLERS PROGRAM, GOVERNOR'S OFFICE FOR CHILDREN, YOUTH AND FAMILIES

Ms. BAGLIN. Good Morning. My name is Carol Ann Baglin and I am the Director of the Maryland Infants and Toddlers Program with the Governor's Office for Children, Youth and Families.

As a birth mandate State, Maryland has evidenced a long history of commitment and services to infants and toddlers. We were one of only a few States with State regulations which required special education services to all handicapped children from birth. We have enthusiastically embraced this new legislative initiative because of its broader commitment and its coordinated interagency early intervention on behalf of infants and their families.

The comprehensive and family-centered nature of this legislation has necessitated certain variations from the previously existing educational model of services, including an expanded eligibility without specific identification or labeling of the handicapped; expanded services to support the family and include a case management function; tracking and data collection with a single point of entry for all services for infants and toddlers; and transition plan for appropriate programs for three-year-olds.

Funding alternatives is very important. A major factor within the system of special education in Maryland is that the State Department of Education and the local education agencies have been required to provide free and appropriate education programs via funding of Public Law 94-142 and State and educational funds. Under Part H these costs are to be assigned as a part of a financial responsibility to the appropriate agency.

Additionally, the services are to be provided via a combination of resources within the State including local and State contribution, Federal sources, private insurance payments and as appropriate, a sliding fee scale. Most importantly, agreements must be developed between the agencies that clearly delineate the financial responsibility for the variety of services available for children and their families.

Legislation was enacted in 1990 by the Maryland General Assembly which established the Interagency Coordinating Council at the State level and the Infants and Toddlers Program within the Maryland Statute. It also included the designation of the lead agency functions to the Governor's Office for Children, Youth and Families. It did not provide funding.

The support and influence of the Governor's Office is critical, however, in soliciting the cooperation and support of multiple State agencies and programs. The attempts to administer programs within peer agencies with them providing leadership, administration, supervision and dispute resolutions is extremely time consuming, frequently counterproductive and misleading. The major thrust of our State interagency efforts in Maryland has been to provide direction under a broader effort and to develop policies and procedures which will be directed towards community-based planning.

Maryland is about to enter its fifth year. In August of 1988, we developed specific components of our State plan through model demonstration projects, in nine of our counties. These projects focused on the development of the interagency agreements, the assignment of financial responsibility, models of case management and the development of a State form for the individualized family service plan. Each Project was permitted to identify their own lead agency and to organize themselves in their own manner to reflect their community-based service system.

Five had local health departments as their lead agency, two selected education and one had a private/non-profit corporation. Most of these projects were able to identify and provide services from their existing resources. However, funding gaps exist in the areas of transportation, respite care, occupational therapy and case management.

In 1989, all 24 local jurisdictions in Maryland were provided with Part H funding for purposes of planning their local system. In October, 1990, all local jurisdictions within our State were also provided funds to develop an individualized family service plan and to provide case management services.

We are planning in July of 1991 that we will complete the system of the early intervention system in the State.

Maryland has limited definition of their population to the developmentally delayed. The estimate at full implementation if each eligible infant and toddler was to be located, identified and provided services, is that approximately 4,000 infants and toddlers and their families would be served. In our recent most reliable count, we recorded that approximately 3,200 infants and toddlers had individualized family service plans.

The State is in the process of piloting an at-risk initiative in order to identify the utilization rates of our estimated 29,000 at-risk infants and toddlers.

The Maryland State Interagency Coordinating Council meets monthly. The general public is invited and our participants are generally over 100. The public interest has been very great in spite of the number of physical relocations and reorganizations at the State level.

We also have developed the Maryland Family Support Network which provides support to the parents and literature that is targeted to parents of the local community.

In analyzing our four years of experience in implementing the provisions of Part H, we have identified the following issues that I would like to bring to your attention.

Funding. The planning and implementation efforts for this program have gone forward in Maryland with the dual purpose of developing an effective program of early intervention services and recognizing the fiscal realities of the late 1980s. Many of the eligible children are already receiving services in some form from a public or private agency. In many instances, prior to the implementation of Part H, these services were provided in a vacuum, independent and unrelated to other services being provided throughout the system. The functional mandate of this program is to provide for coordinated services with both the service and financial responsibilities assigned to the appropriate agencies.

All of these early intervention services are being provided to the children and their families in an attempt to prevent more costly and expensive services later in their life. An effective program in the 1990s will produce savings in both institutional and out of State placement costs in the next century.

An analysis of the identified Federal funding sources in the Act indicates that many of these do not directly provide services to infants; or the States, by the State plan application, may limit the inclusion of infants in their service populations.

In addition, not all of the funding sources are equally available to each State. Case management is essentially an unfunded service. There are insufficient Part H dollars available to use for case management and few other programs provide case management services across the board to infants and toddlers.

My recommendations are that funding be increased for case management and be made available to cover other gap services; that there by incentive funding for States that are prepared to take the plunge and enter the fifth year of this program; that you link the availability of other identified funding sources to the requirement that they implement Part H; that you continue census basis for funding since universal screening is essential to adequately identify birth to three year olds, who may be developmentally delayed, have an established condition or may be at risk; that you continue access to Chapter 1 funds based on the child count; that you medicaid all early intervention services for birth to three year olds; that you increase appropriation levels as incentives to States, so that they continue to participate and then link some of that access funding to State match; and that you modify the requirement that States providing services prior to 1986 must provide these same services at no cost to the current expanded Part H eligible population.

Authority of the Case Manager. Case managers have well defined functions, responsibilities, and activities, both in the actions and regulations. With families receiving comprehensive and multi-agency services, these additional responsibilities are burdensome to personnel who are providing the direct services.

Dedicated case managers may be a more appropriate selection as the case manager. However, existing language which requires that the case manager be from the profession most immediately relevant to the infant's and toddler's or family's needs restricts the types of personnel who can function in this capacity.

In addition, the case manager has a great many designated responsibilities with no corresponding authority to ensure the implementation of such an interagency plan.

My recommendation is to expand the options for the types of personnel that can function as case managers and to clarify the authority of the case manager and the role and relationship of the lead agency to the case manager.

In the area of definition. Part B of the definition "have a diagnosed physical or mental condition—"

Chairman OWENS. Ms. Baglin, could you just, because of the time problem, limit yourself to those recommendations.

Ms. **BAGLIN**. Okay.

That you delineate the criteria for high probability more specifically or provide additional examples and that you have a differentiated entitlement for at-risk populations; that you include family preservation services, not just services for the family that directly relate to the developmental needs of the child; that you link family services to Title XIX and other specific funding to families without regard to their income eligibility.

In the area of transition at age three: that you fund additional Head Start for three years to ensure a continuum of programming and that you target the child care block grant money to create incentives for early intervention services to be provided within child care settings.

That you require a coordinated system of policies and services and funding for early intervention services from birth to mandatory school age.

Lastly, I would like say that I think this program has a wide range of hope of us being able to improve some of the dismal statistics not just in the area of drop-out or teen pregnancy, drug-exposed infants, its a tremendous opportunity for the States and it would be easier if we had some changes.

[The prepared statement of Carol Ann Baglin follows:]

April 11, 1991

Hearing on the Reauthorization of the Early Intervention Program
Part H

Subcommittee on Select Education
Committee on Education and Labor
U.S. House of Representatives

Written Testimony
Carol Ann Baglin
Director, Maryland Infants and Toddlers Program
Governor's Office for Children, Youth, and Families

REAUTHORIZATION ON THE EARLY INTERVENTION PROGRAM

> **"There is nothing more difficult to take in hand, more perilous to conduct, or more uncertain in its success than to take the lead in the introduction of a new order of things."** **Jean-Jacques Rousseau**

P.L. 99-457 launched an ambitious mandate for unprecedented interagency collaboration in the delivery of early intervention services. Maryland welcomes this opportunity to testify on the reauthorization of P.L. 99-457. We have enthusiastically embraced this legislative commitment to early intervention on behalf of infants and toddlers and their families. As a Birth Mandate State, Maryland has evidenced a long history of special education services to infants and toddlers and was one of only a few States with regulations which required special education services to all handicapped children from birth through age twenty. P. L. 99-457 has provided Maryland the opportunity for planning the enhancement of this educational model through systematic integration of health, education, and social services and the expansion of the statewide system of early intervention services for eligible infants and toddlers and their families. The Maryland Infants and Toddlers Program initiative formalizes the commitment at the state policy level to the importance of a continuum of prevention and early intervention services.

BACKGROUND

Prior to the passage of P.L. 94-142 Maryland provided limited early intervention services through targeted public programs, private organizations, and parent associations. Access to early intervention services was limited by geographic location, ability to pay, and the severity of the handicap. Parents began to challenge the practices that excluded handicapped children, and through a consent decree and State Board Resolution in 1974 and 1976, special education services were required to be provided from as soon as the child could benefit. These were phased in so that beginning in SFY '81, all handicapped children birth through age twenty-one were eligible to receive special education and related services in Maryland.

P.L. 99-457, Part H, enacted in 1986, provided Maryland with a phase-in period to enhance and expand this statewide system of interagency services for developmentally delayed infants and toddlers and their families. The comprehensive and family-centered nature of this legislation necessitated certain variations from the existing educational model of services, including:

•EXPANDED ELIGIBILITY REQUIREMENTS The eligibility definition, requiring the identification of a specific handicapping condition, was expanded to include those who are experiencing developmental delays, or have diagnosed conditions which have a high probability of resulting in developmental delay and at the state's discretion, individuals who are at risk of having substantial developmental delay.

•EXPANDED SERVICES An infant and toddler could be eligible for any one or more of the prevention and early intervention services through the health department, education, and social services, independent of a need for "special education services" or "special instruction." The family also became eligible for services depending on their needs assessment related to the child. The case management function to provide interagency coordination of the individualized family service plan expanded access and provided a model for the family to negotiate the system of services on behalf of their child and family.

Finally this program moves away from the emphasis that all services be provided within the framework of the educational system by requiring interagency delivery of early intervention services. This approach includes and supplements many of the services provided by education, as well as the services provided by health and social services. Services are to be coordinated by the case manager under the individualized family service plan (IFSP).

• TRACKING Statewide, interagency tracking and data collection are important components in the implementation of P.L. 99-457. This is being viewed as a single point of entry system for all services for infants and toddlers, birth through age three. The purpose of the tracking system is the early identification of the developmental problems of these infants and linkage with services to meet their needs and the needs of their families. The program will assist parents to have access to and contact with services, primarily through the implementation of the tracking system and the case management model. It will also provide important aggregate data for reporting and planning purposes related to this population (birth to three year olds), and establish a statewide, interagency system of data collection for infants and toddlers in order to plan and improve services in a systematic way.

• TRANSITIONING A plan for each eligible infant and toddler was required to be developed for transitioning to appropriate programs for three to five year olds.

•FUNDING A major factor within the system of special education in Maryland is that the Maryland State Department of Education and the local education agencies are required to provide free and appropriate education programs. This cost has been born primarily via the funding provided by P.L. 94-142 and state and local funds. Under P.L. 99-457 for birth to three year olds, these costs are to be assigned as a part of the financial responsibility to the appropriate agency. Additionally the services are to be provided via a combination of available resources within the State including local contribution, state contribution, other Federal sources such as Medicaid, private insurance payments, and a sliding scale family contribution. More importantly, agreements must be developed between the agencies that clearly delineate the financial responsibility for the variety of services available to young children and their families.

OVERVIEW OF IMPLEMENTATION

P.L. 99-457 has provided Maryland with a unique opportunity for planning, developing, and implementing our statewide comprehensive, coordinated system of early intervention services. On October 25, 1988 Governor William Donald Schaefer signed Executive Order 01.01.1988.15, which established Maryland's Infants and Toddlers Program. The Subcabinet for Children and Youth, through Executive Order 01.01.1989.12, monitors the Infants and Toddlers Program to insure interagency coordination and delivery of early intervention services. Legislation was enacted by the 1990 Maryland General Assembly which established the Interagency Coordinating Council and the Infants and Toddlers Program in Maryland Statute, Article 49D, including the designation of the Lead Agency functions to the Governor's Office for Children, Youth, and Families.

The Maryland Infants and Toddlers Program has the overall planning, administration, and supervision responsibilities for Part H of the 1986 Amendments to the Individuals with Disabilities Education Act. Planning efforts have been underway since 1987, with statewide implementation beginning on October 1, 1990. Specific features of Maryland's system include •single point of entry, •trans-agency case management, •services oriented to the child in the context of the family, •services delivered within community-based systems, and •services financed through a combination of public/private payments.

State attention has recently been focused on the needs of overlapping groups of children and the need for a coordinated service continuum for these children and their families. This legislation enacted policies which are consistent with meaningful changes in how Maryland's professionals, paraprofessionals, private providers, and agencies deliver services - the merging of resources, the involvement of the family, and the coordination of the delivery of services both in the public and private sector.

The greatest challenge of this program for Maryland is to provide an integrated system of the many existing public and private services and resources for infants and toddlers and their families who are in need of a continuum of prevention and early intervention services. State interagency efforts, through the Subcabinet for

Children, Youth, and Families, have provided direction for the coordination of early intervention services.

The support and influence of the Governor's Office for Children, Youth, and Families is critical in soliciting the cooperation and support of the multiple state agencies and programs. Attempts to administer programs with peer agencies providing leadership, administration, supervision, and dispute resolution are time consuming, frequently counter productive, and misleading. Agencies in Maryland at the state and local level are competing for the same fixed resources, both dollar and human. There has been some reluctance to support a new initiative which will be competing for the same resources. The major thrust of our state interagency efforts has been to provide direction for the coordination of early intervention services, to enhance the current systems, and to maximize funding opportunities in all sectors. The State in a much broader effort has been trying to develop policies and procedures to facilitate and enable community-based planning.

The outcomes of this early intervention system include the statewide organization of services for these infants and toddlers and their families using combinations of existing services, family outreach, innovative funding patterns, and as needed specialized services to be utilized to fill the gaps in the service delivery system, in order to enhance the capacity of families to meet the needs of their children. Accomplishing the objectives of P.L. 99-457 is dependent upon the extent to which local jurisdictions can develop their own capacity to implement integrated community based service delivery systems.

IMPLEMENTATION

The Maryland Infants and Toddlers Program, in conjunction with the Interagency Coordinating Council, and the Maryland State Department of Education, the Department of Health and Mental Hygiene, and the Department of Human Resources, began in August of 1988 to develop specific components of the state plan requirements through Model Demonstration Projects in nine counties. These Projects focused on the development of interagency agreements, assignment of financial responsibility, models of case management, and the development of the Individualized Family Service Plan. Each Project was permitted to identify their own lead agency and to organize themselves to reflect their community based services. The results were remarkably successful in 8 out the nine jurisdictions. 5 had health as their lead, two selected education, and one had a private/non-profit. Most of the projects were able to identify and provide services from existing resources. The local funding gaps and resources parallel what we identified at the state level, respite care, specialized day care, and family counseling. Funding gaps exist in the areas of transportation, respite care, OT, and case management.

In 1989, all local jurisdictions were provided funding for planning their local interagency system. Nineteen Local Planning Grants (24 local jurisdictions), the Case Management Coordination Initiative in conjunction with the Casey Project, and the Tracking and Data Collection System (19 local jurisdictions) participating in direct grants for the approved specific purpose of developing the model components at the local level. These components included the development of the Individualized Family Service Plan (IFSP), including the process for multidisciplinary evaluations and assessments of the child and the needs and strengths assessment of the family; the role and description of the case manager; design of agreements between participating agencies; process and models for assignment of financial responsibility; and an integrated interagency data system to track infants and toddlers with developmental delay or at-risk of delay, and their families.

In October of 1990, all local jurisdictions within the State of Maryland were provided funds to develop an individualized family service plan for each eligible infant and toddler and their family, and to provide case management services. In July, 1991 the coordinated interagency system of early intervention services will be fully implemented statewide.

ELIGIBLE POPULATION

Maryland has limited their population, by definition, to the developmentally delayed. Each state has the discretion to target services to the at-risk infant and toddler, in addition to the developmentally delayed population. Some states are including some, if not all, of the biologically and environmentally at-risk populations.

The national average for developmentally delayed in this age range is estimated to be 2.0% of the total birth to 3 population. Applying this average to Maryland's population, the estimate at full implementation, if each eligible infant or toddler was to be located, identified, and provided services, is that approximately 4,000 developmentally delayed infants and toddlers and their families would be served. On February 1, 1991 the local jurisdictions reported that they were currently providing early intervention services through individualized family service plans to approximately 3,200 developmentally delayed infants and toddlers.

MARYLAND INTERAGENCY COORDINATING COUNCIL

The Maryland State Interagency Coordinating Council meets monthly. The general public is invited to each meeting and given the opportunity for input and discussion. The attendance at the State ICC averages between 80 to 100 participants per month. The public interest has remained consistent inspite of a number of physical relocations, change in meeting hours, and reorientation of objectives by the ICC. The ICC takes its role of advice and assistance seriously and has begun to assume the leadership necessary to become a force in developing the statewide early intervention system. Local Interagency Coordinating Councils provide assistance to the local lead agencies and meet regularly with the State ICC.

FAMILY SUPPORT NETWORK

THE MARYLAND FAMILY SUPPORT NETWORK is comprised of families of children with special needs who live in all regions of the State. The primary purpose of this organization is to provide the "FAMILY PERSPECTIVE" to the Maryland Infants and Toddlers Program and the State Interagency Coordinating Council in the planning, implementation, and ongoing activities of Public Law 99-457, Part H. The main objective of the Family Support Network is to increase the scope, intensity of awareness, and knowledge of Public Law 99-457, Part H by families on a statewide basis. This is achieved through: the provision of technical assistance, information, and support to develop Family-to-Family Networks on local levels that will enhance family capabilities in building partnerships for policy and program development; information and support to enhance family skills in the identification, accessing, and utilization of resources and supports; and issue workshops to obtain family input for policy and program development.

The Family Support Network was more formally defined and expanded with the hiring of a Family Coordinator by the Infant and Toddler Program. A video was created from the March 1989 conference "Building Family Strengths," for use in family and professional training. The first edition of the Family Support Newsletter was mailed July 1989. A Family Strengths and Needs Task Force was organized to develop, the Guiding Principles for Identifying "Families Strengths and Needs."

Through the Mentorship Program members of the Maryland Family Support Network meet with newly appointed Interagency Coordinating Council Parent Representatives in order to familiarize them with procedures and ongoing activities related to P.L. 99-457 Part H. Assistance through home visits, reference materials, informative presentations, consultations, and ongoing technical assistance will be provided. This program is available to all parent representatives at both the State and Local level.

SIGNIFICANT ISSUES AND RECOMMENDATIONS:

- ### FUNDING

  Issue: The planning and implementation efforts for this program have gone forward with the dual purpose of developing an effective program of early intervention services for infants and toddlers and recognizing the fiscal realities of the late 1980's. Many of the eligible children are already receiving services in some form from the public or private agencies. In many instances prior to the implementation of P.L. 99-457, these services were being provided in a vacuum, independent and unrelated to services being provided elsewhere in the system. The functional mandate of this program is to provide for coordinated services with both the service and financial responsibilities assigned to the appropriate agency. All of these early intervention services are being provided to the eligible child and their family in the attempt to prevent more extensive and costly services later in life. An effective program in the 1990's will produce savings in both institutional and out of state placement costs in the next century.

An analysis of identified funding sources in the Act indicates that many of these do not directly provide services to infants and toddlers or may by State Plan Application limit the inclusion of infants in their service populations. In addition not all of the funding sources are equally available to each state. Case management is essentially an unfunded requirement. There are insufficient Part H dollars available to use for case management and few other programs provide case management services across the board to infants and toddlers and their families.

Recommendations:

√Increased funding available for case management and other gap services

√Create incentive funding for states entering Year 5

√Link the availability of other related funding sources to implementation of Part H

√Continue census basis for funding since universal screening is essential to adequately identify birth to three year olds, who may be developmentally delayed, have an established condition, or who may be at risk

√Continue access to Chapter 1 funds based on the child count

√Include priority language for infants and toddlers in federally identified funding sources

√Medicaid all early intervention services for birth to three year olds without regard to income limits

√Increase appropriation levels as incentives to states to continue to participate and progressively link access to a state matching dollar %

√Modify the requirement that states providing services prior to 1986 must provide these same services at no cost to current expanded Part H eligible population

- <u>AUTHORITY OF THE CASE MANAGER</u>

Issue: Case managers have well defined functions, responsibilities, and activities. With families receiving comprehensive and multiagency services theseadditional responsibilities are burdensome to personnel who are also providing the services. Dedicated case managers may be a more appropriate selection as the case manager. Existing language which requires that the case manager be from the profession most immediately relevant to the infant's and toddler's or family's needs restricts the types of personnel who can function in this capacity. In addition, the case manager has designated responsibility but no corresponding authority to ensure the implementation of an interagency individualized family service plan.

Recommendation:

√Expand the options for the types of personnel that can function as case managers

√Clarify the authority of the case manager and the role and relationship of the lead agency to the case manager

- DEFINITION

Issue: Part B, §672(1) of the definition, "have a diagnosed physical or mental condition which has a high probability" does not provide sufficient guidance to states for implementation. Some states have developed a laundry list of conditions which may or may not have "high probability." Others are using multiplicity of factors or conditions as a decision making component.

The issue of services to at-risk infants and toddlers is significant for long term prevention and early intervention efforts. A study of the demographic and fiscal impact of providing at-risk services in Maryland was completed. Limited at-risk services will be provided on a pilot basis from 1992-1995 to determine the specific implications for utilization and costs.

Recommendation:

√Delineate criteria for high probability more specifically or provide more examples

√Differentiated entitlement for at-risk populations

- FAMILY SERVICES

Issue: Services to families through the individualized family service plan are a critical component in ensuring that the development of the infant will improve. Families need to remain intact and functioning to support the special needs of these infants and toddlers. Infants develop best in the context of their family and within their community. Services to families need to be expanded and clarified to support this goal.

Recommendation:

√Include family preservation services, not just services to meet the specific developmental needs of the child

√Link family services to Title XIX and other funding specific to families without regard to income eligibility

- TRANSITION AT AGE 3

Issue: Transition services are important for each eligible infant or toddler whether these include Part B services for handicapped preschoolers or community-based programming to support developmental gains. At this time there are few programs available within the community for three year olds not qualifying for Part B services. Very few Head Start programs have slots for three year olds available and enriched day care services do not uniformly exist.

Recommendation:

√Fund additional Head Start for 3 year olds to ensure a continuum of programming

√Target child care block grant money to create incentives for early intervention services provided within child care settings

AND

- BIRTH TO FIVE CONTINUUM

Issue: There is significant variability in access to services between age three and the mandatory school age. The Maryland State Department of Education continues to provide technical assistance, dissemination of materials, and promotes the adoption of promising practices to local education agencies. Examples of technical assistance include: State sponsored inservice training for general and special education personnel, related services and support personnel in all program serving handicapped children. Adoption of promising practices include model programs such as HCEEP and the development and dissemination of resource packets. Additionally, print and media materials have been developed by education staff for use by local education agencies. Flexibility in allowing discretion as to coordination promotes locally applicable responses to coordination of birth to five services. There are, however, gaps in the system which create significant lapses in services for developmentally delayed children at age three.

Recommendation:

√REQUIRE A COORDINATED SYSTEM OF POLICIES, SERVICES, AND FUNDING FOR EARLY INTERVENTION SERVICES FROM BIRTH TO MANDATORY SCHOOL-AGE.

- PERSONNEL

Issue: Personnel development within the context of education agencies is adequately addressed and funded through state education agencies within the targeted funding for the comprehensive system of personnel development plan. Part H has broader training responsibilities. Lead agencies, in general, and particularly those lead agencies without access to education CSPD funds, do not have sufficient Part H funding to set aside the necessary money to adequately address the training needs of health departments and social service agencies. In addition, local community providers have little access to training initiatives throughout the state.

Recommendation:

√TARGET FUNDING TO LEAD AGENCY FOR COMPREHENSIVE SYSTEM OF PERSONNEL DEVELOPMENT FOR EARLY INTERVENTION SERVICES

SUMMARY

Early intervention programs are being asked to look at families in a new way. The family is much different today than ten years ago. Many more mothers are working. Many young children are growing up in single parent families, and many single women are having children at a younger age and with less prenatal care. The families of the 90's will need early intervention systems which are more accessible, more comprehensive, more responsive and flexible, and which are enabling for the family.

Families often define their goals for their children in the longer view, in terms of the quality of life they want their children to have. Responsive services for families of children with special needs can provide parents with the support and the coping skills that will allow them to access their own strengths, ultimately resulting in a higher quality of life for the family and a financial and human savings.

Services to families with special needs must contribute to the balance of their lives and give attention and support to the needs of all the family members.
This program represents a significant opportunity for us to demonstrate our commitment to coordinated services designed for individuals with special and unique needs-- which are supportive to their families, and reflective of their community.

Submitted by
Carol Ann Baglin
Director, Maryland Infants and Toddlers Program
Governor's Office for Children, Youth, and Families
State of Maryland

Chairman OWENS. Thank you.
Dr. Jane Wiechel.

STATEMENT OF JANE WIECHEL, PH.D., DIRECTOR, DIVISION OF EARLY CHILDHOOD EDUCATION, OHIO DEPARTMENT OF EDUCATION

Ms. WIECHEL. Good morning. Mr. Chairman and members of the committee, my name is Jane Wiechel. I am the Director of the Division of Early Childhood Education for the Ohio Department of Education. In that capacity, I have responsibility for administering the Part B fund.

I am here in support of reauthorization today. I am providing testimony on behalf of Ohio's Early Intervention Collaborative Council as a representative and member of that council.

Just to share with you, I guess, some of the indication of the impact and obviously Ohio's interest in both of these programs, if we look at Part H, the potential impact for services in Ohio would be over 26,000 children who have the potential to benefit in the services that the Part H program could provide. In terms of looking at Part B, we are looking at over 20,000 children who could benefit from these services.

At this point, I would just like to share with you briefly some of the progress and share with you why I think that is important for you to hear. In terms of Part H and Part B, Ohio has participated since the passage of Public Law 99-457 in 1986.

With the over $7 million Federal funds for Part H, that have come into Ohio, we have established an early intervention council. More importantly, we have been able to establish 88 local collaborative groups. Those collaborative groups have received most of the funding. We have provided those funds for those local collaborative groups to look at all of the components that need to be in place in terms of providing comprehensive and coordinated services for young children and families.

As we look at beginning of year four of Part H, we can say to you that all of those required components are in place in Ohio and over 13,000 children will benefit from those components and those services.

In terms of Part B, we have been able to successfully implement a mandate, pass rules on the implementation of Part B in our State. With the $8 million, we have been able to initiate a number of services that will help us long-term in terms of how we are going to implement Part B.

More importantly, I share with you that the Federal dollars have truly been an incentive in our State because we have $23 million in State support that I believe is there because of what has happened with Part B and Part H funding.

I share those with you for two important reasons. Number one, I say to you that the incentives that were intended to be a part of Part H and Part B are happening. In Ohio, we have children receiving additional services. We have a mandate. We have rules and we have people talking to each other.

I say to you in Part H, it has made a difference that we have now 88 counties which have local collaborative groups who are very seriously trying to address and put in place programs to be responsive to the kinds of issues we heard from the parents preceding us this morning with their testimony. So it has made a difference.

More importantly, I suggest to you that the key factor I see from a State perspective has been the flexibility that has been in place with both of these parts. I share with you that I think that we hope that in the reauthorization that that focus on flexibility will be continued. It has allowed, I am sure, other States like Ohio the opportunity to put together a structure and an organization that best meets the needs of our families and our needs within our State. So we would encourage you to continue to do that.

In terms of issues, I am not going to get into those. As you are aware, there are quite a number of details in the testimony I provided. I would like to focus on some of our recommendations and point out that we recommend at this point the reauthorization without major changes. The major point of that being that we believe that any extensive statutory or regulatory changes at this point really could interfere with the time and the continued State participation due to all of the efforts that are currently underway.

The other point I would say—and you are well aware from the very eloquent opening statement from Chairman Owens—is that we agree with you in terms of the need to look at Part H participation in the greater scheme of things as we look at needs and services for all children and families. We believe that this approach and the provisions that are allowed under Part H, must be continued because they do demonstrate it. They have a very positive effect on the development of infants and toddlers and their families.

Very quickly, then, I would state to you that we are not without our issues in our State. As you have heard from those families, and I tell you at a State level from a State perspective, we are dealing with issues in terms of State policy and coordination and implementation.

As already pointed out by two other representatives, we also face very serious financial situations in our State.

However, we do have some suggestions that we believe will have tremendous impact as States look at trying to implement these from our State perspective. Hopefully, we will try to make a difference so we can address the issues that the parents so eloquently stated before us.

One is that we would look at trying to enhance the ability of States to move forward with full implementation of Part H by offering a differential of funding and waiver mechanism. Once again, this mechanism will address and reward those States who have made a good faith effort and have all of the services in place to begin year five, but also to provide the continued incentive to those other States who are not quite there so that they will be able to continue to plan and get the types of competency services in place that need to be there.

As I mentioned earlier, in order to make all of that happen, we are also suggesting the continued support and increased appropriations for the program as States move forward for full implementation of Part H.

We also would suggest that to increase the likelihood of coordination and funding of programs at the State level, coordination needs to occur first at the Federal level and recommend that a Federal inter-agency coordinating council be established in the statute to assist us at the State level because we have recognized that the inter-agency collaborative council is a very critical component and truly has advanced collaboration and efforts under way in our State.

We would like to recommend, however, that the current limit of 15 council members be increased to 30 council members. It would allow at least in our State, and I am sure many other States, full participation from the Agency and parents that need to be represented.

With that, we would suggest that the parents also be increased proportionately to that number and also would recommend that we look at not—that we can also include parents of children with disabilities with children who are older.

That way, we can involve those parents on that council and also gain from their perspective an experience that they have had in terms of trying to deal with the system.

The fourth recommendation would be to look at one that has implications not only for Part H, but for Part B. That has to do with the technical age of three. We believe that there needs to be a transition between Part H and Part B that is going to be critical in terms of systems and families not getting delays in service, not being terminated from services. We are suggesting that there should be an amendment to Section 619 that would allow States to set the technical age for three. That also, there should be within the reauthorization of Part H changes that would allow Part H funds to be used to pay for certain services up to that technical age.

I guess, but not least, I know that there have been suggestions made to enhance this notion of a seamless system of birth to five; that we should look at this inter-agency collaborative council as the body that could facilitate that in the State. While we support that concept, our suggestion is that it not be put into the statute as a requirement; that it be left up to State discretion; that, in fact, it be one other mechanism that States would have to look at in terms of how to implement that system. Placing it in statute may undermine or undo some of the already-existing groups that are in place and are working well.

I thank you for the opportunity to present my testimony and share our suggestions.

[The prepared statement of Dr. Jane Wiechel follows:]

TESTIMONY PRESENTED BY: JANE WIECHEL, PH.D.
Director, Division of Early Childhood Education
Ohio Department of Education
(Representing the Ohio Interagency Early
Intervention Council)

Mr. Chairman and members of the Subcommittee. My name is Jane Wiechel. I am the director of the Division of Early Childhood Education for the Ohio Department of Edcuation. I appreciate the opportunity to provide testimony in support of the reauthorization of the Part H program of the Individuals with Disabilities Education Act. The testimony I will be presenting on behalf of the Ohio Interagency Early Intervention Council has been prepared with input from the Department of Health, the Part H lead agency.

Ohio has a statewide population of nearly 11 million. As many as 26,854 infants and toddlers with developmental delays or disabilities in Ohio could be eligible for the early intervention program, about 6% of Ohio's children under age three. If infants and toddlers at risk for delays in development are included in the eligible population, it is estimated that an additional 17% of the birth to three population, over 76,000 infants and toddlers in Ohio, could be eligible for services.

Coupled with the 20,330 children ages three through five years of age eligible for Part B services the associated costs for the provision of comprehensive services are staggering. However, Ohio has made a commitment to participate in the Part H and Part B programs. I will describe progress made in Ohio since 1986, discuss problematic issues, and make recommendations pertaining to reauthorization.

Progress In Implementing Part H and Part B

The state of Ohio has participated in both Part H and Part B since passage of P.L. 99-457 in October of 1986. In March of 1987 Health was designated as the lead agency; a state level interagency coordinating council was established; and interagency planning groups (called county collaborative groups) were organized in each of Ohio's 88 counties. These groups included parents of children with disabilities, service providers and administrators. The state of Ohio had a distinct advantage in implementing Part H because a model of comprehensive, coordinated early intervention services had begun prior to the passage of P.L. 99-457. Through establishment of local interagency groups and a state-level interagency committee, the groundwork had been laid for implementing Part H. Working relationships had been established at the state level between the Departments of Health, Mental Retardation and Developmental Disabilities (MR/DD), and Education. Local service providers, parents, and administrators were informed of the value of interagency coordination and collaboration via training, technical assistance, and incentive grant funds.

Since the passage of 99-457, over $8.3 million in federal Part B funds have come into Ohio to assist in expanding preschool special education and related services. In addition, the state contributes $23 million to support preschool units funded to school districts and county boards of mental retardation and developmental disabilities. Expectations are that this funding level will rise in the future, particularly with the incentives provided by P.L. 99-457. As of July 1, 1991, Ohio school districts will be mandated to provide appropriate special education and related services to children beginning at age three who have a disability. Mandated services provided by local education agencies will be provided in accordance with new preschool special education rules adopted by the State Board of Education in March 1991. Several statewide initiatives in the areas of service delivery, research, personnel preparation, interagency collaboration, and information dissemination have been implemented to promote a comprehensive service delivery system.

For Part H in the first three years, Ohio received approximately $7 million per year to create a more comprehensive system. Most funds were distributed through competitive grants to county collaborative groups to create comprehensive local systems of early intervention services. Grants addressed public awareness, early identification, intake and referral, service coordination (case management), and planning. Each county's collaborative planning group developed a written plan for implementing a comprehensive system. Early intervention services required for Year 4 participation in Part H (child find, evaluation and assessment, individualized family service plan development and service coordination) are available statewide. Over 13,000 infants and toddlers were reported by state agencies and local projects to be receiving early intervention services. Ohio received a federal grant from the Handicapped Children's Early Education Program (HCEEP) for developing an information management system for Part H. The central resource directory system utilizes an existing network of parent-staffed information and referral sites throughout Ohio. Progress on implementing the required 14 components has been steady.

The Ohio Interagency Early Intervention Council has met bi-monthly since July 1987. Departments of Health, Education, Human Services, Mental Retardation and Developmental Disabilities, Mental Health, Drug and Alcohol Addiction Services and the Ohio Developmental Disabilities Planning Council are actively involved (the latter two as ex officio members) on the council. Head Start, private providers, university personnel, legislators from the House and Senate and parents are involved as voting members. The seven committees of the Council (Child Find, Target Population, Finance, Individualized Family Service Plan, Service Coordination, Transition, and Legislation and Standards) meet bi-monthly also to develop policy statements and guidance materials for review by Council. Governor Voinovich last week signed an Executive Order to provide ongoing authority for Ohio to participate in Part H. In public and legislative hearings, Ohio has received positive testimony about the family-centered, collaborative model of services being created.

The flexibility allowed in both Part H and Part B has allowed Ohio to design a comprehensive service delivery system based on its own unique needs and structure. It is critical to maintain this focus on flexibility during this reauthorization so states can continue to creatively organize their resources to meet the needs of families and children.

Issues Related to Part H Implementation

State level implementation is complex. These issues can be grouped best into general categories relating to lead agency authority, interagency cooperation, and establishing state policy.

Lead agency authority The authority given to the lead agency under Part H is not realistic for most state agencies. The Health Department is one of the smallest stata agencies with one of the smallest state budgets. It does not provide direct early intervention services, has no direct authority over local health departments, and has no authority over other state agencies or private providers. Interagency goodwill and written agreements provide the major vehicles for determining such responsibilities as who provides services, and who pays for and monitors the services. In fact, these interagency agreements are only binding to the extent that the state agencies have the authority over their local affiliates. For example, although the Health Department has developed policies related to data collection and tracking of infants and toddlers receiving early intervention services, there is no authority to require local public (and especially private) agencies to report data. Only by working through state agencies and providing funds to projects at the local level can such a system be developed.

Interagency Cooperation Our biggest challenge has been building mutual trust and cooperation between agencies at state and local levels who provide and/or finance early intervention services. While no one rejects the principle of providing early identification of and services for children with disabilities and their families, longstanding "turf" issues and competition for children and dollars often interfere with this process. Ohio has been promoting interagency collaboration as the vehicle for coordinated, quality services since 1983; fragmentation and piecemeal approaches to service delivery still have not been entirely overcome. The mandate for interagency cooperation required under Part H is vital to ultimate success and must be recognized as a developmental process requiring a longer time line than the five years outlined in the law.

Establishing State Policy To address the state-level policy requirement under Part H, Ohio has used an Executive Order which provides the authority for continued participation in the program. Permanent statutory authority must be achieved through legislation to be introduced this year. Recognizing the difficulty of obtaining financial support, eligibility criteria in the draft legislation have been limited to those children with a diagnosed physical, mental or medical condition known to cause disability and children with a measurable developmental delay. Children at risk are excluded. This decision has received criticism from many early intervention advocates who stress the benefits of prevention.

A state policy issue for Part B is the definition of age three. To facilitate the smooth transition of children from the Part H program to preschool services under Part B states should be allowed to determine the definition of the "technical" age of three. States need this authority to assure that services are not unnecessarily terminated or delayed. States need to be able to decide at what point transition from early intervention to preschool services is most appropriate.

Recommendations for Reauthorization

P.L. 99-457 should be reauthorized without major changes. States received final regulations for Part H only in June of 1989. Extensive statutory or regulatory changes at this time would interfere with continued state participation.

This program provides states with the opportunity and incentives to develop a more coordinated, family-centered approach to delivery of early intervention services. Given the financial picture, implementing P.L. 99-457 fully will be difficult. It is a program which must be continued if we are to have positive effect on the development of infants, toddlers and families.

Recommendation 1 To enhance the ability of states to move toward full implementation of Part H, a differential funding and waiver mechanism might be developed. Under such a mechanism, states who are ready for full implementation according to the five-year time line (i.e, ready to entitle all services to all eligible children) would receive their full allocation of Part H planning funds and additional funds to implement [illegible]. States who are not ready to enter Year 5 would receive up to two additional years of planning time and funds (at Year 4 funding levels). The waiver would apply to states who could assure that all but one or two of the Year 5 components were in place. These states could request a waiver (up to two years) for implementation of specific components while still receiving the full Year 5 allocation.

These mechanisms for states making good faith efforts at implementation would allow planning to continue on the comprehensive system (up to two additional years) and provide a reward for those states ready for full implementation of Year 5. Year 5 implementation funds should be increased substantially over the current level of funding. In Ohio entitlement for all eligible children beginning Year 5 would require additional, but unavailable, state funds. Without adequate funds, service systems, and personnel, the law's assurances become fallow, and states may be reluctant to proceed.

Recommendation 2 To increase the likelihood that coordination of funding and programs occurs beginning at the federal level, it is recommended that the Federal Interagency Coordinating Council (FICC) be established in statute. Membership should include parents of children who have received early intervention services and state Part H representation. FICC responsibilities should include reviewing the legislation, regulations and policies of programs which overlap Part H and recommending changes in these policies to the appropriate governmental agencies which could help in coordination of funding and service provision.

Recommendation 3 The interagency coordinating council (ICC) is a critical component of the early intervention system. The current limit of 15 council members is insufficient to accommodate voting membership of all appropriate agencies, parents, and private providers. The membership of the ICC should be set at a minimum of 15 and a maximum of 30 members. The number of parent representatives should be increased proportionately. The current "age of the child" requirement should be changed enabling additional parent representatives with children over the age of 6 years with disabilities.

Recommendation 4 In order to facilitate transition of children from the Part H program to preschool services under Part B, it is recommended that Section 619 be amended to assure that states are able to fund services to children starting at the "technical" age of three.

Recommendation 5 A final recommendation relates to the confusion and fragmentation caused by creating separate birth to 3 and 3 to 5 service systems. To alleviate some of this confusion, it has been suggested that the ICC be made responsible for addressing the issues of the early intervention system under Part H and Part B. This would enable states to use this approach as one means of facilitating comprehensive and coordinated planning for children with disabilities from birth through age five. Because the state educational agency is responsible for children with disabilities from age three through 21, it is recommended that this approach be at state discretion, and not a requirement under Part H. States need to continue to have the flexibility to choose which option best meets their needs.

Thank you for permitting me to share the Ohio Interagency Early Intervention Council's views with the Committee. We look forward to other opportunities to work together to enhance the Part H Program.

Chairman OWENS. I thank you. I want to thank all of our witnesses. We certainly will take your recommendations under consideration.

I have a couple of questions. One for Ms. Booth. It seems to me that your operation has a tremendously difficult job because children are moved all the time.

Could you just elaborate a bit on your recommendation that financial incentives might help?

Did you mean financial incentives so that each State would be more interested in taking care of children because there would be some kind of voucher or payment to go along with it?

What did you mean by financial incentive?

Ms. BOOTH. The recommendation for financial incentives for States to serve children at risk for developmental delay. That was our recommendation. The law doesn't mandate that States have to serve children who are diagnosed as being at-risk. For instance, children who are at failure to thrive or low-birth weight infants.

We would like to see some kind of financial incentive included into the law or monies available to the States that would allow them to expand their services. The monies are tight. Of course, the children who are indeed diagnosed with developmental disabilities or developmentally delayed certainly need the services.

We know from early intervention that the children who are at risk can also benefit from these services.

Chairman OWENS. What would happen if we attached the money to the moving child? A voucher system, sort of. Would that help with the problem of the unfriendly reception they get from one State to another?

Ms. BOOTH. That sounds like a great idea, just as I hear it.

Chairman OWENS. Anybody else care to comment?

Ms. Baglin, you said that your State does not fund your office at all?

Ms. BAGLIN. No, it doesn't. We do not have any targeted State funding for early intervention. There is funding available through the different agencies that is either Federal or its origin is in the Federal or State special education formula; certainly those funds can be available for the local education agencies that are providing special instruction to this age group.

Chairman OWENS. Dr. Wiechel, did I hear you say that your State has been very generous?

Dr. WIECHEL. Yes. One comment regarding the notion of the dollars following the child: that might be a successful means of looking at long-term, I guess the concern I would have is that in the immediate sense that concept would not create the need for the comprehensive and coordinated services that need to be in place in order when that child does move.

I guess I would look at the notion of creating a system and getting a system in place so that when there is movement, you know that child is moving into a system that exists and can meet the needs of that child.

Chairman OWENS. I meant that in reference to migrant children only who are moving from one State to another.

I see my colleagues have stepped out for the moment. I have no further questions. I appreciate all of you coming. Your written testimony and these recommendations will certainly be taken into full consideration.

Thank you for testifying.

Our keynote witness is Dr. Robert, Davila, Assistant Secretary of the Office of Special Education and Rehabilitative Services, Washington, DC.

Following Dr. Davila will be Ms. Deborah Sosa Tisdale, Member of the Federal Interagency Coordinating Council, Tacoma, Washington.

We'll take Dr. Davila's testimony first. If there are any questions, we'll ask them at that time.

We apologize for being a little bit behind schedule, Dr. Davila.

STATEMENT OF DR. ROBERT DAVILA, ASSISTANT SECRETARY OF THE OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES, WASHINGTON, DC

Dr. DAVILA. Thank you, Mr. Chairman.

It is a pleasure to appear before this panel to express the Administration's full support for reauthorization of Part H of the Individuals with Disabilities Act.

I am here to outline and to urge you to approve our reauthorization proposal which we plan to transmit to Congress in the near future. We believe this program can make a real difference in helping to meet our national goals of improving school readiness of all the young children, including young children with disabilities.

I will summarize my statement and submit a more detailed statement for the record.

During the past four years, we have been impressed by the spirit with which the States have accepted the challenge of Part H Preschool Grants program.

Currently, most States are working to develop procedures for each of the 14 required components that must be in place by the beginning of the fourth year of 9 States' participation in the Part H program. Although States are not required to provide Part H services until the fifth year, States reported in 1989 they were serving an estimated 247,000 children. The States have also made impressive progress implementing the preschool program.

Today, fifty States and jurisdictions have mandates. Two of the remaining six are very close to enacting mandates.

Thus, I am pleased to report that the challenges presented by the creation of the Infants and Toddlers with Disabilities program and the amendments to the Preschool Grants programs have been accepted by the States and they are working diligently and creatively to develop the comprehensive system envisioned by the Congress.

As Chair of the Federal Interagency Coordinating Council (FICC), I am also pleased to note the increasing collaboration among Federal agencies as we have provided support to the States. Four national conferences have been hosted by the FICC to help establish networks to disseminate information and to identify resources to support Part H planning within the States. Technical assistance documents have been developed and disseminated. The FICC has also coordinated a development of policies and proposed regulations related to Part H.

In November of 1990, the FICC held public hearings that provided an opportunity for organizations and individuals to present issues that should be considered during the reauthorization process. Currently, the FICC is completing an interagency agreement between the Departments of Education, and Health and Human Services, dealing with early identification and eligibility of young children with special needs.

I expect the FICC to continue to play an important coordinating role for agencies at the Federal level and to continue to provide a forum for the exchange of information about the problems States confront and the solutions they have found as they implement their programs for young children.

Although guidance and technical assistance have clarified many implementation issues, some can only be addressed through changes in the legislation. The Administration's proposal will address changes that we believe would help States implement the statewide systems of early intervention.

Several of the changes we are proposing would provide States with greater flexibility in implementing the program. For example, to help States better address the needs of young children, we are proposing amendments that would allow States to use Part H funds after a child with disabilities turns three and to use preschool grant funds prior to the age of three to facilitate a smooth transition of children from early intervention to preschool services.

This change would help States reduce the accounting and administrative burdens associated with financing the services during that transition period that would enable States to decide how their resources can best be used for children in transition. We do not expect it to have any significant net cost impact on either Part H or Section 619.

We are also proposing to eliminate a requirement that the State Interagency Coordinating Council (ICC) be composed of no more than 15 members. While we believe that proportional representation required under current law should be retained, we believe that the decision regarding the maximum size of the council should be left to the States.

The Administration is also proposing that States be given flexibility to determine what services would be provided to children who are not disabled, but who are at risk of developmental delay if early intervention services are not provided. We hope this change would encourage States to address the needs of children at risk, including children prenatally exposed to drugs.

In addition to the changes I have already described, the Administration's bill would reauthorize Part H through 1996. It would clarify that assistive technology is an early intervention service that can be provided under the program. It would require each State's Part H comprehensive system of personnel development to be consistent with its system under Part B.

Finally, recognizing that States may find it necessary to use Part H funds to pay for direct services, our bill will provide strong encouragement to States to establish sliding fee schedules for direct services to be paid for with those funds.

In conclusion, I want to stress the Administration's strong support for the reauthorization of the Infants and Toddlers with Disabilities program, which can help us address our national goal of improving the school readiness of all young children, including young children with disabilities. This program has the potential to significantly affect the lives of young children with disabilities and their families.

Thank you, Mr. Chairman, for the opportunity to present the Administration's reauthorization proposal.

I will be able to answer questions.

[The prepared statement of Dr. Robert Davila follows:]

DEPARTMENT OF EDUCATION

Statement by Robert R. Davila
Assistant Secretary for Special Education
and Rehabilitative Services
on
Reauthorization of Part H of the
Individuals with Disabilities Education Act

Mr. Chairman and Members of the Subcommittee:

It is a pleasure to appear before this panel to express the Administration's full support for reauthorization of Part H of the Individuals with Disabilities Education Act (IDEA). I am here to outline, and to urge you to approve, our reauthorization proposal, which we plan to transmit in our legislative proposals in the near future. There are many Federal programs that can provide services and benefits for infants and toddlers with disabilities and their families, but Part H has this population as its sole focus. We believe this program can make a real difference in helping meet the national goal of improving the school readiness of all young children, including young children with disabilities.

In creating the Infants and Toddlers with Disabilities program in 1986, the Congress provided families with a vision and a promise of a coordinated system of services that would help them ensure the growth and development of their young children with disabilities. This program was special in its design because it focused on the family's role of nurturing young children with disabilities. The legislation sought to support that role by drawing together an often fragmented system of services to meet the unique needs of infants and toddlers with disabilities. It did this through a focus on interagency cooperation, service coordination, and case management.

In 1986, the Congress also amended Section 619, the Preschool Grants program authorized under Part B of the Act, to require States, by fiscal year 1991, to make available a free appropriate public education to all children with disabilities age three to five, inclusive. This amendment helps to ensure that preschool children with disabilities will receive the special education and related services they need to succeed in school.

During the past four years, we have been impressed by the spirit with which the States have accepted the challenge of the Part H and Preschool Grants programs. During the first three years, all eligible States and jurisdictions participated in the Part H program. Each State has designated a lead agency and has identified the programs and services within the State that will be part of its comprehensive statewide early intervention system. Each has adopted policies to establish and operate a statewide system and has identified the criteria upon which infants and toddlers will be determined eligible for services within the State. Currently, most States are working to develop policies and procedures for each of the 14 required program components that must be in place by the beginning of the fourth year of a

State's participation in the program. This is an intensive activity requiring an extraordinary level of interagency cooperation and coordination. Nonetheless, to date, 24 States and jurisdictions have submitted final fourth-year applications and another 13 have filed draft plans. We are confident from our contacts with States that more States will submit final applications in the near future and that most or all States will have submitted applications by July 1991. It is worth noting that, although States are not required to provide Part H services until the fifth year, States reported that in 1989 they were serving an estimated 247,000 children.

States have also made impressive progress in implementing the Preschool program. Since fiscal year 1987 all States have participated in the program. During this time, the number of children with disabilities age three through five served by the Preschool program has grown from 261,000 during the 1985-86 school year to 352,000 children in the 1990-91 school year. Prior to the passage of P.L. 99-457, only 20 States and jurisdictions mandated services for all three-through five-year-olds with disabilities. Today 50 States and jurisdictions have mandates and two of the remaining six grantees are very close to enacting mandates. Thus, I am pleased to report that the challenges presented by the creation of the Infants and Toddlers with Disabilities program and the amendments to the Preschool Grants program have been accepted by the States, and that they are working diligently and creatively to develop the comprehensive systems envisioned by the Congress.

As Chair of the Federal Interagency Coordinating Council (FICC), I am also pleased to note the increasing collaboration among Federal agencies as we provide support to States. Four national conferences have been hosted by the FICC to help establish networks to disseminate information to and identify resources to support Part H planning within the States. Technical assistance documents have been developed and disseminated. The FICC has also coordinated the development of policies and proposed regulations related to Part H.

In November 1990, the FICC held public hearings that provided an opportunity for organizations and individuals to present issues that should be considered during the reauthorization process. Currently the FICC is completing an interagency agreement between the Departments of Education and Health and Human Services dealing with early identification and eligibiltiy of young children with special needs. I expect the FICC to continue to play an important coordinating role for agencies at the Federal level and to continue to provide a forum for the exchange of information about the problems States confront and the solutions they have found as they implement their programs for young children.

At the same time we have been watching the excellent progress of States in implementing the Part H and Preschool Grants programs, we have also become aware of the need for changes in the programs that would facilitate this progress. Through technical assistance workshops, bulletins, and policy letters, we have provided guidance and clarification on a number of issues.

For the Part H program, these issues include the application requirements for each year, the uses of Federal funds, the responsibilities of lead agencies, and the definition of eligible children. Under the Preschool Grants program, we have addressed concerns regarding distribution of basic and bonus grant funds, placement in the least restrictive environment, and children's eligibility for services beginning on their third birthday. We have also provided guidance regarding the transition of children from the Part H program to the Preschool program and the operations of birth through five systems in States desiring such "seamless" systems.

Though guidance and technical assistance have clarified many implementation issues, some can only be addressed through changes in the legislation. The Administration's proposal will address changes that we believe would help States implement their statewide systems of early intervention. Our proposal, however, would not require States to redesign the systems they have been developing with such intensity. Our concern was that major changes in any of the 14 components would significantly delay States in meeting the requirements of the fifth year and thus delay the provision of services to all infants and toddlers with disabilities.

Several of the changes we are proposing would provide States with greater flexibility in implementing the program. For example, to help States better address the needs of young children, we are proposing amendments that would allow States to use Part H funds after a child with disabilities turns three and to use Preschool Grant funds prior to age three to facilitate a smooth transition of children from early intervention to preschool services. This change would help States reduce accounting and administrative burdens associated with financing services during the transition period and would enable States to decide how their resources can best be used for children in transition. We do not expect it to have any significant net cost impact on either Part H or Section 619.

We are also proposing to eliminate the requirement that the State Interagency Coordinating Council (ICC) be composed of no more than 15 members. The restriction on the size of the ICC has meant that, in some States, key agencies in the statewide system could not be represented on the Council. While we believe the proportional representation required under current law should be retained, we believe that the decision regarding the maximum size of the Council should be left to the States in order to allow for differences in State size, in governmental structures, and in interagency relationships. In addition, we are proposing that the ICC be permitted to include parents of children up to age 12 so that States, at their discretion, may retain parent members as their children grow older.

The Administration is also proposing that States be given the flexibility to determine what services would be provided to children who are not disabled but who are at risk of developmental delay if early intervention services are not provided. Though surveys taken during the first two years of the program indicated that many States intended to serve children who were at risk, concern about the possible costs of providing full services to at-risk children has led many States to reverse their original plans to serve these children. We hope this change will encourage States to address the needs of children at risk, including children prenatally exposed to drugs.

In addition to the changes already described, the Administration's bill would reauthorize Part H through 1996. It would clarify that assistive technology is an early intervention service that can be provided under the program, and require each State's Part H comprehensive system of personnel development to be consistent with its system under Part B. It would extend authority in Part H for the lead agency to monitor programs that do not receive Part H funds but are part of the services network for infants and toddlers and their families under the State plan. This would help ensure that the statewide Part H system meets the needs of this population. It would also ensure that States keep records demonstrating that Part H funds are used for direct services only to the extent permitted by the Act and are not substituted for funds that would have been paid from another public or private source. Finally, recognizing that States may find it necessary to use some Part H funds to pay for direct services, our bill will provide strong encouragement to States to establish sliding fee schedules for direct services paid for with those funds. This is consistent with the Administration's policy of focusing Federal funds for services on people with the least ability to pay. While the sliding fee schedule approach is our preference, we are eager to work with the Congress and recognize that there may be other ways of achieving this objective. An alternative that Congress may want to consider would be to require States to target all Part H funds used for direct services on the neediest families and children.

In conclusion, I want to stress the Administration's strong support for the reauthorization of the Infants and Toddlers with Disabilities program, which can help us address our national goal of improving the school readiness of all young children, including young children with disabilities. This program has the potential to significantly affect the lives of young children with disabilities and their families. Our proposed changes to the legislation will facilitate implementation of the program, but will not slow the impressive progress that has been made to date.

Thank you, Mr. Chairman, for the opportunity to present the Administration's reauthorization proposal on Part H. My colleagues and I will be pleased to respond to questions.

Chairman **Owens**. Thank you very much, Mr. Secretary. We look forward to working with you. We appreciate your enthusiasm for the reauthorization of this legislation.

We have a few questions, though.

In terms of the interagency agreement between the Department of Education and the Department of Health and Human Services, can you clarify the role of the Medicaid program in the implementation of each State's Part H program?

Dr. **Davila**. I will ask Dr. Schrag to respond to that particular question.

Dr. **Schrag**. The role of Medicaid is very important.

Chairman **Owens**. For the record, do we have your name?

Dr. **Schrag**. Yes. My name is Judy Schrag, Director of the Office of Special Education Programs.

Chairman **Owens**. Thank you.

Dr. **Schrag**. Mr. Chairman. Medicaid is an important source of funding for the States to assist with screening and medical services and so forth. Within our interagency agreement, we have delineated coordination in screening to also include Headstart and other programs as well.

Chairman **Owens**. That is spelled out in detail in your agreement?

Dr. **Schrag**. It is.

Chairman **Owens**. Can this committee be supplied with a copy of that agreement?

Dr. **Schrag**. Yes, it can.

Chairman **Owens**. Thank you.

In your testimony, Mr. Secretary, you state that you will strongly encourage the States to establish a sliding fee schedule for direct services under Part H. This statement is in contrast to your other statements, which recommend great flexibility to the States.

Can you tell us how you would determine who is least able to pay under this sliding fee schedule?

Dr. **Davila**. Mr. Chairman, we have to understand that we have limited Federal dollars to provide support to all children who are covered under this Act. So the Administration has taken the position that we should give our funds to those children and families least able to pay. We would be willing to explore other options that would be possible that would accomplish the same intent.

We are concerned that services be provided to those children who are a high priority inasmuch as their families would not be able to pay. We want to give the States the flexibility to determine the identity of children and families who are considered least able to pay.

Chairman **Owens**. So States could impose a means test of any kind that is reasonable and you would have to approve it?

Dr. **Davila**. That would be one way. The statute already authorizes the States to establish sliding fee schedules. Some States are considering proposals to do so, but of course, we would leave it to the States to determine the identify of people eligible for this.

Chairman **Owens**. We would like for you to submit additional clarifying information on how you see that operating. We would appreciate that for the record.

Dr. **Davila**. Yes, sir.

Chairman OWENS. Without objection, I would like to enter into the record at this point a statement by Congressman Jefferson who had to leave.

[The prepared statement of Hon. William J. Jefferson follows:]

STATEMENT OF HON. WILLIAM J. JEFFERSON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF LOUISIANA

Mr. Chairman and my esteemed colleagues on the Subcommittee on Select Education: I would like to take this opportunity to make a few brief comments in support of the reauthorization of Part B and Part H of the Individuals with Disabilities Education Act, and to voice some of the concerns my State Louisiana has about its participation in Early Intervention Programs.

I commend this subcommittee and the Congress as a whole for passing Public Law 99-457, the Education of the Handicapped Amendments of 1986, and providing the catalyst for nationwide efforts to provide comprehensive, coordinated services to infants, toddlers and preschoolers with special needs as well as to their families.

All States have chosen to participate on Part H, and desire to provide individualized service plans for infants and toddlers from birth to age three that have disabilities and developmental delays. But four years later, many States, including Louisiana, are uncertain if they will be able to realize such a mission.

Throughout the State of Louisiana, early intervention service providers reach about 800 infants and toddlers. With four years of very hard work in Louisiana, meeting the fourth year requirements will be difficult given limited funding and support. ARC, the Association for Retarded Citizens in Baton Rouge, estimates that less than one third of the State agency's budget request will be considered in the State of Louisiana's upcoming legislative session. When States cannot meet the requirements of the stages set out in Part H the only alternative is to drop out of program.

I bring Louisiana's situation to your attention to stress the point that States not only need Federal encouragement to continue participation, they need Federal dollars. Like many States, Louisiana is under great financial strain. States are worried about the long-term financial implications of their commitment to provide services to so many needy children. Louisiana would like to see timeline extensions with Federal funding to allow for their continued participation in Part H programs.

States should not be punished by being forced to drop out of the program because their States lack the monies and resources required to fully implement Part H early intervention programs. Rather, States making good faith efforts should be rewarded by increased Federal support. If States are forced to end their participation, disabled and developmentally delayed children are the ones that suffer the greatest loss.

We know that early intervention is the critical factor that determines how well a disabled or developmentally delayed child performs when he or she reaches school age; we know that early intervention minimizes the need for special education later on in life, as well as minimizes the need for institutionalization. We also know that funds are needed to provide the quantity and quality of service these young children need. Let's not ignore what we know to be true. I urge Congress to grant States the support they so desperately need.

Chairman OWENS. Mr. Ballenger.

Mr BALLENGER. Thank you, Mr. Chairman.

Mr. Secretary, it is good to see you again.

In the discussions we have had here this morning, differential funding caused by the shortage of funds in general and the difficulties that various States have had in meeting the demands because of the economies, they have requested, it would appear to be almost unanimous in requesting differential funding.

Could you express an opinion on how the Federal Government feels about the funding for States that are already there, say, the 17 that have already done and the others—do you have an idea in your own mind as to the best way to go about that?

Dr. DAVILA. Yes, sir. We are hopeful that all of the States will submit application for four-year funding. This has been our expectation. We have been providing technical assistance and support to the States during the process of planning for fourth year applications, the deadline of which is the end of June. However, it should be the position of the Congress to extend up any time. We would support a differential funding arrangement in order that we could recognize the States that have prepared the application on time.

Mr. BALLENGER. I am glad to hear that. After hearing Congressman Espy's statement, for the poorest counties in the United States where they have a trial program there, I would hate to see it disappear just because the Federal Government was unwilling to be a little bit flexible. I thank you for that opinion.

I have no more questions, Mr. Chairman.

Chairman OWENS. Mr. Secretary, as usual we have very few questions. We look forward to working with you to resolve those questions that we do have. Thank you very much for testifying.

Dr. DAVILA. Thank you, sir.

Chairman OWENS. Our final witness is Ms. Debbie Tisdale.

STATEMENT OF MS. DEBORAH SOSA TISDALE, MEMBER OF THE FEDERAL INTERAGENCY COORDINATING COUNCIL, TACOMA, WASHINGTON

Ms. TISDALE. I was going to say good morning, but I looked at the time and it is now good afternoon.

My name is Deborah Sosa Tisdale. I am a parent from Washington State.

I want to express my appreciation for this opportunity to address this small committee today. I wanted to let you know that today the reason why I am speaking to you is because I am a parent of a child with special needs. I have been actively involved with Public Law 99-457 for 3.5 years.

My son, Joshua, was fortunate to receive early intervention services at a young age. At times, it was difficult for us to assess services we felt he needed. Often, Joshua's needs translated into hardships for our family.

While he was involved in various early intervention programs, I realized that many children, and especially those of color, do not have an advocate parent who is able to speak on their behalf. This fact has sustained my involvement on my county, State and the Federal Interagency Coordinating Council.

Today, I was asked to address my views on how the Federal Interagency Coordinating Council has helped in the implementation and support of early intervention and preschool programs throughout our Nation. For the past year and a half that I have served on the FICC, I have witnessed the development of interagency agreements, the development and dissemination of technical assistance documents for various components of Public Law 99-457 and the organization of the national conferences. All of these efforts have circulated best practice, information and resources and have assisted State systems and parents to better understand the spirit and intent of Public Law 99-457.

Most importantly, I have seen Federal agencies come together for the sake of children and families, providing a forum where Federal agencies whose missions involve infants, toddlers and young children, can hear how the policies and programs have been translated and the effect these programs and policies have on children and families.

Traditionally, businesses providing a service keep abreast of the problems their customers encounter, and if necessary, make changes. Historically, as with the education of the Handicapped Act, it takes years to get feedback from consumers as to the realities in the field, what barriers exist to keep children and families from being served, and changes that consumers feel need to be made.

With the formation of the FICC, parent participation and continuous contact with State ICCs, issues and problems of implementation have been allowed to be brought to the Federal council to be addressed. This forum is not only good business practice, but it is good financial management.

As States go into coordinated systems of service delivery, they are discovering that some of the obstacles they are encountering are originating on a Federal level. The FICC has been a means to address these obstacles.

In States where duplication of services are occurring, coordination encourages better use of funding. The same is occurring on the national level due to the collaboration of Federal agencies brought to the formation of the FICC. In evidence, we now have interagency agreements on the Federal level.

When State councils were formed, many States found themselves in a quandary as to exactly what they were to do. Many States established regional or county councils to obtain grass roots feedback from services providers and especially parents.

These local councils look to State councils as models. In that same regard, the States can look to the Federal ICC as a model for collaboration and to provide leadership in the coordination of services for infants, toddlers and preschool-aged children with special health care needs.

Since October of 1987, I have seen Federal agencies transition from an isolationist stance into a collaborative position. This is truly representative of Public Law 99-457—collaboration, communication and a philosophical transition to what is best for children and families.

I would recommend the following changes to strengthen the FICC as a model for the Nation and to assist the council and the work that it is effecting and could possibly accomplish in the future. First, we could require in statute the Federal Interagency Coordinating Council with adequate authority, staff and resources for its activities.

As a parent, I have real concerns about the possible lack of participation and representation of participating agencies due to administration changes or agendas. I do not feel that it is fair to children and families that the FICC's existence be predicated upon administrative philosophy.

Secondly, I would designate members of the FICC to include current programs or agencies, parent representatives, Part H directive representative, an ICC chair representative, a Section 619 coordinator representative, a representative from the Bureau of Indian Affairs, from Indian Health Services, from the Department of Defense school, from Handicapped CHAMPAS, and from the testimony that I have heard today, possibly from the Migrant Council. Also, as the council deems necessary, include any representative of an agency or program directly affecting the provisions of services to children and families.

It is important for me to know that as a parent all players on the Federal level that are providing services for young children are working together; that through a process of representation, all State and territories have a voice on the FICC. Although these are my personal recommendations, I feel strongly that the FICC should have the flexibility to address the size and constituency of the Federal council as it deems appropriate for issues being addressed.

Third, I would suggest that the FICC be authorized to address issues for all young children with disabilities and especially those classified at risk for disability. Since many States are opting not to serve young children classified at risk under Public Law 99-457, it is important that the FICC sustain the model for inclusion of these children.

Many States are servicing these children on a selected basis through other programs. It is vital that any program serving children classified at risk be kept involved on the State and national level.

Fourth, the FICC should have certain responsibilities that should be developed as a group process. These might include reviewing of Public Law 99-457 implementation policy statements from Federal agencies; being a forum for review of procedural safeguard decisions and appeals as implementation occurs across the Nation; clarification and interpretation of policy and assignment to Federal agencies as appropriate. This would be reflective of the interagency collaboration that is being fostered.

Foster participation that assures that all infants and toddlers and young children throughout the United States and territories, including dependent children of civilian and military personnel serving with the armed forces on overseas duty assignments, be afforded the opportunity of services under Public Law 99-457.

Last, to foster a national standard of best practice for infants, toddlers and young children among Federal agencies.

Thank you.

[The prepared statement of Deborah Sosa Tisdale follows:]

STATEMENT OF DEBORAH SOSA TISDALE, MEMBER, FEDERAL INTERAGENCY COORDINATING COUNCIL, TACOMA, WASHINGTON

Mr. Chairman and members of the subcommittee· My name is Deborah Sosa Tisdale. I am a parent of two children age 5 and 7. My oldest, Joshua, has cerebral palsy and is visually impaired. I appreciate this opportunity of addressing you today in support of your efforts regarding the reauthorization of the Early Intervention Program (Part H) and the Preschool Program (Part B section 619) of the Individuals with Disabilities Education Act. I am speaking with you today because I am a parent of a child with special needs. I have been actively involved with Public Law 99-457 for 3½ years. My son, Joshua, was fortunate to receive early intervention services at a young age. While he was involved in various programs, I realized that many children, especially those of color, do not have an advocate parent who is able to speak on their behalf. This fact has sustained my involvement on county, State, and Federal Interagency Coordinating Council.

Today, I have been asked to address my views on how the Federal Interagency Coordinating Council (FICC) has helped in the implementation and support of early intervention and preschool programs throughout our Nation. In the past year and a half that I have served on the Federal Interagency Coordinating Council (FICC). I have witnessed the development of interagency agreements. The development and dissemination of technical assistance documents for various components of Public Law 99-457, and the organization of national conferences. All of these efforts have circulated best practice information and resources, and assisted State systems and parents to better understand the spirit and intent of the law. Most importantly I have seen Federal agencies come together for the sake of children and families. A forum where Federal agencies whose mission involves infants, toddlers and young children hear how their policies and programs have been translated and the effect these programs and policies have on children and families.

Traditionally a businesses that is providing a service keeps abreast of problems their customers encounter and if necessary makes appropriate changes. Historically, as with the Education of the Handicapped Act (now IDEA) it takes years to get feedback from consumers as to the realities in the field, what barriers exist that keep children and families from being served, and changes consumers feel need to be made. With the formation of the FICC, parent participation and continuous contact with State ICC's, has allowed issues and problems of implementation to the council to be addressed. This forum is not only good business practice but it is good financial management. As States go into a coordinated system of service delivery they are discovering there are some obstacles originating on the Federal level. The FICC is a means to address these obstacles. In States where duplication of services are occurring, coordination encourages better use of funding. The same is occurring on the national level due to the collaboration of Federal agencies brought through the formation of the FICC.

When State councils were formed, many States found themselves in a quandary as to exactly what they were to do. Many States established regional or county councils to obtain grassroots feedback from service providers and parents. These local councils looked to the State councils as models. In the same regard States have looked to the FICC as a model for collaboration and to provide leadership in the coordination of services for infants, toddlers, and preschool aged children with special health care needs. Since October of 1987 I have seen Federal agencies transition from an isolationist stance into a collaborative position. This is truly representative of the spirit of Public Law 99-457; collaboration, communication and a philosophical transition to what is best for children and families.

I would recommend the following changes to strengthen the FICC as a model for the Nation. and assist in the efficacy of the work it is effecting and could accomplish in the future.

Require in statute the Federal Interagency Coordinating Council, with adequate authority, staff, and resources for its activities. (This could include parent reimbursement, staff, office expenses, training and special projects.) As a parent I have concerns about the possible lack of participation or representation of participating agencies due to administrative changes and agendas. I do not feel it is fair to children and families that the FICC's existence be predicated upon administrative philosophy.

Designate membership of the FICC to include current programs/agencies, parent representatives, a Part H director representative, an ICC chair representative, a 619 coordinator representative, a representative from the Bureau of Indian Affairs, a representative from Indian Health Services, a representative from the Department of Defense Schools, a Handicapped CHAMPUS representative. and as the council deems necessary, any representative of an agency or program directly affecting the provision of services to children and families. It is important for me to know that all players involved with young children are working together. That through a process of representation all States and territories have a voice on the FICC. Although these are my personal recommendations I feel strongly that the FICC should have the flexibility to address the size and constituency of the council as seems appropriate for issues being addressed.

Authorize the FICC to address issues for all young children with disabilities and especially those classified "at risk" for disability. Since many States are opting not to serve young children classified "at risk" under Public Law 99-457 it is important that the FICC sustain the model for inclusion of these children. Many States are serving these children on a selective basis through other programs. It is important that programs serving children classified "at risk" are kept involved on a State and national level.

The FICC should have certain responsibilities which should be developed as a group process. These might include: review of draft Public Law 99-457 implementation policy statements from Federal agencies; forum for reviewing procedural safeguards decisions and appeals as implementation occurs across the Nation; clarification and interpretation of policy and assignment to appropriate Federal agency(s) if appropriate. This would be reflective of the interagency collaboration that is being fostered. Foster participation that assures all infants, toddlers, and young children throughout the United States and territories, to include dependent children of civilian and military personnel serving with the armed forces on overseas duty assignments, be afforded the opportunity of services under Public Law 99-457; foster a national standard of best practice for infants, toddlers, and young children among Federal agencies.

In closing I want to again express my support for this bill and say that as a parent of a child with special needs I appreciate the progress that the FICC has helped to facilitate across the Nation. I feel strongly that the hearts of this country are returning to its children. My hope is that the sense of commitment I have encountered across this Nation is felt by members of this committee today. Please help keep that momentum going.

Chairman OWENS. Thank you very much. You have been involved at all three levels of these parent participation bodies?

Ms. TISDALE. Right.

Chairman OWENS. How have you been able to do that?

Ms. TISDALE. My husband stays at home with our children. That is how it is. We have made lots of sacrifices. My husband has not been employed for the last two and a half years so that I could become involved on all of these levels. We have a personal commitment to this.

Chairman OWENS. What about the experience of other parents? Do you find that there is a reasonable number of parents involved?

Ms. TISDALE. I think it is extremely difficult for most parents, even for myself, financially The indirect costs that are involved makes it very difficult for parents to sustain involvement, even on a State or county level. Just the demands of having a child with special needs—running to doctors, running to therapies—really impede on the time that is available for parents to become involved on a system-wide level.

Chairman OWENS. In what ways could the Government provide greater incentives for parent participation?

Ms. TISDALE. I think as we go into implementation with Public Law 99-457, I think that is going to be alleviating a lot of the problem. Currently, I have been known to drive 130 miles a days when we were receiving early intervention services for my son. I didn't have time for much else, not even my other daughter. We barely had time to get baths and get meals made. I think that's a reality for most families. As we go into a system of community-based care, hopefully, services will be very easy to access for families. They will not have to have services and obtain services that are miles away from where their home is.

Chairman OWENS. I meant in terms of participating on something like the Interagency Coordinating Committee. How often does that bring you to Washington? Once a year?

Ms. TISDALE. More often than I would like to imagine. Even this month, I had two trips here to Washington. Usually, it is at least on a quarterly basis. On the State level, minimum of once a month or twice a month that I have to attend meetings. Usually, it is sometimes on a weekly basis that I have to go to either a center in our State or to the State capital for meetings or other business. On the county level, it is usually just on a monthly basis.

One of the most difficult things for parents is that so often we feel like we have to go begging for funds to be able to get ourselves anywhere. Having the extenuating medical expenses for a child with special needs does not always allow me to use free money. There is no money in our budget. Oftentimes, I have heard families refer that they are using their grocery money to be able to go to conferences and get more information and to learn advocacy skills for themselves and for their child.

I think what would be really helpful would be to first—you mentioned earlier with the parent-training information centers across the country as a resource for parents—give some money to them. They are so involved right now with the majority of their children being from six on up, that they don't always have a lot of time to work with families and parents of children with younger infants and toddlers.

Secondly, I think I would like to see an increased budget for parent participation on the State and Federal level.

Chairman OWENS. Well, we would like for the record to show that we greatly appreciate your time and energy and other resources that you have put into this and that other parents like yourself have put into this.

Thank you very much for testifying. We would like to thank all of our witnesses for testifying today.

We would like the record to show that this hearing is not adjourning; we are recessing until tomorrow when the hearing will be continued.

[Whereupon, at 1 p.m., the subcommittee recessed, to reconvene at 10 a.m., Friday, April 12, 1991.]

[Additional material submitted for the record follows.]

STATEMENT OF HON. JOSÉ E. SERRANO, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Mr. Chairman I am pleased that you have convened these hearings to address the growing needs of an underrepresented population.

Education for the disabled has undergone many changes as a result of judicial and legislative actions. We have in a short time learned that special education does make a difference, and that preschool programs and early intervention services provide disabled children a better chance of achieving their potential.

I believe that Part H holds the promise of long overdue reforms and improvements in the way we serve infants and toddlers with special needs and their families. I am ecstatic that families are recognized in the act. For parents are the true advocates in obtaining civil rights for their children. The changes and practices of special education are the results of diligent parents' efforts seeking to redress the flaws with the education their children were receiving.

It is in our national interest to continue funding for these programs. As many States move toward the full implementation of the early intervention services, I believe that a continued Federal commitment is essential to assure that all eligible infants and toddlers and their families will be served.

I concur with Chairman Owens and will work toward increasing opportunities for minority, Native American children and, the economically and educationally disadvantaged to fully participate and benefit from these programs. Effective preschool programs have demonstrated the likelihood of a successful transition when children leave special education programs. That, I believe is the goal; to develop a "special" population ready to further their education, contribute to the work force and become civic minded responsible citizens.

I look forward to listening to the testimony of our distinguished panelists.

STATEMENT OF HON. DONALD M. PAYNE, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Mr. Chairman, let me commend you for calling this hearing on the Individuals with Disabilities Education Act (IDEA), which is the main Federal law that provides for the education of disabled infants, toddlers, children, and youth from birth through age 21.

The basic State grant and preschool grant are permanently authorized in Part B of the act. These programs assist the States in serving children and youth with disabilities. It also provides educational services for Native American children and it strengthens the comprehensive system of personnel development under the State plans.

Additionally Part H authorizes a formula grant program to assist States in developing and implementing a statewide program of early intervention services for infants and toddlers under the age of 3 and for their families.

We must continue to provide adequate funding for these programs that provide crucial services for children with disabilities and their families.

Moreover, we must continue to reach out to black. Hispanic, Native American and other previously underserved populations and offer those children and their families educational and support services.

As you know last year, President Bush signed into law the Americans with Disabilities Act, which is the most comprehensive civil rights measure since the Civil Rights Act of 1964.

As it was stated many times during the fight for approval of the act, "People with disabilities have the same inalienable rights as other people to participate in the mainstream of society."

Mr. Chairman, hopefully, through the services that will be provided for in this act, we can begin to identify as early as possible which children need the early intervention services and we can begin to help them and their families as they try to become as independent and productive as they possibly can.

I would like to welcome the witnesses and I especially look forward to hearing about the experiences of the parent representatives. I would also like to welcome our colleague and good friend Mike Espy, from the State of Mississippi.

STATEMENT OF TESTIMONY

on

Legislation to Reauthorize Part H of the Individuals with Disabilities Education Act

Respectively Submitted

to the

Select Education Subcommittee
House Committee on Education and Labor

The Honorable Major R. Owens, Chairman

National Association of State Mental
Retardation Program Directors, Inc.

April 11, 1991

I. Introduction

The National Association of State Mental Retardation Program Directors is a non-profit organization consisting of the designated officials in the fifty states and territories who are directly responsible for the provision of long term care services to a total of over one-half million children and adults with developmental disabilities. The principal role of NASMRPD member state agencies is to finance and coordinate the delivery of residential, daytime and support services for persons with severe, lifelong disabilities, the vast majority of whom are adults. In a real sense then, state mental retardation/developmental disabilities agencies deal with the consequences of society's past failure to prevent disabilities and ameliorate the consequences of such conditions through early intervention services. This year, for example, state MR/DD agencies collectively will spend more than $13 billion on services to children and adults with severe disabilities.

NASMRPD member state agencies have a special interest in legislation to amend and extend Part H of the Individuals with Disabilities Education Act (IDEA). In roughly one third of the states, the state MR/DD agency serves as the lead agency for Part H planning and implementation. Even in states where the MR/DD agency is not the designated lead agency, it generally is represented on the state's interagency coordinating council for early intervention services and often is one of the major loci of responsibility within state government for financing such services.

The recent history of the field of developmental disabilities offers a powerful illustration of the benefits of early intervention services. In 1965, over 91,000 children and youth were residing in public mental retardation institutions. By 1989, the number of state facility residents under 21 years of age had plummeted to just a little over 9,000.[1] This precipitous decline in the number of institutionalized children over the past twenty-five years is the product of many forces, but certainly the wider availability of resources through the public schools and other community based social service agencies has been a principal factor in allowing children with disabilities to remain part of their families and communities. With the average cost of a public institutional placement now exceeding $70,000 a year, ***state MR/DD agencies would be spending close to $6 billion more each year if the 1965 childhood institutional census had not declined over the past quarter century.***

In view of both the human and fiscal payoffs associated with early intervention services for infants and toddlers with disabilities, ***NASMRPD strongly supports the enactment of legislation to extend and amend Part H of the Individuals with Disabilities Education Act.*** The creation of a comprehensive, responsive, statewide network of early intervention services for such youngsters and their families deserves to be a national goal of the highest priority.

The accomplishment of this goal, however, will not be furthered by ignoring the very real fiscal and programmatic realities many states have encountered in their attempts to institute a comprehensive early intervention system. The challenge before this Subcommittee, as it undertakes the difficult task of revising and updating the provisions of Part H, is to strike a proper balance between addressing such realities in a sensitive manner and assuring that the original vision of the 1986 legislation is achieved as expeditiously as possible.

II. Status of Part H Implementation

The Carolina Policy Studies Program (CPSP) at the University of North Carolina at Chapel Hill recently issued a report on the status of the states' progress in implementing Part H of P.L. 99-457. This report, based on feedback from the Part H coordinators in 50 states and the District of Columbia, concluded that the states, in general, had achieved "substantial progress across all of the fourteen components..." of a comprehensive early intervention system delineated in the Act. However, the CPSP researchers also pointed out that "[i]t appears that the states are moving more slowly toward the accomplishment of the implementation goal [of Part H] than Congress expected".[2]

Among the principal barriers to full implementation of Part H that are identified in CPSP's report are:

- **Concerns about the financial ramifications of a new entitlement program**, particularly in view of the precarious fiscal outlook facing many states. As the authors of the report note: "The introduction of a new entitlement program with an uncertain, but clearly significant financial commitment is viewed with apprehension by state public decision makers."

- **The inadequate level of federal financial assistance.** As CPSP notes in its report, "there are some policymakers at the state level who wish to see a greater financial commitment from the federal government, even though there is a recognition that the financial problems of the federal government are enormous."

Earlier this year, NASMRPD conducted a survey of its member state agencies to determine the views of state MR/DD officials regarding legislation to extend and amend Part H of IDEA. Several of the key findings of this survey highlight the problems many states face in complying with the current timeframes spelled out in Part H:

* An overwhelming majority of the respondents cited the lack of adequate funding for early intervention services as the single most important barrier to meeting the statutory objectives of Part H (i.e., establishing a comprehensive, statewide service delivery system that is capable of providing appropriate and needed early intervention services to all infants and toddlers with disabilities). When asked to rate the relative significance of five potential barriers to achieving the objectives of Part H (on a scale of 0 to 3), thirty-six (36) of the forty-four (44) respondents indicated that inadequate state/local funding was a "most

significant" barrier. The median rating for all respondents on this potential barrier was 2.82 out of a possible 3.0.

- Another closely related barrier that was ranked high by the survey respondents was the inadequate level of federal financial assistance available through Part H, combined with the current statutory restrictions on the use of such funds. Thirty (30) out of the forty-four (44) survey respondents rated the shortage of federal funds as a level 3 (or most significant) barrier to implementing Part H. The median rating for all respondents on this item was 2.52 out of a possible 3.0.

- The shortage of trained personnel also was viewed as a significant barrier to full implementation by many respondents. Eleven (11) respondents rated this area as a "most significant" barrier, while twenty-one (21) indicated it was a "moderately significant" barrier. The median overall rating for this potential barrier was 2.02 out of a possible 3.0.

- Ineffective interagency coordination and poor access to generic funding sources (such as Medicaid EPSDT benefits, etc.) were viewed as less significant barriers by most respondents. The median rating for poor interagency coordination was 1.0 on a scale of 3.0, while lack of access to generic funding sources was rated 1.64.

- Significantly, very few respondents indicated that there states faced "no major outstanding problems" in achieving implementation of the Part H requirements within the current statutory timeframes. The median rating on this item was only 0.11, with just two (2) out of forty-four (44) respondents indicating that there were no major implementation problems in their states.

III. Statutory Timelines

Thus far this fiscal year over thirty states have been forced to make mid-year budget cuts; and, trapped between declining revenue estimates and rising demand for services (fueled in part by federally enacted mandates), the fiscal outlook for the upcoming year in most states is even more dismal. A recent analysis of the budget situations in 40 states, conducted by the Office of the Governor of New York, revealed that, collectively, these states will have to find ways of filling a budget gap of $33 billion.

With most states either in or about to enter the fourth year of the Part H planning/implementation cycle, it is now quite clear that faced with the prospect of meeting the "full service" mandate by the fifth year of federal funding, as required under current law, or terminating their participation in the program, some states may be forced by the current budgetary realities to adopt the latter option. The withdrawal of states from the Part H program would serve no one's interests, least of all families in these states who carry the primary responsibility for raising thousands of infants and toddlers with disabilities.

NASMRPD, therefore, joins with the Education Task Force of the Consortium for Citizens with Disabilities as well as many other groups in urging the Subcommittee to adopt amendments to Part H which empower the Secretary of Education to waiver existing statutory requirements for receipt of Year 4 and Year 5 funding for a maximum of two years, providing the requesting state is able to demonstrate to the Secretary's satisfaction that it has made a "good faith" effort to implement the Part H mandates but will be unable to achieve this objective in the absence of the requested waiver. We believe that such a special, time-limited waiver authority would strike a proper balance between recognizing the legitimate impediments many states face in their attempts to fully implement the Part H mandates and maintaining the momentum generated by the 1986 enactment of P.L. 99-457.

IV. Funding Formula

In retrospect, the original 1986 legislation creating the Part H program was built on the faulty premise that financial support for the full range of early intervention services required by infants and toddlers with disabilities could be obtained through existing health, education and social service funding streams, and, therefore, only a limited amount of federal "glue money" would be required through Part H to orchestrate the design and implementation of a comprehensive, coordinated statewide service delivery system. As a consequence of this premise, the existing Part H funding formula specifies that available funds are to be distributed among the states on the basis of general population.

The states' experiences over the past four years in developing plans to implement comprehensive statewide networks of early intervention services, however, generally indicate that there are significant gaps in funding for such services that are unlikely to be made available through existing health, education and social service programs. As a result, if the comprehensive statewide network of services that is envisioned in Part H legislation is to become a reality, new or supplemental funding authorities will need to be created in many states. Certainly, the federal government bears a responsibility for assisting the states in meeting such direct service costs.

This objective should be addressed through the establishment of a new Part H funding formula that: (a) recognizes the federal government's obligation to participate in a more substantial manner in the cost of furnishing early intervention services; and (b) ties future federal funding (above a base allocation level) to the projected number of enrollees in state/local early intervention programs/services, rather than the present approach of linking federal funds solely to general census figures. This revised allocation formula should be divided into two parts. First, to cover the cost of establishing and maintaining an administrative infrastructure for early intervention programs as well as the costs of planning, training and interagency coordination, a state should receive a base allocation, which is adjusted upward to account for general population differences between the states. The remainder of the funds appropriated for the Part H program then should be distributed among the states on the basis of the number of infants and toddlers who are expected to be enrolled in early intervention programs during the subsequent year. Adjustments for under or overcounting can be made during the state's next annual funding cycle.

In moving to such a "child count" funding formula, it is particularly important that reasonable transition provisions be built into the legislation in order to avoid unnecessary dislocations in state planning and implementation activities. In particular, the amended allocation formula should take cognizance of the fact that states are at very different stages of implementing Part H and reward them accordingly. The proposal advanced by the Carolina Policy Studies Program -- i.e., to differentiate between planning funds and implementation funds and allow states three years to reach full implementation once they begin to provide direct services in accordance with their comprehensive early intervention system plans -- strikes us as a reasonable approach. Such an approach, as CPSP pointed out in a recent report, would recognize that "implementation of a new system of policies is not a single static event, but a dynamic act that takes place over time."[3] No state can be expected to leap from the planning stage to full implementation overnight and, therefore, the funding formula should reward states for increasing the number of participants in early invention programs so that they have direct financial incentives to achieve the full service mandate of Part H.

V. Authorization Levels

It should be obvious from the discussion above that NASMRPD believes that a substantial increase in the level of federal financial participation will be necessary if the original vision of Part H is to be realized in all fifty states. Should Congress decide to adopt the Administration's proposal to consolidate Chapter 1 ESEA and Part B IDEA funding, the need for increases in Part H support will be all the more pressing, especially in those states which have relied heavily on Chapter 1 funds to support early intervention services for infants and toddlers with disabilities.

Under the circumstances, NASMRPD recommends that an authorization level of at least $250 million be established for FY 1992, with higher levels in subsequent fiscal years to reflect the anticipated growth in the total number of infants/toddlers receiving early intervention services. The proposed FY 1992 spending level would represent a federal contribution of roughly $1,000 per child, while still allowing for continued federal participation in the costs of state-level planning, training, coordination and administrative activities under Part H.

VI. Need for Increased State Flexibility

One criticism that has been levied against the planning/implementation process laid out in Part H statutes and regulations is that it is based on a unilateral vision of what a comprehensive early intervention system should include and, consequently, leaves too little room for local initiative and true involvement of families in the formulation of policies and practices.

When Part H was originally drafted, an effort was made to establish a set of broad policy goals and a process through which each state would be able to build upon the resources and capabilities at its disposal to construct a comprehensive, statewide system of early intervention services. As time has passed and states have proceeded with their planning/implementation efforts, however, NASMRPD has received an increasing volume of complaints from the states that the statutory and regulatory requirements of Part H are unnecessarily rigid and force states into developing clinically driven models of early intervention services. These compliants are echoed by families in some states, who believe that early intervention services are being structured in a way that emphasizes the role of the clinician, rather than being family-driven.

We recognize that the Subcommittee will be asked during the reauthorization process to add further specifications in Part H to memorialize the roles of various clinical sub-specialities in the delivery of early intervention services. For our part, we hope Congress will resist such entreaties and instead focus on ways of eliminating unnecessary details from the existing law and promote a more family-centered approach to programming and policy development.

* * * * * *

We wish to express our thanks to the Subcommittee for this opportunity to offer our organization's views regarding legislation to reauthorize Part H of the Individuals with Disabilities Education Act. If we can be of further assistance to the members and staff of the Subcommittee as this legislation is prepared and marked up, please feel free to contact us.

Footnotes

1 1990 Chartbook: Services for People with Developmental Disabilities, Center for Residential and Community Services, Institute on Community Integration, University of Minnesota, 1990, p. 24.

2 Harbin, G.L., J.J. Gallagher, T. Lillie and J. Eckland, "Status of States' Progress in Implementing Part H of P.L. 99-457: Report #2", Carolina Policy Studies Program, Institute for Child and Family Policy, Frank Porter Graham Child Development Center, The University of North Carolina at Chapel Hill, October 9, 1990, pp. 20-23.

3 Gallagher, J., G. Harbin, R. Clifford, J. Eckland, P. Place, P. Tullager and K. Huntington, "Recommendations for Reauthorization: Part H of P.L. 99-457", Carolina Policy Studies Program, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, January 29, 1991.

EARLY CHILDHOOD INTERVENTION
Interagency Coordinating Council
100 North First Street • Springfield, Illinois 62777-0001

Public Testimony Regarding:

Public Law 99-457, The Education of the
Handicapped Act Amendments of 1986

Presented to:

Division of Early Childhood/Council of
Exceptional Children - March 16, 1990

Presented by:

Sue Walter, Parent Representative
Illinois Interagency Council on Early Intervention

Home address: 150 Sunflower
Highland, IL 62249

Good afternoon, Chairman Ziegler and members of the receiving panel. I am Sue Walter, a parent representative on the Illinois Interagency Council on Early Intervention. I am accompanied this afternoon by the Illinois Part H Coordinator, Audrey Witzman. I am pleased to be presenting on behalf of the members of the Illinois Interagency Council regarding the reauthorization of Public Law 99-457, The Education of the Handicapped Act Amendments of 1986.

My husband and I are parents of two children; our preschool age daughter has cerebral palsy. Since I have been involved with the planning and implementation of Public Law 99-457 for several years, I have been able to view this endeavor not only globally, from a statewide perspective, but also from a parent's point of view. Today I will discuss six issues, each of them impacting on the family as well as the statewide system. The issues are:

1) funding from the federal government;
2) timelines for planning and implementation;
3) lack of appropriate services in community-based, non-segregated settings;
4) expansion of the number of members able to participate on the Council;
5) fee for service structure; and
6) the eligibility for Council membership based on the age of our handicapped child.

Funding From the Federal Government

Illinois was disappointed to learn about the minimal increase of Part H funds for the Years Four and Five. We understand there is the possibility of accessing at least 16 different Federal programs to assist us with funding, but there are difficulties related to this effort. The Federal programs have differing eligibility criteria, differences in funding approaches, discretion in setting priority for funding, and discretion in determining the target of assistance, such as the provider, family or individual as the recipient.

Just as our complex State is experiencing difficulties in determining how much of an agency's money is presently going for some aspect of early intervention, we envision accessing multiple federal program dollars to be just as frustrating. In the meantime, we must make decisions about a statewide system and legislation with possible federal and state funding levels yet to be ascertained. Part H funding needs to be increased in these last two years, allowing states to phase-in needed programs and have access to start-up costs. After that, funding levels need to remain for three to five years to allow states to adjust costs for participating agencies and assume the total financial responsibility on a phase-in basis accessing all the complex resources possible.

Timelines for Planning and Implementation of the Statewide System

Five years for planning, developing, and implementing assumes all states are similar in resources and legal systems. Our State, like others, is very complex. Our Council has representation from nine agencies. Our diversity of populations and geographic areas cannot be disputed. Because our State chose to use some planning monies for pilot efforts, we find ourselves in a dilemma of rushing to legislate a statewide system without definite answers concerning levels of possible Federal program funds or delaying our fourth year application and risking a cutback on successful pilot programs we fund, only to enlarge them next year and search for dismissed staff.

There needs to be five years of actual planning for states as large and complex as ours without risking cutbacks in needed and successful programming. A two year phase-in time before actual services are provided statewide would ensure better services at a growth rate a state could manage. Illinois has made great strides in serving at risk preschoolers. We do not want to jeopardize our momentum for needy young children and risk a negative reaction from our legislators because we hurried a very complex endeavor.

Need for Community-Based Non-Segregated Settings

Speaking of hurrying a complex endeavor, I am concerned that infants and toddlers will be placed in settings for handicapped children rather than provide our children the opportunity to receive services in community-based non-segregated settings. This third issue deals with the fact that least restrictive environment needs to start with this age group. The settings are not yet available nor the personnel to staff them.

Number of Members on Council

My fourth concern is in regard to the size of the Council. Even though we can grow beyond 15 with ex officio members, we need more parents in relation to the number of professionals sitting on most Councils. Allowing states to set their own maximum, possibly up to 25, seems more logical because each state is so different.

Fees

I am probably most concerned that states may establish a schedule of sliding fees. I understand this could be necessary to access certain public funds, but parents with handicapped children already view themselves as an underclass. The sheer fact that the lives of family members are complicated by medical and social issues suggests that families should not be penalized again by financial constraints for these services. Free and appropriate services should be available to all, especially the working poor. Families who can, might be urged to donate resources for others less fortunate, but services should not depend on your monthly income or whether your job is secure or in jeopardy this year. When programs base services on a family's ability to pay, some families might not receive the services as often or as in-depth as other families.

Council Members Eligibility

My final issue concerns the statement in the law that I must give up my voice and vote on the Council when my daughter reaches six years of age, which in my case will be May, 1990). As a non-professional parent, I have worked hard to learn all I can about Public Law 99-457. Just when I become most valuable, most confident, and most informed, I must leave my membership on the Council to another parent because my child turns six. Even though my child grows older, I can still remember our anguish and frustration in those early years of searching for answers. Expand the age range of the member's child to nine or ten. Let the knowledge we parents have gained work for you.

STATEMENT ON THE REAUTHORIZATION OF P.L. 99-457, PART H AND B-619

The NATIONAL CONGRESS OF AMERICAN INDIANS is the oldest, largest, and most powerful of all Indian organizations. NCAI membership includes 216 Indian and Alaskan Native tribes in the United States, and represents approximately 80% of the 1.6 million American Indians and Alaskan Natives.

The NCAI's Issues Committee on Disabilities was established to provide advocacy for Americans with developmental and acquired disabilities birth through sunset years. The Committee is therefore submitting the following statement to the Congressional Committee on Education and Labor, Subcommittee on Select Education, House of Representatives.

P.L. 99-457, PART H AND B-619

Issue 1: Congressional hearings held in Washington, D.C., effectively prohibit many American Indians from testifying because of the location's inaccessibility due to costs and travel distance. Results of hearings reflect white, middle class concerns instead of a broad scope of minority populations from across the United States.

Recommendation: Hearings should be held in each state at a time and place designated by the Developmental Disabilities Council of the state, in cooperation with concerned agencies. Hearings should be publicized well in advance, and disabled persons and/or their families, especially minorities and American Indians, should be encouraged to attend and testify.

Issue 2: Lack of cooperation between agencies that provide services to individuals. Most agencies view themselves as "provider of last resort," which often means a child goes without services while the agencies squabble about which one of them will take responsibility (pay the bill).

Recommendation: Wording in "Medical and other non-Part H services" S303.344(e)(1) should be rewritten to include consumable items such as pampers, skin creams, disposable hygiene wipes, and bed/chair disposable pads, etc. as required medical supplies. Wording should also specify a time-frame in which the case manager is mandated to determine the source of the "other" services.

Issue 3: The recent priorities of P.L. 99-457 are quite restrictive, and differ considerably from the original priorities, leading to less local control over program development.

Recommendation: Administration at the National level needs to return more local control of program development to communities, which know their clients, families, resources, and cultures.

Issue 4: American Indian infants are being born with disabling conditions at three times the rate of all other babies in the United States, yet Part H and Part B are often not available to Indian infants and toddlers because of rural area barriers, low income, program guideline barriers, and cultural factors.

Recommendation: Amend Section 623 to specify a priority for states to undertake expanded outreach to low income and minority and underserved populations. The priority should include the participation of tribes, Indian organizations, and Indian persons in the development of all phases of program development.

Issue 5: A family member may wish to be the case manager for a child within the extended family. Reluctance to have a non-Indian "manage" the child and the family is common, yet family members are prohibited from being case managers.

Recommendation: The IFSP section should be amended to include the possibility for a family member to be a case manager (service coordinator would be a better term), to receive training, and to be paid for his/her work.

Issue 6: Many of the educational components are unfamiliar to American Indian parents, who are frequently already overwhelmed by their child's disability. Parents need to learn how to advocate for their child, how to participate in the IFSP, and how to work cooperatively with their child's educational program.

Recommendation: Modify current priorities for parent training by Parent Training and Information Centers to include training for parents of infants and toddlers, to stress outreach to minority, low-income, and underserved populations, and to emphasize cultural sensitivity in PTI staff training.

Submitted by:

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Pediatric Nutrition Practice Group
Pediatric Nutrition—A Building Block for Life

April 21, 1991

Honorable Donald Payne
Chairman, Subcommittee on Select Education
Education and Labor Committee
House Annex 1, Room 518
New Jersey and E Street, S.E.
Washington, DC 20515

Dear Mr. Chairman:

I am pleased to submit comments on the re-authorization of P.L. 99-457, Education of Children with Special Needs, for the Pediatric Nutrition Practice Group (PNPG), a dietetic practice group of The American Dietetic Association (ADA). As the nation's largest association of food and nutrition professioanls, ADA's more than 60,000 members promote health and nutritional status of the population through quality dietetic practice, education and research.

P.L. 99-457 recommends nutrition services for handicapped children, a vast improvement of P.L. 94-142, which omitted a necessary health and nutrition component. The inclusion of nutritionists as early intervention service providers and nutrition services as part of a comprehensive service model ensures that the growth, nutrition and feeding issues which face many children and their families served under Part H are adequately addressed.

The essential role of optimum nutrition for infants and children in achieving their full potential is well documented in the literature. The impact of many of the nutrition, feeding, and/or growth issues on a child's development and on the family, need to be addressed as part of a comprehensive system to prevent or ameliorate developmental disabilities. Often times the growth, feeding and/or nutrition concerns faced by these families in caring for their infants and toddlers are readily identified by the family through the Individualized Family Service Plan (IFSP) which serves as the focal point of the early intervention service system. However, experience has shown that it has remained difficult for families to have these concerns addressed unless a provider trained in special needs nutrition, such as a registered dietitian, is part of the early intervention team. With nutrition services included as part of comprehensive care under Part H, the problem of resource identification and availability should be alleviated, once states have their systems in place.

A PRACTICE GROUP OF
THE AMERICAN
DIETETIC
ASSOCIATION

A recent survey of infants and children in Public Health Region IX found that forty-nine percent of the 0-2 and 3-5 year olds were at nutritional risk. These children manifested slowed growth rate, feeding problems and nutritional deficiencies. These data are supported by the preliminary findings of a SPRANS project, Early Start (Region 1) which is currently documenting nutrition and feeding issues in the 0-3 population in Massachusetts. Initial reports indicate that forty-three percent of all the children (N=327) have shown a delay below the 5th percentile in one or more growth parameters (weight/age, height/age, and/or weight/height), that is similar to children with Failure to Thrive. Over twenty percent of the children had delayed introduction to baby, junior or table food and/or use of cup, fingers or spoon for self-feeding. Initial impressions of required services indicate that in order for adequate nutrition services to be provided, systems of care must be developed within states to ensure that appropriate referral and coordinating mechanisms are in place, and that sufficient time for nutritional assessment, intervention and monitoring is provided.

Re-authorization of P.L. 99-457 will give the states the necessary time to more adequately develop systems for the 0-3 year old population served under Part H. Re-authorization will also provide states with the time to address personnel needs by identifying gaps in services and to provide training to assure that adequately trained staff will be available to meet operational standards. Three federally funded courses presently exist to train nutritionists and other health professionals on nutritional and service needs of the child with special health care needs. However, there still remain large numbers of dietitians and other health professionals who require this training. Continued funding of nutrition training and nutrition services is pivotal to provision of service to the child and family served under Part H.

In summary, nutrition services need to be a component of the Early Intervention intake and ongoing evaluation process if early identification and nutrition intervention in this at-risk population is to take place in a family centered, community based model of service. Our clinical experience indicates that nutrition services as outlined in Part H of P.L. 99-457 should be a mandatory component of Early Intervention services.

We would like to request that these comments become part of the public record. Thank you for the opportunity to address these concerns.

Sincerely,
Susan Krug-Wispe
Susan Krug-Wispe, MS, RD, LD
1990-91 PNPG Chairman

HEARING ON REAUTHORIZATION OF THE EARLY INTERVENTION AND PRESCHOOL PROGRAMS UNDER THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

FRIDAY, APRIL 12, 1991

House of Representatives,
Subcommittee on Select Education,
Committee on Education and Labor,
Washington, DC.

The subcommittee met, pursuant to call, at 10 a.m., Room 2175, Rayburn House Office Building, Hon. Major R. Owens [Chairman] presiding.

Members present: Representatives Owens and Ballenger.

Staff present: Maria Cuprill, Patricia Laird, Wanser Green, and Sally Lovejoy.

Chairman Owens. The Subcommittee on Select Education will come to order.

Today's session is a continuation of the hearing begun yesterday. I will not reread the opening statement. However, I would like to begin by commenting that the task that we are undertaking with respect to these hearings on the reauthorization of this important legislation, is as vital as any task taken anywhere in the Capitol with respect to education for children.

The way we treat our most fragile children sets the pace and the tone for the way we treat our children in general. For that reason, we place a great deal of importance on these hearings.

I yield to my ranking member, Mr. Ballenger, for an opening statement.

Mr. Ballenger. Thank you, Mr. Chairman.

I made a short statement yesterday, and I would like to commend you for pulling together this hearing, because as you know, I am new at being the senior member of this subcommittee, and I am receiving an education from the hearings, and becoming more knowledgeable about what these witnesses want, and what I think is possible.

I would again say we are fortunate to have somebody like you in charge.

Chairman Owens. Thank you very much.

I want to thank you for the tremendous contributions of North Carolina, both yesterday and today. We are quite impressed.

We are going to have two panels. Panel one consists of the following persons: Dr. James Gallagher, Carolina Institute for Child and Family Policy, University of North Carolina, Chapel Hill, North Carolina; Dr. Samuel Odom, Peabody College, Vanderbilt University, Nashville, Tennessee; Lieutenant Colonel F. Christian Sautter, West Point, New York; Ms. Virginia View, speaking for Ruth Rucker, Low-Income and Minority Parent, Empowerment Task Force, Mental Health Law Project, Washington, DC.

The Consortium for Citizens with Disabilities, Washington, DC., will be represented by Lourdes Putz and Dr. Mary Beth Bruder, Director, Family Support and Early Intervention, MRI Institute for Human Development, Valhalla, New York.

We will begin with North Carolina, Dr. James Gallagher.

STATEMENTS OF DR. JAMES GALLAGHER, CAROLINA INSTITUTE FOR CHILD AND FAMILY POLICY, UNIVERSITY OF NORTH CAROLINA, CHAPEL HILL, NORTH CAROLINA; DR. SAMUEL ODOM, PEABODY COLLEGE, VANDERBILT UNIVERSITY, NASHVILLE, TENNESSEE; LIEUTENANT COLONEL F. CHRISTIAN SAUTTER, WEST POINT, NEW YORK; VIRGINIA VIEW, FOR RUTH RUCKER, LOW-INCOME AND MINORITY PARENT, EMPOWERMENT TASK FORCE, MENTAL HEALTH LAW PROJECT, WASHINGTON, DC; LOURDES PUTZ, PARENT, AND DR. MARY BETH BRUDER, DIRECTOR, FAMILY SUPPORT AND EARLY INTERVENTION, MRI INSTITUTE FOR HUMAN DEVELOPMENT, VALHALLA, NEW YORK, REPRESENTING THE CONSORTIUM FOR CITIZENS WITH DISABILITIES, WASHINGTON, DC

Mr. GALLAGHER. Thank you very much, Mr. Chairman. It is a great honor to be here.

I appreciate your having these hearings and giving me a chance to make some statements on it. I am Director of the California Institute for Child and Family Policy at the University of North Carolina at Chapel Hill.

For the past three and a half years, we have been with the Department of Education tracking the implementation of Part VIII. We have been trying to answer the questions of the law: what are the forces which are facilitating this implementation; what are the barriers which hold back the implementation?

We have collected surveys, telephone——

Chairman OWENS. Dr. Gallagher, please pull the mike closer to you.

Mr. GALLAGHER. In the search for answers to these questions, we have used telephone interviews, document analysis. We have gone to six States to do case studies of those States, and the testimony that I am about to give will, in large measure, come from the information we collected in this study.

I provided to the committee a larger set of recommendations on the reauthorization, but I would like to focus my time today on four issues. One is finance, the other is at-risk children, personnel preparation, and birth through 5 issues.

During the three and a half years that we have been working in the States, we have been impressed first of all by the enormous energy the States have given to this problem.

We think there is a good-faith effort being made by thousands of people out there, and we think it is because this is an issue whose time has come. I think the professionals in the field recognize that this is a good effort and one that should have been done a long time ago in terms of service to infants and toddlers and their families.

We also have found four major reasons why States have been not as fast in implementation as might have been originally anticipated.

First of all, the law calls for major reforms. They call for professionals to do things very differently than they have been doing them in the past. They call for interagency collaboration. They call for policies related to families. They call for coordination of finances. And all of these things represent new ways of doing things.

The second is that the States have had to generate new policies that have had few precedents, and the lead agencies and interagency coordinating councils haven't really had the power or the clout to make their wishes reality.

And so, all the decisions have had to be made through compromise through negotiations, and that takes time.

Also, the sheer number of separate policies, the interagency coordinating council can't look at personnel preparation and finances and family policy and all of the other dimensions at the same time. And so, there are a large number of issues that have to be dealt with.

And, finally, there is the major issue of finance in the States themselves. The States collectively are in difficult times from a financial standpoint. I had one person tell me in one of the States that, we like this program very much, we think it is a thing that we want to do.

We are also underfunded in a large number of other programs, and so, we are struggling with how we are going to be able to carry out what we know we want to do.

So, our data suggests that many States will be ineligible to participate in this program if the current time lines are strictly adhered to.

I provided the committee with a figure, a chart, which shows where the States are collectively in the 14 components required. As you can see, the States have made good progress in defining developmentally delayed and timetable development and child finance systems, in contracting services.

Their lowest area is in finance. Financial—establishing financial responsibility and timely reimbursement.

The second chart shows a policy of approval, and as—that means some official body of the State has said this is our policy on interagency agreements or on financial responsibility.

So, let me talk briefly about finance. The evidence from our studies clearly indicates that the States have made the least progress in those dimensions related to financial responsibility and timely reimbursement and interagency coordination. This is not just because of a shortage of funds. It is because of lack of authority of the lead agency to assign financial responsibility, and the difficulties in coordinating the various funding sources.

So, we recommend two areas in this dimension: That the Federal Government needs to embark on a two-level Federal contribution in partnership with the States. First, the Federal Government should allocate planning money to allow States that show good-faith effort to continue planning until they are ready for full implementation.

Second, to aid States in making the expensive transition to full service, that funds should be provided up to 100 percent increment in current allotments to aid the State in reaching full service.

Second, we also recommend that the law redirect the financial responsibility from lead agency to State by changing the language that discusses the responsibility of the lead agency.

It is one thing to ask the lead agency to coordinate things, it is another to have them have the power to do it. We would recommend the power be given to the State to coordinate it and let the State decide what the responsible authority should be that would be able to carry out this coordination.

Second, the area of at-risk children. This is one of the most innovative aspects of this law, that trying to provide services for youngsters who would be at risk for handicapping conditions unless early intervention took place.

Originally, in our earlier studies, we found 22 States that were interested in providing—including at-risk children in some way in this law. The financial conditions in the State have worsened, and as the States realize what the cost would be, many of the States, including our large industrial States, have backed off.

We now have, at most, about 10 States who are currently suggesting they are still interested in including at-risk children, and we have provided a chart of the States for you. On this—we think this is unfortunate, and we would propose the following:

That the legislation should be amended to provide incentives to the States to serve at-risk children at the level of routine periodic screening, tracking, monitoring, and referral to existing services. We think that States would be interested and eager to try and do that, as long as they are relieved of the responsibility of the comprehensive service to every youngster they would call at-risk.

As soon as a youngster showed evidence of a handicapping condition, then they should be referred and put into a different category and given comprehensive services.

Second, we would ask for a special analysis of funding sources from laws other than Public Law 99-457 to identify public, private, State and local funds that could be utilized to provide services to at-risk children.

We think this is one of the most innovative parts of the law, and we think it should be implemented, but it will not be implemented under the current conditions, because the States are backing off; they are afraid of the financial consequences.

It was clear to the framers of this law that comprehensive services should be delivered by qualified personnel. Our various studies show major shortages in all of the dimensions of personnel to provide qualified services in this particular area.

We also have found that the States have not been very active in developing either personnel standards or a plan for personnel preparation.

We believe that this lack of concern is not because of their lack of interest, but because they have been worrying about other issues, such as finance, family policy, et cetera.

It seems clear that personnel preparation, being a long-term problem, has yielded the center stage to other more immediate, pressing issues. So, we are recommending that a personnel set-aside—personnel preparation set-aside of 5 to 10 percent of the Part H funds—be specifically expended by the States on the development and implementation of a comprehensive plan for personnel development, which includes pre-service and in-service training.

We would also ask that a study be done of the various Federal personnel preparation initiatives in order to see where the gaps and duplications might be from the various agencies that are currently supporting personnel preparation programs.

Finally, the birth through 5 issue. There are many people in the States who are concerned about the transition period when the child reaches age 3, and then as—comes under another area of authority under section 691.

And the current Part H requirements for interagency coordination, for family empowerment, for IFSP, for case management, seems to us to fit the current knowledge of families and child development most effectively.

So, we believe that the changes in the law and regulations should move in the direction of the current Part H model. We would recommend, therefore, that Congress attempt to achieve a seamless program from birth through 5, and to modify both Part H and section 619 with this goal in mind.

We also believe that IFSP should write one set of regulations to cover the birth through 5 age range. There are many other issues that are listed in our paper called "recommendations for reauthorization" that has been provided to the committee.

We appreciate the opportunity to appear. We welcome any questions from the committee on this testimony.

[The prepared statement of Dr. James Gallagher and attachments follow:]

TESTIMONY OF DR. JAMES J. GALLAGHER ON THE EARLY INTERVENTION PROGRAM, PART H, AND PRESCHOOL PROGRAM, PART B/SECTION 619, OF THE INDIVIDUALS WITH DISABILITIES ACT

April 12, 1991

TO: SUBCOMMITTEE ON SELECT EDUCATION
HOUSE OF REPRESENTATIVES

My name is Dr. James Gallagher, and I am the director of the Carolina Policy Studies Program at the University of North Carolina at Chapel Hill. For the past three-and-a-half years, our policy studies program has been analyzing and following the implementation of Part H of P.L. 99-457 in the fifty states and the District of Columbia. We have conducted case studies of six (6) diverse states, and have conducted surveys, document analyses of state policies, focus group interviews, and telephone interviews, in order to collect information about: (a) how the states were progressing, (b) what factors facilitated states' progress in implementing this monumental legislation and (c) what barriers stood in the way of effective implementation of this law. My testimony today will rely heavily on the findings that we at the Carolina Policy Studies Program CPSP have accumulated. I have brought a few of our policy reports with me in addition to the more extended recommendations regarding the reauthorization process.

Today, I will briefly discuss the broad context facing states as they implement this law and then present four areas that based upon our research need to be addressed in reauthorization: finance, at-risk children, personnel preparation, and birth through five programs. These four policy areas were selected from a list of ten that are included in our written testimony.

During the three-and-a-half years of our study, we have become increasingly impressed, at CPSP, with the enormous energy being placed on the implementation of this law within each of the states. Literally thousands of people around this country have been engaged in conscientiously trying to take the federal mandate and apply it to their own particular state situation. In large measure states have shown a "good faith" effort to comply with the various mandates of the law. However, there are four major reasons why states have not progressed further in implementation

1. The law has encouraged major reforms in the human services delivery system in the states. These reforms include coordination of funding sources, cross-discipline cooperation, family empowerment policies, the development of a statewide system of personnel preparation, and many other long delayed actions.

   Thus, states often have had to generate new policies that have few precedents and that is always time consuming.
2. Since, within each state, no one person or agency has the authority to direct or command the required action, lead agencies and Interagency Coordinating Councils have had to reach decisions through compromise, consensus and negotiation. This, too, is time consuming.
3. The sheer number of separate policies that have to be negotiated among various agencies and groups of providers is another barrier to rapid completion of the federal mandate.

4. Finally, this exercise in major reform of child services was done during a time when the majority of states face serious financial shortfalls, the difficulties of meeting the time requirements of the law have been extensive.

Our data indicate that despite the effort and progress made, many states will be ineligible to participate in this important federal program if the current timelines are strictly adhered to. What is needed now is federal action that recognizes both the constraints that states are operating under and the new phase of implementation.

Finance

The evidence from our policy studies clearly indicates that states have made the least progress in those components of the law that require assignment of financial responsibility, timely reimbursement and interagency coordination. This is not just because of a shortage of funds although that is a major problem. In addition, there is the lack of authority of the lead agency to assign financial responsibility, and the difficulties in coordinating the various categorical funding sources. As a result, we recommend that the federal government assist states by engaging in a multifaceted approach to this problem.

1. **The federal government needs to embark on a two-level federal contribution in partnership with the states. First, the federal government should allocate planning money to allow states that show good-faith effort to continue planning until they are ready for full implementation. Second, to aid states in making the expensive transition to full service, funds should be provided to the level of a 100%**

increment in current allotments to aid the states in reaching full service.

2. **The law should redirect the financial responsibility from lead agency to state, by changing the language in the component that discusses the responsibility of the lead agency.**
3. **Conduct a study that examines other approaches to funding at the federal level instead of the current approach of categorical funding.**

Such gestures would show the states that the federal government is interested in this partnership, and would provide needed incentives for the states to move into the full implementation stage. One of our reports focuses upon alternative long range funding options since the judgement of our financial consultants is that the current method is unworkable in the long run.

At-Risk Children

One of the most innovative aspects of this law has been allowing the states to include, in their definition of children eligible for Part H services, those children who might be at-risk for a handicapping condition unless some early intervention took place. Initially, the states reacted quite favorably to this provision which encouraged the prevention of disabilities, and at one point in our studies, we found twenty-two (22) states planning to serve some groups of at-risk children. As the financial conditions in the states have worsened, and as states realize that serving children at-risk will increase the number of children needing services, and hence raise the cost of the program, many of the states, including our largest industrial states, have backed away from including children at-risk as part of this program. We at CPSP feel that this is very unfortunate. We would propose the following:

1. **The legislation should be amended to provide incentives to states to serve at-risk children at the level of minimum routine periodic screening, tracking, monitoring and referral to existing services.**
2. **We suggest a special analysis of funding sources from laws other than P.L. 99-457 in order to identify funds (public and private, federal, state, and local) that could be utilized to provide services to at-risk children.**

Personnel Preparation

It was clear to the framers of this law that the comprehensive services should be delivered by qualified personnel from a variety of professional disciplines. Thus states would have a special responsibility for developing a plan for personnel preparation and for developing appropriate standards for certifying that professionals possess the skills necessary to work with infants and their families. Despite these intentions, our studies have indicated that states have experienced difficulty with both developing a plan and developing standards.

Not, we believe, because of a lack of concern for this topic, but rather because other issues, such as financing services, developing IFSP policies, defining the eligible population, were more pressing.

It seems clear that personnel preparation, being a long term problem, has yielded the center stage to other -- more immediately pressing -- issues, and that a set-aside is necessary to encourage the states to start what is essentially a long process of organizing an effective personnel preparation program for this age group.

1. **We would recommend, therefore, a personnel preparation set aside of 5-10% of the Part H funds to be specifically expended by the states on the development and implementation of a comprehensive plan for personnel development which includes preservice and inservice training.**
2. **We also recommend that a study be conducted of all of the federal personnel preparation initiatives in the various federal agencies in order to reduce gaps and duplication.**

Birth through Five Program

There are numerous differences between the provisions of Part H of P.L. 99-457 and Section 619 of P.L. 94-142 in eligibility, service delivery, and program administration. There is deep concern among parents, service providers, and state policy makers that infants and toddlers who are receiving services under Part H would become ineligible, during the transition from Part H to Section 619, at age three.

The current Part H requirements for interagency coordination, family empowerment, use of IFSP, and provisions for case management, seem to fit the current knowledge of families and child development most effectively, and we believe that the changes in the law and regulations should move in the direction of current Part H standards.

1. **We would, therefore, recommend that the Congress attempt to achieve a "seamless" program from birth**

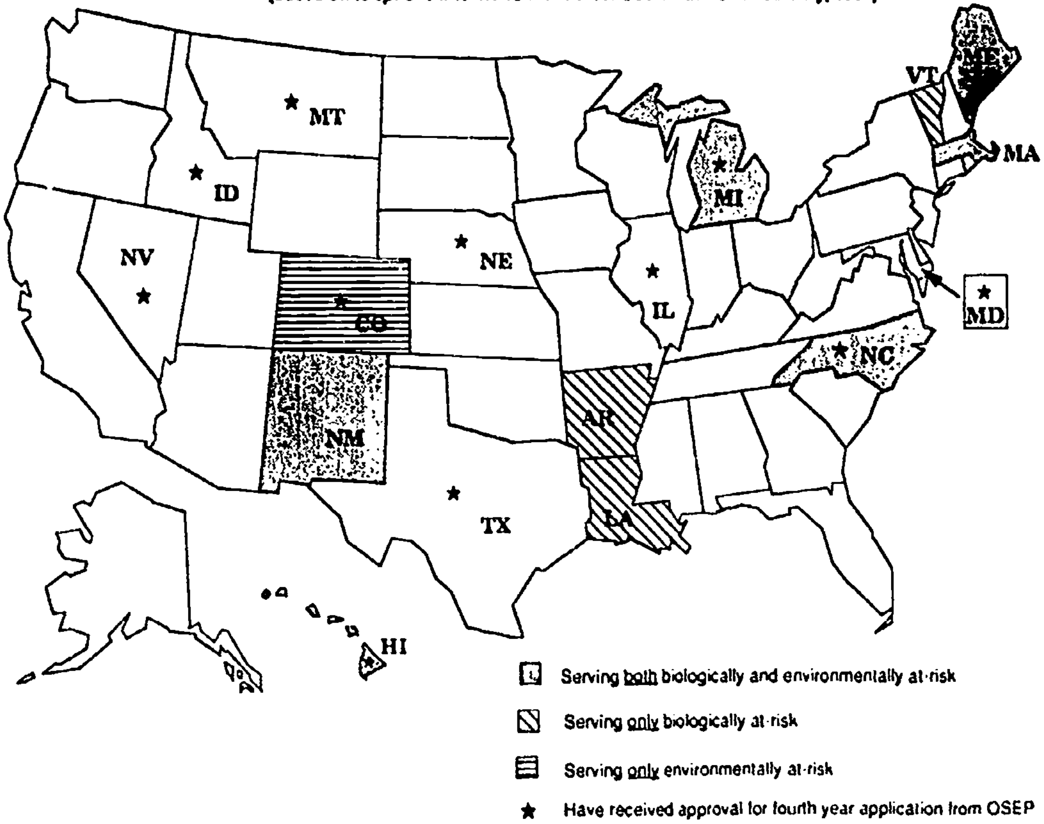
through five, and to modify both Part H and Section 619 with this goal in mind.

2. **We also believe that OSEP should write one set of regulations to cover the birth through five age range.**

There are many other issues that are listed in our paper, Recommendations for Reauthorization, that has been provided to the committee. We appreciate very much the opportunity to appear, and we welcome any questions from the committee on this testimony or on the more extended reports provided for the record.

Figure 6

States Planning to Continue Including At-Risk in their Definitions
(based on telephone interviews with Part H Coordinators in February, 1991)



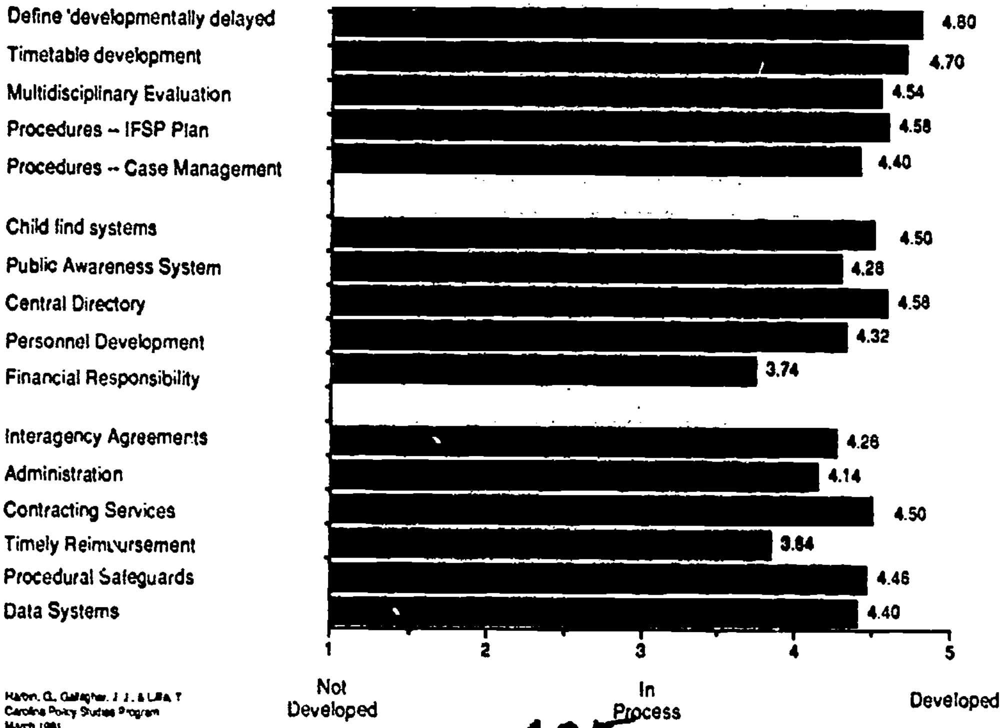
▧ Serving both biologically and environmentally at-risk

▨ Serving only biologically at-risk

▤ Serving only environmentally at-risk

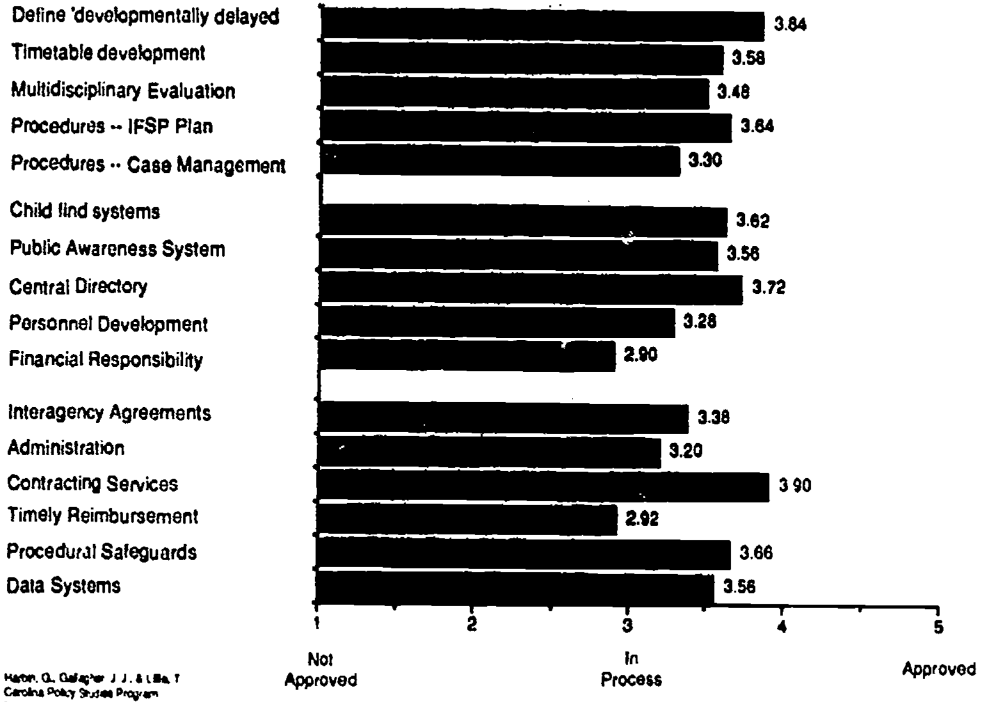
★ Have received approval for fourth year application from OSEP

Figure 1: State Progress in the Implementation of PL 99-457, Part H
POLICY DEVELOPMENT, 1991, N=50



Harbin, G., Gallagher, J. J., & Lillie, T
Carolina Policy Studies Program
March 1991

Figure 2: State Progress in the Implementation of PL 99-457, Part H
POLICY APPROVAL, 1991, N=50



Harbin, G., Gallagher, J. J., & Lillie, T.
Carolina Policy Studies Program
March 1991

RECOMMENDATIONS FOR REAUTHORIZATION

PART H OF P.L. 99-457

Carolina Policy Studies Program

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January 29, 1991

The Carolina Policy Studies Program, through a cooperative agreement with the U.S. Department of Education, has been studying for the past three years the implementation of Part H of P.L. 99-457--Programs for Infants and Toddlers and Their Families.

This brief set of policy concerns and recommendations is directed toward the reauthorization of this important law. It draws upon a series of policy studies on eligibility, finance, health coordination, personnel preparation, family policy, plus six case studies of how states are implementing this law. In each instance, the suggestions will be referenced with data gathered from various CPSP studies, plus other resources.

Overall Considerations

This impressive and ambitious law has done more than provide a planning framework through which the states can provide comprehensive services to infants and toddlers with developmental delays and their families. The law has encouraged major reforms in the human services delivery systems in the states. These reforms include coordination of funding sources, cross-discipline cooperation, family empowerment policies, the development of state-wide system of personnel preparation, and many other long delayed actions.

The consequence of all of these requirements for new policies is that the states have been faced with an enormous agenda for the establishment of policies. Instead of minor changes in existing policies, they often have had to generate new policies that have few precedents. As a consequence of this unique set of tasks, deadlines within the federal legislation have been hard to meet. The sheer number of separate policies that have to be negotiated between various agencies and groups of providers is another barrier to rapid completion of the federal mandate.

Since, within each state, no one person or agency has the authority to direct or command the required action, lead agencies and Interagency Coordinating Councils have had to operate through compromise, consensus and negotiation to achieve a final result. This, too, is time consuming. Moreover, this exercise in major reform of child services was done during a time when the majority of states face serious financial shortfalls, the difficulties of meeting the time requirements of the law have been extensive.

Despite these factors, our policy studies suggest that the states, in large measure, have shown a "good faith" effort to comply with the various mandates of the law, and that what is now needed is federal action that recognizes the new phase of implementation the states are now approaching.

ISSUE #1: STATE FUNDING NEEDS FOR FULL IMPLEMENTATION

While the evidence of our policy studies clearly indicates a "good faith" effort on the part of most of the states, there is also evidence from our case studies (1, 13)* and our reports on overall progress towards implementation (16, 17) that states are having difficulty as they near full implementation requirements. The deteriorating financial conditions in many states have visibly retarded their progress towards implementation. It is possible that a number of states will drop out of the program because of the inability to finance the promise of comprehensive services.

Recommendation #1

CPSP proposes a two-level federal contribution to this program in partnership with the states:

1a. PLANNING MONEY TO ALLOW STATES THAT SHOW "GOOD FAITH" EFFORT TO CONTINUE PLANNING UNTIL THEY ARE READY FOR FULL IMPLEMENTATION.

1b. IMPLEMENTATION MONEY TO AID STATES MAKING THE EXPENSIVE TRANSITION TO FULL SERVICES FOR INFANTS AND TODDLERS WITH HANDICAPPING CONDITIONS AND THEIR FAMILIES. SUCH FUNDS COULD REPRESENT AN ADDITIONAL SUM OF 50-100% OVER THE PLANNING FUND LEVEL.

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*Numbers refer to CPSP studies listed in the bibliography.

ISSUE #2: ENTITLEMENT OF SERVICES

While all states agree with the importance of providing services to every developmentally delayed infant and toddler, many states are concerned about the far-reaching consequences of an entitlement of this magnitude, and some are seriously considering terminating their participation in Part H (16, 17).

Even those states that previously had developed a system of services and have been serving infants and toddlers for some time, are worried that they will not be ready for full implementation to all eligible children within the timelines required by the law. States are in the process of large multiagency system changes to comply with Part H and this takes time (4, 13, 15).

The entitlement to services requires a significant investment of state resources. This occurs at a time when most states are experiencing a revenue shortfall. Thus, it is difficult for many states to continue their current level of commitment and funding to early intervention services, let alone significantly increase their fiscal commitment (1, 13).

Recommendation #2

2a. USE OF A TWO-LEVEL FUNDING APPROACH WHICH PROVIDES A SUBSTANTIAL INCREASE IN FEDERAL FUNDING FOR STATES THAT ARE AT THE IMPLEMENTATION LEVEL (SEE RECOMMENDATION #1).

2b. USE OF A THREE-YEAR TIMELINE THAT REQUIRES STATES TO BE AT THE LEVEL OF FULL IMPLEMENTATION THREE YEARS AFTER THEY BEGIN THE IMPLEMENTATION LEVEL OF FUNDING. IMPLEMENTATION OF A NEW SYSTEM OF POLICIES IS NOT A STATIC SINGLE EVENT, BUT A DYNAMIC ACT THAT TAKES PLACE OVER TIME. A THREE-YEAR PERIOD WOULD ALLOW STATES TO GRADUALLY IMPLEMENT THEIR POLICIES.

2c. CONSIDER THAT AT-RISK CHILDREN BE ENTITLED TO A DIFFERENT OR LIMITED SET OF SERVICES.

ISSUE #3: AUTHORITY FOR AGENCY COORDINATION

The responsibility carried by the designated lead agency for the general coordination and funding of the service system is a significant element in the new law. We have found through various CPSP studies that the assumption that the lead agency has the authority to do this is not justified (1, 13, 19). States have found this responsibility the most difficult, and report the least progress, in implementating those tasks that require interagency coordination (16, 17, 19).

In addition, there are a wide variety of other federal programs that are also related to the target population of Part H (EPSDT, Children's Medical Services, Developmental Disabilities Act, etc.). The various laws and regulations make coordination with Part H difficult (1, 16, 17, 19, 23). The problem facing states is to take a variety of separate, sometimes conflicting, categorical programs and merge them into a coordinated service system.

Recommendation #3

3a. WE RECOMMEND THAT COMPONENT #9 OF THE MINIMUM COMPONENTS, A SINGLE LINE OF AUTHORITY, BE REWORDED TO REFLECT THE MULTIAGENCY INTENT OF THIS LEGISLATION. THE STATE, INSTEAD OF THE LEAD AGENCY, SHOULD BE ASKED TO ENSURE SHARED RESPONSIBILITY AND ACCOUNTABILITY. THIS WOULD ALLOW THE STATE TO DEVELOP AN ADMINISTRATIVE STRUCTURE CONSONANT WITH ITS PATTERN OF GOVERNANCE TO ENSURE THE NEEDED COORDINATION.

FOR EXAMPLE, THE STATE CAN SET UP A MECHANISM/STRUCTURE (I.E., POLICY COUNCIL) THAT IS ACCOUNTABLE TO THE GOVERNOR AND, THROUGH LEGISLATION AND INTERAGENCY AGREEMENTS, DELINEATE RESPONSIBILITIES OF VARIOUS AGENCIES. ANOTHER APPROACH COULD BE THE APPOINTMENT OF A SINGLE AGENCY LOCATED IN THE GOVERNOR'S OFFICE (E.G., OFFICE FOR CHILDREN) THAT HAS THE RESPONSIBILITY OF ENSURING THE SHARED RESPONSIBILITY ACROSS AGENCIES, WITH THE STATE ATTORNEY GENERAL RESOLVING ANY DISPUTES. MANY OTHER POSSIBLE ADAPTATIONS ARE AVAILABLE TO STATE LEADERSHIP PERSONNEL.

3b. WE RECOMMEND THAT CONGRESS SHOULD CALL FOR A POLICY ANALYSIS OF OTHER RELEVANT FEDERAL PROGRAMS TO DETERMINE AREAS OF CONFLICT AND OVERLAP WITH PART H SO THAT NECESSARY COORDINATION MIGHT OCCUR AT THE FEDERAL, AS WELL AS THE STATE, LEVEL. ALTERNATIVELY, THE FEDERAL INTERAGENCY COORDINATING COUNCIL COULD BE MANDATED TO EXECUTE SUCH A STUDY AS ONE OF ITS RESPONSIBILITIES.

ISSUE #4: SHORTAGE OF QUALIFIED PERSONNEL

Despite the universally acknowledged importance of well-trained personnel to the success of this law, the development of plans to construct personnel standards and provide a comprehensive system of personnel development have been slow in most of the states (12, 16, 17). This limited progress has been made despite the general acknowledgement of the long lead time necessary to put such personnel preparation systems in place (2). In addition, personnel attrition from early childhood programs is moderate to high (25) and major shortages clearly exist in areas such as Occupational Therapy, Physical Therapy and Speech Language Pathology (33).

Evidence is also available to the effect that higher education institutions are not eager to enter this field given financial limitations of their own and the uncertainties regarding long term state and federal commitments to this program (12).

Recommendation #4

We recommend the consideration of two possible mechanisms to encourage states to focus on the issue of personnel preparation:

4a. A PERSONNEL PREPARATION SET ASIDE OF 5-10% IN PART H FUNDS TO BE SPECIFICALLY EXPENDED BY THE STATES ON THE DEVELOPMENT AND IMPLEMENTATION OF A COMPREHENSIVE PLAN FOR PERSONNEL DEVELOPMENT.

4b. FUNDS COULD BE RESERVED BY OSEP AND COMPETITIVELY PROVIDED TO STATES THAT NEED SPECIAL HELP IN DEVELOPING A COMPREHENSIVE PERSONNEL PREPARATION PLAN.

ISSUE #5: VARIATION IN ELIGIBLITY CRITERIA

CPSP policy studies have confirmed that there is great variance in how children are being defined as eligible across states (18, 20). There is a lack of consensus regarding the criteria to be used in determining: (a) level and type of delay needed to be classified as developmentally delayed; (b) which physical and mental conditions have a high probability of resulting in developmental delay; (c) which factors place a child at-risk of developmental delays unless intervention is provided (18, 20).

The result of this variation is that a child may be eligible for services in one state, but not in another. Flexibility is certainly a desirable characteristic of federal policies, in order to address the diversity among states. In this instance, however, diversity in eligibility criteria across states may have negative consequences for the families we intend to serve.

Recommendation #5

5a. PROVIDE MORE SPECIFICITY AND EXAMPLES IN LAW, AND/OR REPORT LANGUAGE, ON THE INTENT OF CONGRESS REGARDING WHAT GROUPS OR TYPES OF CHILDREN SHOULD BE ELIGIBLE FOR SERVICES.

5b. ENCOURAGE THE FICC TO BRING TOGETHER KNOWLEDGEABLE CONSULTANTS TO REACH SOME LEVEL OF CONSENSUS ON ELIGIBILITY STANDARDS. CPSP ALREADY HAS COLLECTED DATA THAT COULD ASSIST SUCH A GROUP IN THEIR DELIBERATIONS.

ISSUE #6: MEMBERSHIP OF INTERAGENCY COORDINATING COUNCIL

The Interagency Coordinating Council (ICC) is one of the important devices for communication and planning in the implementation of this legislation. In many states it has performed admirably in dealing with a variety of policy development issues. Some ICCs, however, are hindered by the limitations on the number of members that they could appoint and on some specific limitations regarding parents who as members. Our policy studies (8, 26, 30) suggest that there are many parents whose children are beyond the age of three who could provide valuable service to this program. Furthermore, the current limitation of fifteen members has caused some states to leave out key persons who could be very valuable in the complex communications and coordination tasks required by this law.

Recommendation #6

6a. WE RECOMMEND THAT THE MEMBERSHIP OF THE ICC BE SET AT NO LESS THAN FIFTEEN MEMBERS AND NO MORE THAN THIRTY MEMBERS. THIS SHOULD GIVE ADEQUATE LEEWAY FOR EACH STATE TO INCLUDE THE KEY MEMBERS IN THE STATE CONCERNED WITH THE IMPLEMENTATION OF THIS LAW.

6b. WE RECOMMEND THAT THE "AGE OF CHILD" REQUIREMENT BE DELETED AS ONE OF THE REQUIREMENTS FOR PARENT REPRESENTATION.

6c. WE RECOMMEND THAT THE HEALTH COMMUNITY BE MANDATED REPRESENTATION ON THE ICC AS ONE MEASURE TO HELP NEEDED COORDINATION (31, 32).

ISSUE #7: TRANSITION PROBLEMS AT AGE THREE

CPSP policy studies have revealed that a number of states have been frustrated in their attempts to develop a "seamless" system of services for children from birth to age five (14, 19). Differences in Part H (0-3) and Section 619 (3-5) in eligibility, service delivery, and program administration have caused administrative problems in the states. This will certainly increase as states move into full implementation. The thought that some infants and toddlers would become ineligible for needed services at age three by being transferred to Section 619, with different rules, is particularly bothersome to state planners (14, 19).

Recommendation #7

7a. WE RECOMMEND CONGRESS ATTEMPT TO ACHIEVE SIMILAR REQUIREMENTS FOR CHILDREN WITH SPECIAL NEEDS FROM AGES 0-5, AND TO MODIFY BOTH PART H AND 619 ACCORDINGLY. THE CURRENT PART H REQUIREMENTS FOR INTERAGENCY COORDINATION, FAMILY EMPOWERMENT, USE OF IFSP AND CASE MANAGEMENT SEEM TO FIT CURRENT KNOWLEDGE OF FAMILIES AND CHILD DEVELOPMENT EFFECTIVELY AND CHANGES IN LAW AND REGULATIONS SHOULD MOVE IN THE DIRECTION OF PART H STANDARDS.

7b. OSEP SHOULD WRITE ONE SET OF REGULATIONS TO COVER THIS AGE RANGE.

ISSUE #8: ENTITLEMENT TO FAMILY SERVICES

State agency personnel, service providers, and families have indicated confusion about which services a family member is entitled to receive under Part H (26, 30).

The Report which accompanied P.L. 99-457 identified some family services that must be included in the early intervention system (e.g., family training, counseling, home visits and case management). The Report goes on to state that "The early intervention services included in the bill are not meant to be exhaustive; rather they are intended to be illustrative of the types of services a handicapped infant or toddler may receive under this program" (National Center for Clinical Infant Programs, 1989, p. 8). However, policy makers, providers, and families are confused about the nature and extent of the services to which the family is entitled under this program. This lack of clarity may well lead to very different services across and within states (26, 30).

Recommendation #8

WE RECOMMEND THAT CONGRESS PROVIDE CLARIFICATION ABOUT THE SERVICES TO WHICH A FAMILY IS ENTITLED UNDER THE EARLY INTERVENTION SYSTEM. SUCH CLARIFICATION CAN BE ADDRESSED THROUGH REPORT LANGUAGE ACCOMPANYING THE RE-AUTHORIZATION, OR CAN BE PROVIDED BY INCLUDING A LIST OF ENTITLEMENT SERVICES IN THE ACT ITSELF.

ISSUE #9: RESPONSIBILITY FOR AUTHORIZING SERVICES

States need clarification regarding the person who is responsible for authorizing the services to be included in a child's IFSP as "entitlement" services under Part H. The Education of the Handicapped Act of 1988 (EHA) requires that the IFSP contain "the name of the case manager from the profession most immediately relevant to the infant's or toddler's or family's need who will be responsible for the implementation of the plan and coordination with other agencies and persons" (Sec. 1477 (d)(6)).

A comparable requirement, which is included in information about Part B. Sec. 300.344 of the EHA regulations, requires that a "representative of the public agency, other than the child's teacher, who is qualified to provide, or supervise the provision of, special education" must be present at a child's IEP meeting.

Part H requires the establishment of an interagency early intervention system. Because of this interagency component, states have indicated great concern about who can/should be responsible for authorizing services. Given the importance of this designation of responsibility, the re-authorization should address this issue (26).

Recommendation

WE RECOMMEND THAT CONGRESS INCLUDE LANGUAGE SIMILAR TO THAT IN THE REGULATIONS FOR PART B ABOVE TO REQUIRE THE ASSIGNMENT OF THIS RESPONSIBILITY TO SOME PERSON. STATES SHOULD BE LEFT WITH THE FLEXIBILITY TO DETERMINE WHO THIS PERSON WILL BE.

ISSUE #10: LONG TERM FINANCIAL SUPPORT

One of the earlier recommendations for a two level financial support to the states from the federal government, for (1) planning and (2) transition to full service is designed to deal with the short term problem of states entering the full implementation stage of the program. We believe that the full implementation of the law requires long range solutions that include a substantial reconceptualization of financial services under Part H.

It is clear that states are having great difficulty in implementing the concept of financing services as envisioned in the law. States are slow to implement the financing provisions of the law, according to our surveys of state progress (16, 17). Our case studies of individual states have convinced us that even states which are relatively advanced in terms of meeting the requirement of the law are having considerable difficulty financing services (1). States are experiencing substantial gaps between available resources and funding of services needs, even in the early stages of service implementation.*

The current categorical approach to the financing of services is dysfunctional for several reasons. Each different source requires a major investment of time and effort for state administrators. It is not unusual for personnel to spend a year or more working on access to a single source. Approval of state plan changes by the Health Care Financing Administration, for example, has been particularly slow. In addition, regulations change frequently, requiring constant work to keep up with the changes. Coverage of services under private health insurance has been unstable. Issues of "payor of last resort" have often been difficult to resolve. Determination of eligibility of expenditures for meeting matching requirements has been problematic. All of these combine to make the expectation that states access the multiple resources unrealistic.

Recommendation #10

The reauthorization should call for a major study of long term financial support for this program. A variety of options for financing the services required under Part H should be examined. Three options, as examples, are:

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*Kates, D. (July 1990). EPSDT. Paper presented at the Partnerships for Progress IV Conference, Alexandra, VA.

10a. FUND ALL PART H SERVICES UNDER MEDICAID. ALL CHILDREN AND FAMILIES WOULD BE COVERED UNDER MEDICAID, REGARDLESS OF INCOME, FOR SERVICES REQUIRED UNDER P.L. 99-457 PART H. SERVICES COVERED UNDER MEDICAID WOULD BE BROADENED TO INCLUDE ALL PART H SERVICES FOR INFANTS AND TODDLERS.

10b. EARMARK PORTIONS OF EACH MAJOR PIECE OF FEDERAL LEGISLATION AFFECTING CHILDREN TO ASSIGN FUNDS FOR PART H SERVICES. INCREASE APPROPRIATIONS TO COVER THE EARMARKED PORTION.

10c. TRANSFORM PART H INTO A NEW FUNDING ENTITLEMENT PROGRAM FOR SERVICES FOR INFANTS AND TODDLERS WITH DISABILITIES AND THEIR FAMILIES.

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Chairman OWENS. Thank you very much.

Dr. Odom.

Mr. ODOM. Mr. Chairman and members of the subcommittee, I am Dr. Sam Odom, Associate Professor of Special Education and Investigator at the John F. Kennedy Center for Research on Education and Human Development at Vanderbilt University.

I am honored to present testimony today about the reauthorization of Part H and Part B of the Individuals with Disabilities Education Act, IDEA, that is the part of the Act that relates to early intervention services for infants and young children with disabilities and their families.

I bring to you the perspective of a special education researcher, an editor of a journal that publishes research and scholarly articles on early intervention, a teacher educator, an early intervention program manager for infants with special health care needs and their families, a former teacher, a parent of a child without disabilities, and a private citizen.

You have my written testimony, and I want to summarize a few points from that. I am not going to cover all the points. In fact, some were covered by Dr. Gallagher, and I am very much in agreement with his testimony.

I want to talk for one moment about the effect of your law, the law that has been passed, Public Law 99-457. In 1986, 26 States and territories had mandates for three to five-year-old children with disabilities.

As of a couple weeks ago, it looks like 50 have passed mandates, at least beginning in 1991. That I see as—is a success, a statement of success for the passed law. And I think you, as Congressmen, should feel very proud about the effect your law has.

State policy has changed the nature of service delivery for young children with disabilities and their families. I encourage you to examine aspects of that law that have produced changes, which I feel are a combination of fiscal incentives and sanctions for providing services or not providing services, and build on your accomplishments.

I am going to talk about mainly three aspects of research in special education that I feel have relevance for the new law, at least the authorization of law. One relates to the at-risk population. In the 1990s, in coming from the 1980s, we have a new generation of children with disabilities.

My colleague at Vanderbilt, Al Balmeister, has talked about the new morbidity or the interaction of early profound biological insulins in combination with sociological or environmental circumstances that infants and families sometimes find themselves in.

Three populations have been discussed with relation to the new morbidity, and I think have relevance for this law. One is low birth weight, premature infants with special health care needs; second is infants who have been exposed to drugs pre-natally; and third, infants who test positive for the HIV virus.

Those represent biological, at-risk factors, but they magnify when combined with environmental factors such as low income or poverty, teenage pregnancy, maternal education level. In combination, those multiple factors create a very high risk for disabilities as children grow out of the infant years and into the preschool years.

That risk does not always show up in developmental delays early on, so I encourage you in your law to include strong language that encourages States to provide services to infants, young children who are at risk for disabilities, by this dual index.

The second point that I want to highlight in my written testimony is related to normalization. At least the provision of services in the least restrictive environment has been a guiding force in, first, Public Law 94-142, and now Public Law 99-457. There is—for providing services to preschool children, there is a problem.

School systems typically do not have access to a normalized environment; that is, an environment that contains children without disabilities. The purpose for the LRE requirement was to try to create situations in which children with disabilities receive services or participate in a life that is very much like children without disabilities.

School systems, LEAs, if they are serious about pursuing least restrictive environment, have to create those environments within their system or search outside of the public domain to find placements and to deliver a program for children with disabilities, along with children without disabilities.

The law is very unclear on what States' responsibility are and what program responsibilities are. Some States interpret this as not having to pursue the LRE option for children—young preschool-age children with disabilities. Some States are very assertive and open to pursuing this option.

So, I encourage you in your enactment of the new law to specify, to become clear in the language about the least restrictive environment for pre-school children with disabilities, and also for infants and toddlers with disabilities. States really need that guidance.

Last, I would like to talk a little bit about the support for research that exists within the Department of Education and the Office of Special Education and Rehabilitation. The Early Childhood Branch at the Office of Special Education has been crucial, I think, in their support of research in early intervention.

Without their support, our field, I think, would not have progressed to the state it is today. Their research and development activities were in model demonstration projects and early childhood research projects that have addressed really important questions for the field.

In your reenactment, I encourage you to continue that support for research. I can't emphasize how strongly a vital research and development effort is for pushing our field forward. Our knowledge about disabilities and handicaps for children doesn't cease. It is pulled in by the basic research supported by other branches, but we have to have a way of translating that research into practice.

In my written testimony, I identify three themes of research that I feel are very important. One is related to the—again, the at-risk population, and I spoke about that a minute ago. We need more information about the risk variables that lead to the—that definitely lead to disability.

A second theme of research, I feel, is research on effective practices that may be in place in least restrictive environment programs, early childhood education programs that primarily serve children without disabilities.

A third theme of research I feel that is important is the effects of early intervention programs for children from—children with disabilities from culturally and linguistically diverse families. We have some guidance about how to create early intervention for those children and those families, but not very much.

And I feel that that is—in looking to the future, and given that pluralism is a characteristic of our society today, I feel that is a very important future direction.

I want to thank you for the opportunity to speak today, and I would be glad to respond to any questions you might have.

[The prepared statement of Dr. Samuel Odom follows:]

TESTIMONY TO THE HOUSE SUBCOMMITTEE ON SELECT EDUCATION

DR. SAMUEL L. ODOM

DEPARTMENT OF SPECIAL EDUCATION

JOHN F. KENNEDY CENTER FOR RESEARCH ON EDUCATION AND HUMAN DEVELOPMENT

VANDERBILT UNIVERSITY

Mr. Chairman and members of the subcommittee, I am Dr. Sam Odom, Associate Professor of Special Education and Investigator at the John F. Kennedy Center for Research on Education and Human Development at Vanderbilt University. I am honored to present testimony today about the reauthorization of Part H and Part B of the Individuals with Disabilities Education Act (IDEA), that is the part of the Act that relates to early intervention services for infants and young children with disabilities and their families. I bring to you the perspective of a special education researcher, an editor of a journal that publishes research and scholarly articles on early intervention, a teacher educator, an early intervention program manager for infants with special health care needs and their families, a former teacher, a parent of a child without disabilities, and a private citizen.

In my testimony today, I will identify current issues related to early intervention (also called early childhood special education) programs for infants and young children with special needs and their families. For each of these issues, I will propose implications for the re-authorization of Part H and the amendments to Section 619 of Part B of the IDEA and make recommendations.

Current Status of Practice

First, I would like to say a few words about the effect this law. The effects of Part H and particularly the amendments to Part B (619) have been nothing less than revolutionary. More progress has been made toward providing services to young children with disabilities and their families in the last five years than anytime in our history. In 1986, 26 of the 56 states and territories had introduced legislation to support services for 3-year-old children with disabilities (Cavazos, 1990). As of April 1, 1991, all but six states will have created a mandate for such services that will be implemented in 1991-92. By this summer, all states will have submitted their plans for providing services for infants with disabilities and their families. These plans represent progress toward planning early intervention services for infants and very young children with disabilities and their families. This progress would not have occurred without the current law. For that gentlemen, you should be very proud. Your legislation is doing what you hoped it would do -- that is, affect positively the lives of young children with disabilities and their families.

Now is the time to build on your accomplishments. There are six states that have not passed the preschool mandate. Rumors are, with some supporting data, that some states may choose not to continue their participation in Part H. I urge you to look at the actions that have most effectively resulted in changes in state policy in the last five years. A combination of increased funding and mild fiscal sanctions produced clear effects on service provision in Part B programs. The level of funding and sanctions were not in place for Part H programs and much less progress occurred. Given this history, I have three recommendations for the re-authorization.

Recommendations:

1. By the end of the next five year period, increase funding to states for early intervention for children with disabilities from birth through two years and their families (Part H), to the level that is provided to states for three to five year old children (Part B). With increased funding for services, require that states provide services to all eligible children and families by the end of the next five year period.
2. By the end of the next five year period, impose the same fiscal sanctions for noncompliance with Part H requirements that will be imposed for noncompliance with Part B.
3. Continue the level of funding currently being provided through Part B.
4. Broaden the sanctions for noncompliance with Part B and Part H to include access to all funds generated under the IDEA.

New Generation of Infants and Young Children with Disabilities

In the 1980s, a new generation of children with disabilities has emerged. Disabilities faced by the children are the result of advances in medical technology and sociological events, which Baumeister and others (Baumeister, Kupstas, & Klindworth, 1990) have labeled the "new morbidity". This concept is not new, but its application to the population of young children in society is important. Three groups of children have often been identified in discussions of the "new morbidity": very low birth weight, premature infants with special health care needs related to their prematurity (Cohen, 1991), infants exposed to drugs such as cocaine and alcohol *in utero* (Schneider, Griffith, & Chasnoff, 1989), and infants and young children who test positive for the HIV virus (Dokecki, Baumeister, & Kupstas, 1989).

The characteristics of this group broadens and redefines our definition of risk. The early and sometimes profound biological insult to the developing child creates a risk for the later development of disability, yet our prediction of later disabling conditions are not always accurate.[1] For example, most low birth weight, premature infants become healthy, active, nondisabled children as they grow older.

Our prediction of disabilities for children experiencing sociological risk factors such as low SES, maternal education level, maternal IQ, parental disability, teen-age pregnancy, and others, noted above is not highly accurate. That is, some teen-age mothers possess very competent parenting and child care skills; most parents from low SES families do fine jobs of parenting. Yet, when early biological insults, noted above, combine with sociological risk factors, the risk for disability in later life increases (Sameroff & Fiese, 1990).

For infants and young children experiencing these risk factors, the appearance of developmental delays or disabilities may not become apparent until later in childhood; this is the embodiment of risk. I believe that the intention of Part H and Part B of the IDEA was not to provide early intervention services for children who experience only the sociological risks that I are mentioned above. This statement should not belittle the clear and substantial needs of that population, but other programs address their needs. However, I do feel that when early biological insults is combined with sociological risk factors, risk of disability is increased greatly. This heightened risk status justifies the inclusion of this population of infants and young children with disabilities under Part H of IDEA. The rationale for providing services for these children and families is that early intervention may prevent or reduce the magnitude of development delays, thus reducing the need for services in the future. At this point, many states have excluded "at-risk" from their criteria for services provided under Part H.

Recommendation:

1. Revise the current law to include language that would strongly encourage states to provide early intervention services to infants, young children and families who meet a restricted definition for risk that includes early biological insult paired with sociological or demographic risk factors noted above.

Family-Oriented Nature of Early Childnood Special Education

Early childhood special education is very strongly family-oriented (Simeonsson & Bailey, 1990). Rather than being a downward extension of special education, early childhood special education represents a concerted effort to involve families in the planning, implementation, and evaluation of programs for their children with disabilities. In order to work with families, program must address families' needs as they relate to their children's development. The family-oriented nature of our field and the nature of families themselves have several important implications for the law.

Transitions for families. Families, and particularly parents, who have children with disabilities experience a number of transitions, as their children grow older. When family members first learn that their infant or child is disabled or delayed, the family experiences a sometimes extended period of confusion and disorganization. During this time, if all goes well, they adapt to this knowledge about the new or current member of their family. Many families do adapt to this knowledge of the child's disability and reach a state of equilibrium where the family functions well again. In fact, many parents of children with disabilities indicate that these children enrich their lives and the lives of other family members. However, when transitions for the child occur for the child with disabilities, the families are often again thrown into periods of disequilibrium, disorganization, and stress. The transitions most frequently discussed during the early childhood years are (a) transition from the hospital to home, if the child were premature or had a disability diagnosed at birth, (b) transition from home to an early intervention program (Part H), (c) transition from an early intervention program to a preschool program (Part B, 619), and (d) transition from preschool to regular education program (Rice & O'Brien, 1990).

Part H has specifically addressed the need for planning for transitions from infant and toddler programs to the next environment. This is an insightful aspect of the law and should be maintained. However, the transition may be limited by exit requirements for the Part H programs (i.e., when children no longer qualify for service) and the entrance requirements of the Part B programs (i.e., when children may begin these programs) For example, a child might turn three in April, not be able to continue to qualify for early intervention services under the Part H program, but not be able to enter the public school, Part B program until the following September. Furthermore, some children who may have qualified for services under the "at-risk" categories may not qualify at all because of different classification systems used across agencies.

Recommendations:

1. Include in the re-authorization strong language that would ensure the continuity of services during the transition from Part H to Part B programs.

2. Encourage states to adopt the same definitional or qualifying criteria for services under both Part H and Part B. One solution would be to authorize the use of the category "developmental delay" for three to five year old children, which is now available for use by Part H programs.

Family-oriented nature of Part H and Part B programs. Part H programs, by law, are family-centered in that they require the assessment of family strengths and needs, development of a plan to address family needs as well as child needs, and appointment of a case manager (i.e., service coordinator is now the term preferred by families and professionals) to assist families in locating or coordinating services for their children. Part B programs tend to be more like traditional special education in that the family is usually involved only in planning and approving children's individualized educational programs (IEP). The abrupt shift across modes of service is not only disconcerting for some parents, but also leaves a vacuum that Part B programs, as they are currently constructed, are not able to fill. Many professionals in the field feel that the family-oriented nature of Part H intervention programs reflects best practice for all young children with disabilities.

Recommendation:

1. Revise procedural requirements under Part B to require that programs for three to five year old children with disabilities adopt a family-oriented approach to early intervention. This would require revising the current IEP requirements to include identification of family strengths and needs and proposing family goals, as they relate to the child. In effect, the IEP should resemble or be identical to the IFSP.

Service Delivery in Normalized Environments

Normalization is a principle that has pushed early childhood special education and the large field of special education, since the early 1970s (Wolfensberger, 1972; 1991). It provided the impetus for the least restrictive environment (LRE) clause in PL 94-142. The concept of LRE indicates that a range of service options should exist, but to the extent appropriate, the child should be placed in a setting that is like the setting in which children without disabilities participate. The most optimal placement is in normalized or mainstreamed early intervention programs (Bailey & McWilliam, 1990). In fact, integration with children without disabilities is viewed as an aspect of best practice in early childhood special education (Guralnick, 1990; Hanline & Hanson, 1989). Although there is evidence that certain skills may be acquired more efficiently and maintained in such integrated placements (Strain, 1983; Jenkins, Odom, & Speltz, 1989), the majority of research to date indicates that the quality of the educational program is a stronger influence on children's development than integration per se (Odom & McEvoy, 1988). The imperative that pushes LRE and integration is the philosophy that children with disabilities should not be excluded from a life that is as close to normal as possible.

A dilemma exists for Part B programs. For these programs there is not a normalized equivalent within the public education system. Normalized placement for most children are child care or preschool classes that are not part of the public school system (i.e., either Head Start programs, preschools funded by other public agencies, private preschools). This public/private distinction has created considerable barriers to the provisions of services in normalized environments (Odom & McEvoy, 1990). Language in the PL 94-142 has lead to some confusion, and clarification did not occur with the amendments to Part B in PL 99-457. Unfortunately, some LEAs interpret the law as meaning that a normalized service alternative does not have to be provided if the system does not fund preschool for children without disabilities.

Although professionals consider normalized early intervention the placement of choice for most children with disabilities, it is very important to note that placement decisions must be based upon children's individual needs and families' preferences. Some families may prefer that their children be placed in nonintegrated special education classes, and given the family-oriented nature of early childhood special education, these families' decisions should be respected. Also, it may be difficult or impossible to meet the educational needs of some children with certain disabilities (e.g., special health impairments, extreme self-injury or aggression, etc.) in a mainstreamed setting, although alternative integration experiences should exist for those children.

Recommendation:

1. Include language that states specifically that a normalized service delivery option should be provided for young children with disabilities. This service delivery option should include provision of early intervention services in the normalized setting (e.g. child care center) through consultation or direct teaching.

Research on Early Intervention

The Early Childhood Branch of the Office of Special Education and Rehabilitation Services has funded research related to early intervention on a consistent basis for the last 15 years. This research has been funded through the Handicapped Children's Early Education Program, now the Early Education Programs for Children with Disabilities, in the form of Research Institutes directed to address specific problems (i.e., mainstreaming, family issues), program features projects directed to investigate instruction in specific developmental content areas (i.e., language, social development, etc.), and nondirected research/demonstration projects.

The major mode for translating research results into practice has been through the model demonstration projects which have been funded since 1968. I strongly endorse the continued support for and expansion of these research initiatives. The 1990s and the 21st century hold many challenges for early intervention professionals, infants and young children with disabilities, and their families. The continued elaboration of our knowledge-base (through research) and translation of that knowledge base into practical intervention strategies is essential for meeting the needs of the current and future generations of infants and young children with disabilities and their families. Although the research supported by the Early Childhood Branch of OSERS is addressing many important issues, there are emerging issues that have relevance for current and future early intervention practice.

***Early intervention strategies for children with culturally and linguistically diverse backgrounds and their families.** The demographics of this country are changing, with cultural pluralism rather than homogeneity being the reality of our society. Increasing numbers of children requiring early intervention are from families with culturally and linguistically diverse backgrounds. Although model demonstration projects have been developed for specific ethnic groups, we really do not have a research base that has examined adaptations to intervention models and their effects. Investigations in this area will require different approaches than have been used in the past.

***Performance and effects for children with disabilities in programs that follow an early childhood education philosophy, or that embed special education in an early childhood education model.** The move to normalized settings has resulted in much discussion about effective classroom practices for young children with disabilities. In the next five years, there will be an ongoing dialogue between early childhood educators and special educators about "Developmentally Appropriate Practice" and its impact on children with disabilities. Research initiatives designed to better understand the differences between these instructional approaches will be timely and important.

***<u>Examination</u> **of a risk index that includes both early biological insult and sociological variables.** The "new morbidity" concept is an important addition to our understanding of early causal factors and developmental delay or disability. However, to be useful, this approach will need to be delineated precisely and validated through research. In addition, investigation of intervention strategies designed for this new generation of children will provide much needed information for the field.

Recommendation:

1. Continue to indicate in the law that support should be provided for research on and development of early intervention programs for infants and young children with disabilities and their families.

Thank you very much for the opportunity to present this testimony today.

Footnotes

[1] The exceptions to this statement include most infants and young children who test HIV-positive, although not all infants who test HIV-positive develop AIDS. Also, for premature, very low birthweight infants, certain health-related conditions are strong predictors for later disability (e.g., bronchopulmonary dysplasia, grade IV intraventricular hemorrhages).

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Chairman OWENS. Thank you.

Lieutenant Colonel Sautter.

Lt. Colonel SAUTTER. Congressman Owens and other members of the subcommittee, it is an honor and a privilege to address you today concerning IDEA, the Individuals with Disabilities Education Act, and how it is currently implemented within DOD.

My remarks today are given from the perspective of a parent of a child with cerebral palsy who has spent the past three years in a DOD Section VI school. I do not wish to have my remarks interpreted as an official Army position as I am appearing before this subcommittee solely in my personal capacity.

I will, however, temper my opinions since my family is currently in litigation with the Federal Government over denial of rights for our son, but I believe that I will be able to present sufficient information outside our court case to illustrate the inadequacies of the system as implemented and practiced by DOD.

Today is not the first time these issues within DOD have been presented to Congress. In a 1989 report to the President and Congress entitled, "Education of Students with Disabilities: Where Do We Stand?", the National Council on Disabilities found it "unconscionable that our Nation's military families are not enjoying the same access to educational services as other citizens."

In the two years since that report, little has been done to correct these documented deficiencies. In fact, DOD has recently confirmed that they are not mandated to serve pre-school handicapped children under Public Law 99-457.

In order to appreciate the extent of these issues, one must first understand the system. The DOD operates two large school systems. The first is the DODDS, Department of Defense Dependent Schools, system which are overseas and service approximately 150,000 students.

The second system is the Section VI schools, servicing approximately 35,000 students in 18 Section VI schools within CONUS and Puerto Rico. It is important to note that these two school systems exist under one office, "The Director of Education" within DOD. Now, despite their common control, these systems do not have similar regulations. Each system interprets their own rules for compliance with IDEA.

The issue that needs to be resolved is, how does the DOD Director of Education, who is responsible for the eighth largest school district in the United States, implement both Public Law 94-142 and Public Law 99-457 within these schools?

Can DOD be allowed to be selective in the parts of the Federal law that they choose to follow, or will they be required to follow the complete mandate of Congress to achieve the goal of a free and appropriate education for all children?

A question that is asked is, why is IDEA and specifically the 3 to 5-year-old program such an important program within DOD? The answer is easily seen in the demographics of our military families. Present company excluded, we are a military of youth. The average age of the military member is 27.

This youth has families that are primarily young children. In fact, approximately 40 percent of the families enrolled in the EFMP have children under the age of 5.

The military has always prided itself with being able to take care of its own, but families with disabled children have found that they are often better provided for when they live in the civilian sector.

This is graphically illustrated by letters received by our advocacy group, STOMP, Special Training of Military Parents, where parents have documented the degradation of services for their disabled children when they have been transferred to a base that has a Section VI school.

The opposite story has also been told where services have increased when the transfer took the military family away from a Section VI school to a location where schooling was provided by the local educational agency.

IDEA has been with us for some time. To understand what that Act means to me, I will quote from the original Congressional hearings that led to passage of the Act:

"This legislation will prove to be the long-awaited step towards a national program to 'insure' quality education to all handicapped Americans."

The emphasis here is on all Americans. How can we allow people to be treated differently just because they are not residents of a specific State, but rather, are residents of Federal land within the United States? The claims by DOD that the families are fully protected have done little more than laid claim to a system that can be classified as separate but equal.

For example, under current policies, the children of a criminal in Federal prison or an illegal alien who is not on the tax rolls have the rights guaranteed under IDEA from age 3 to 22, and those rights are protected by the Constitution.

Concerning another group residing on Federal land, the Bureau of Indian Affairs, BIA, has been brought into full compliance under IDEA. The single group that does not have these same rights are the 185,000 children of our service men and women that have been charged and tasked very recently with defending the same Constitution that protects these children.

It appears that only legislative action can ameliorate this deplorable situation for the thousands of service men and women whose young families so desperately need the services provided under IDEA.

The full compliance with both Public Law 94-142 and Public Law 99-457 has a two-fold impact on our military. First, by addressing problems early when they can many times be remediated quickly and cheaply, the solution is more cost-effective.

The second benefit, and I attest to this, of these programs is an increase in the effectiveness of our military. I can assure you that when a military parent has a disabled dependent with an unresolved problem, that burden weighs heavily on the whole family. The result is that it dramatically affects the military member's job performance. No matter how much one tries to keep their problems at home, you cannot work at peak efficiency with a child at risk.

The establishment of viable programs for our disabled youth will allow them to become productive members of our adult society. To balance the budget on the backs of children and to pick and choose the laws that you care to follow is a short-sighted approach and a slap in the face of our military.

The families of military members deserve the same educational access and rights as their civilian counterparts.

Thank you, sir.

Chairman OWENS. Thank you.

Ms. Virginia View.

Ms. VIEW. Good morning, Mr. Chairman, and committee members.

It is certainly a privilege to have an opportunity to talk with you this morning. I am with the National Center for Clinical Infant Programs, and am representing that organization as a member of the National Low-Income and Minority Parent Empowerment Task Force.

This task force, this group of 26 members, was convened by the Mental Health Law Project, and it is comprised of parents, early intervention professionals, service providers and family advocates.

Our intent is to present a case for full participation of low-income and minority families in the Part H programs around the country. This is a national organization, and our representatives and members represent a number of States and programs.

The task force is supportive of the reauthorization of Part H and is pleased with the support that Congress has provided to the legislation and the program thus far.

For approximately two years, I was the Director of the District of Columbia early intervention programs for infants and toddlers. And from that vantage point, I had an opportunity to make some observations about the implementation of the program in States around the country.

I had an opportunity to travel around the country and see how other programs were operating and meet with State representatives and develop some observations, and I would like to share a few of those observations with you and indicate how they coalesce with the concerns of the task force.

One observation that I made was that the Part H program could be a real blessing to low-income families, families that don't have the resources to employ preventive practices and strategies that will keep their children from becoming either developmentally delayed or more delayed if they are already delayed, but there was always a question in my mind as to the extent of full participation of these families in the Part H programs.

I was always concerned as to whether I was seeing the numbers of people who could be eligible for the services as actually being represented as recipients of the services.

Another observation was that the very families that lack these resources, often low-income families or families of color, comprise a significant percentage of the population that is likely to be eligible for the program.

As Chairman Owens indicated yesterday, their numbers are projected to increase over the next few years, so this was a point of concern on the part of many of us.

A third and more troubling observation was the low level of representation of this population among the planners and providers of services in the Part H programs around the country.

I was one of a very, very few, if not the only Part H director who was a person of color during the time I was associated with the program, even among parent advocacy groups, who, by the way, are doing a wonderful job of monitoring programs and ensuring the States are moving toward more family-centered provision of services, but in many States, there is a glaring discrepancy between the number of low-income and minority families that are likely to be eligible for the services and their participation in parent advocacy groups.

In yesterday's hearing, testimony was given by Native American parents who described the extreme measures they had to go to to find out about and access services. One parent indicated even after locating services, there was a lot of concern they were not provided in ways that were respective of or sensitive to their cultural values.

Another parent testified about the time and financial demands of her participation in advocacy efforts. She indicated the primary source for her support for her participation was her husband, who was at home all the time, and was willing to take care of the children.

She mentioned parents who used grocery money in order to attend meetings and workshops and participate in training for parents. Clearly, time and financial demands are real problems and obstacles to many young families, especially single-parent, low-income families.

These are obstacles of not only participating in advocacy activities, but they are obstacles in getting services for the children.

The National Low-Income and Minority Parent Empowerment Task Force—that name is quite a mouthful—shares the concern that grew out of my own observations about how States will assure that low-income and culturally-diverse families have access to early intervention services.

Infants and toddlers will benefit most from early intervention when the services are provided in a way that are accessible and compatible with the beliefs of the family. Yet, today, few States have made coordinated efforts to overcome barriers created by poverty, language and culture differences that prevents eligible families from accessing the services.

The State of Maryland has instituted a program we find impressive, and a description of that program is attached to the written testimony we did submit.

The task force also has submitted a more comprehensive set of concerns than I am expressing here today, and I am sure that is the testimony that will be included in the record.

However, I would like to highlight a few concerns, and then present our recommendations. If you examine the implementation of the program around the country and look at the existing minimum requirements, the 50 requirements you see, there is ample opportunity for States to increase their efforts of outreach and provision of services to low-income families and culturally-diverse families and families of color.

Just taking a few of the requirements: The child-find public awareness, one component. In addition to publicizing the program in the standard places, the doctor's office, the health clinic, the schools, we would like States to find more creative approaches that include publicizing programs in places where low-income families are more likely to find themselves, in the laundromat, in convenience stores, in a gas station, or something of that sort.

We are concerned that assessment instruments be evaluated for their cultural competence before they are applied and before they are used to make sure the assessment of children as a part of the program is culturally relevant, but we also want to be assured the service providers who work with the families have the capability of relating to families, establish a rapport that will get the best response from families in terms of follow-through and implementation of programs.

The central directory is another example. We would like to be—to see some indication that States are developing a central directory that is truly inclusive, and including the kinds of programs that have staffs that are culturally diverse and have cultural competence and training as part of their service provision package.

Personnel development is a critical issue in terms of implementation of this program. Just two examples of the kinds of things we think would be important, provision of incentives, funding, outreach to attract more persons of color to go into programs that train speech therapies, physical therapists.

The numbers become more dramatic when you look at the number of people of color entering those programs. Clearly, some outreach needs to be encouraged.

Another area of concern is the outreach to educational institutions that have culturally-diverse faculties and training resources, including Historically Black Colleges and Universities. We are concerned that a lot of the technical assistance that is being provided to service providers, while certainly an attempt has been made to develop materials that can be used to improve their cultural competence, we think that not enough has been done to include actual programs, training programs, institutions, universities that have culturally-diverse faculties and that serve a significant culturally-diverse population.

We also would like to see planning bodies that reflect low-income families and a more culturally-diverse population. We would like to see planning bodies that are truly reflective of the communities that they serve, and, of course, the best example is the ICC, the Interagency Coordinating Committee.

There are a couple of recommendations that we had made and, of course, they are discussed in detail in the written testimony. I would just like to sum up by saying that we would like to recommend that the legislation build in assurances that States will have to respond to in terms of indicating their efforts to implement some of these strategies that we have identified to make sure that their programs really are more responsive to the needs of the growing percentage of the population that they will be providing services to.

And our other recommendation was that there be some financial incentives for States in order to do this. We know that funding is—continues to be a major issue, and it was not our intent that we suggest something that was cumbersome and not doable.

We are also recommending that some financial incentives be provided to encourage States to do that. Again, I want to thank you for the opportunity to talk to you today, and to say again that Part H is a program that is good, not only for all of the infants and toddlers of the country, it is good for the country, and we support it.

[The prepared statement of Ruth Rucker follows:]

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U.S. HOUSE OF REPRESENATIVES COMMITTEE ON
EDUCATION AND LABOR

SUBCOMMITTEE ON SELECT EDUCATION

HEARING ON REAUTHORIZATION OF PART H
(PL 99-457)

April 12, 1991

Testimony of Ruth Rucker, Executive Director of the Edward C. Mazique Parent Child Center, Washington, D.C., and member of the National Low-Income and Minority Parent Empowerment Task Force.

Introduction

My name is Ruth E. Rucker. I am the Executive Director of the Edward C. Mazique Parent Child Center, Inc., in the District of Columbia. I am pleased to have this opportunity to testify today on behalf of the Parent Child Center (PCC) and the Low-Income and Minority Parent Empowerment Task Force.

Our PCC, in the District of Columbia, is one of 36 nationally, established in 1968 under the presidency of the late Lyndon B. Johnson. Its mission is to deal with the health, education, social services and environment of infants, toddlers, pregnant women and teens and their families. PCCs were established in response to the need for early intervention during the prenatal and formative years of a child's life.

The Low-Income and Minority Parent Empowerment Task Force was convened by the Mental Health Law Project. Its 26 members include parents, service providers and early intervention professionals and advocates. The group has come together to work for full participation by low-income families and families of color in Part H programs. A list of task force members is attached for your information (Attachment A).

Funded By DHHS—UPO—United Way—Department of Human Services

The Part H early intervention program signals new directions in federal policy. It is the first indication of a broad-scale federal commitment to infants and toddlers with developmental delays and disabilities. It breaks new ground by moving toward family-centered rather than child-centered services and incorporating parent training and counseling with therapeutic services for children. In so doing, it represents a significant departure from the way most states have viewed early intervention.

Our Task Force is most concerned about how states will assure that low-income and culturally diverse families have access to appropriate early intervention services. Infants and toddlers will benefit from early intervention only if the services are provided in ways compatible with the beliefs and the culture of the family. Yet, to date few states have made more than piecemeal efforts to overcome the barriers created by poverty, language, geographic location and cultural differences. These obstacles need to be addressed systematically in states' Part H planning. A monograph published by the Georgetown University Child Development Center states:

> Within ethnic groups, there are many cultures and subcultures, though some common history may be shared. Cultural competence refers to a program's ability to honor and respect those beliefs, interpersonal styles, attitudes and behaviors both of families who are clients and the multicultural staff who are providing services. In so doing, it incorporates these values at the levela of policy, administration and practice.

In this context, the Task Force has identified a number of concerns pertinent to the reauthorization of Part H.

1. We are concerned about cultural competence. Few current service-delivery systems are able to provide appropriate services to all families in a culturally diverse community. Yet little, if any, serious effort is being made by state Part H policymakers to include low-income parents and parents of color in the Part H planning process. Their direct knowledge of the culture and beliefs of the families to be served is essential to the success of the system in serving a culturally diverse community. It is indeed troubling that sensitivity to the issue of cultural competence is lacking on such a broad scale throughout the states.

A basic reason to promote culturally competent Part H systems is to assure that poor families will be adequately served. While poverty is on the rise among all children, children of color are more likely to live in poverty than white children -- especially if they live in a single-parent home. Further, single-parent households headed by African American or Hispanic women with children 18 years and under are one-and-a-half times as likely to be in poverty as those headed by white women.

2. Another major concern of ours is personnel. The Task Force is extremely troubled both about the nationwide shortage of early intervention therapists and about the lack of such personnel from culturally diverse backgrounds. In the District of Columbia, for example, despite a growing need for their services, there are fewer people than ever before in the areas of physical, occupational and speech therapy. And nationwide, the number of college students going into these areas of training has dropped drastically.

Specific personnel issues identified by the task force include the following:

First, while the Part H statute gives states the discretion to establish standards for "qualified personnel," some states are adopting standards that exclude candidates with expertise and foreign certification. Such candidates do not receive any credit for educational work completed.

Second, outreach and financial assistance are inadequate to encourage people of color to pursue careers in the early intervention professions. Minority paraprofessionals receive little, if any, encouragement to pursue more formal training programs.

Third, the unavailability of culturally competent professionals to serve isolated rural areas is particularly troublesome.

Fourth, properly trained interpreters are often unavailable. And even where they are, some programs are refusing to pay for interpreter services. This practice effectively denies early intervention services to a child in a non-English speaking family.

3. A third area of concern is child-find and public awareness. Families of color and low-income families are not receiving sufficient information about the Part H program and are not being asked to participate in the planning of Part H services in a meaningful way. Although the implementing regulations provide that Part H systems coordinate their activities with existing programs, few states are making the necessary efforts to work with programs that serve low-income families and families of color.

4. Financing is another concern. States cite the cost of providing services and the cost of developing adequate training programs as the reasons they are not making the extra efforts necessary to find and to serve families of color and low-income

families and to develop culturally competent programs. Without an adequate investment in these efforts, however, many infants and toddlers in these states will not benefit to any significant degree from the Part H program. Furthermore, children who are at risk of disability may not see a sign of early intervention programs unless adequate financial resources become available.

Taking these concerns into account, we would like to make the following recommendations for revisions in the statute that we believe could result in constructive improvements at both state and local levels.

RECOMMENDATION 1

To promote cultural competence in statewide early intervention systems and to stimulate access of low-income families and families of color to services, we recommend that an assurance be added to Section 678(b), Statement of Assurances, which would read:

> (7) provide satisfactory assurance that policies and practices will be adopted (a) to ensure meaningful involvement of traditionally underserved groups, including low-income families and families of color, in planning and implementation of the Part H system; and (b) to ensure that these families have access to culturally competent services within their own local areas.

We would urge that the Committee report accompanying the bill contain the following list of policies and practices, which states should use to satisfy the Department of Education that this assurance has been met:

- memberships and committees of the state and local Interagency Coordinating Councils (ICCs) reflect the racial and cultural diversity of the population served;
- child-find and public-awareness campaigns are community-based and well connected to contact points for low-income families and families of color;
- the state's Central Directory for Part H includes individuals and organizations with staff that are culturally diverse and that provide family support and advocacy services for low-income and culturally diverse communities;
- Part H staff reflect the ethnic and cultural diversity of the community being served and receive training to help them work positively with culturally diverse families;

- bilingual staff are hired when needed and properly trained translators are made available when bilingual staff are insufficient;

- assessment tools are evaluated for cultural appropriateness <u>before</u> being used;

- Part H case managers will receive training about the various federal and state benefit programs to enable them to alert families to the availability of benefits and to help them apply for them;

- the comprehensive system for personnel development (CSPD) will include colleges and universities with culturally diverse student bodies and faculties and encourage use of families and paraprofessionals from the community in developing personnel for Part H.

The state of Maryland has adopted a child-find goal in its fourth-year application that offers one example. The goal is to establish a minority advisory committee, and the activities would have an impact beyond the child-find and public-awareness systems. Attachment B contains a copy of Maryland's goal and activities.

<u>RECOMMENDATION 2</u>

States that seek full participation of low-income families and families of color in their Part H systems certainly need financial resources to support their effort. We believe that a combined strategy of incentive grants for outreach and an expansion of Part H funding for services will give states the support they need.

To fund outreach we recommend modification of the Early Childhood Education program to encourage states to undertake expanded outreach to all low-income families. States would have to apply for the grants and specify how they would use the dollars to reach underserved populations. The grant would be in addition to a state's allocation of Part H service funds.

To expand services, we recommend that Congress consider an allocation system that rewards the states that are making progress on Part H while continuing to support the states that are taking longer to develop their statewide systems. We believe that Part H must provide more than glue money if states are going to find and serve all families well.

In conclusion, permit me to state that the reauthorization of Part H comes at a time when national concern about the condition of children's lives is high, particularly about the level of infant mortality and morbidity, the growing number of crack- and alcohol-addicted infants and the tragic consequences of boarder babies. As a result, the needs of children are receiving proportionately more attention on Capitol Hill. It is obvious that Congress is listening to those of us who speak on children's behalf and it is obvious that Congress is hearing what we are saying.

Part H is good for children and it's good for the country. We are glad it has wide congressional support.

We urge the Committee to consider the recommendations in this testimony. They are proposed in an effort to make an excellent program even more effective.

Attachment A

Minority and Low-Income Parent Empowerment Task Force

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Child & Adolescent Service System Program
Washington, DC

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East Coast Migrant Head Start Project
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Virginia View
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Attachment B

The Maryland Example

G. Minority Advisory Committee

The State of Maryland recognizes the multi-ethnic, multi-cultural diversity of its people, and it plans to reach out to those communities who have been unserved or underserved by intervention programs in the past.

Goal G: To increase public awareness/and liaison with the minority/culturally diverse community who may have been unserved or underserved by intervention programs in the past, and to increase participation in the development of the state plan.

G 1.0 Establish a Minority Advisory Committee to facilitate liaison between the Infants and Toddlers Program and the community. The Minority Advisory Committee should have representatives from the various minority groups that make up the population of Maryland, with special interest in the three largest minority groups: Africa-Americans, Hispanics and Asians.

G 2.0 Contact minority organizations with special interest in children and health issues.

- a. Make awareness presentations to these groups when possible.
- b. Request representatives of organizations to be members of the Minority Advisory Committee.

G 3.0 Hold regional workshops on PL 99-457 targeting the minority population.

G 4.0 Hold a statewide multi-cultural, multi-ethnic conference on PL 99-457 for parents, professionals, health providers, advocates and state and local agencies.

Accountability requirement

1. Account for number of workshops held and number of attendees.
2. Account for increases in early intervention services to minority children.
3. Account for increased participation of minorities in planning for and implementing PL 99-457 in the State of Maryland.

Chairman **Owens**. Thank you.

Mrs. Lourdes Putz and Dr. Mary Beth Bruder.

Dr. **Bruder**. Good morning, Mr. Chairman, members of the subcommittee. My name is Dr. Mary Beth Bruder, and I am the Director of Family Support/Early Intervention Services at the Mental Retardation Institute, which is a university-affiliated program in Valhalla, New York, and I am also an Associate Professor of Pediatrics at the University of Connecticut School of Medicine.

I have been involved in the provision of early intervention services for children age birth to 5 and their families for the past 15 years. While I was born and raised in New York, I have only been back a year. My 15 years of experience have been within four States, all of which provided some level of early intervention to children and their families.

I am happy to be here today to represent the Education Task Force of the Consortium for Citizens with Disabilities, CCD, and testify on the reauthorization of Part H of the Individuals with Disabilities Education Act. The Education Task Force of CCD has identified a number of issues that they recommend be included in your reauthorization legislation. I request that the written CCD testimony, which I believe you have before you, be included in the record.

During my training and career, I have always learned the most about the value of early intervention from the families I have been fortunate to meet. I am happy to introduce to you one such parent, Mrs. Lourdes Putz and her son Jonathan, and her husband.

As a parent, she represents the reason Part H of IDEA was designed. I would like her to share with you some of the issues she feels are extremely important to the continued success of Part H legislation.

Mrs. **Putz**. Good morning. My name is Lourdes Putz. I am the proud parent of six children. I guess this qualifies me to say that every child has special needs. Some require more attention than others, but they all require attention.

The youngest of my children is Jonathan. He will soon turn 5 years old. He was born with Downs Syndrome. We were very fortunate in that from the very first day, we received much support and directional assistance from many resources. As a result of this, Jon began an early intervention program at six weeks old, where he received educational services, and speech, physical and occupational therapies.

Unfortunately, most parents are thrown for a loop once they have been made aware that their child has a disability. They may go day to day, floating in a cloud without really being in touch with the world around them.

In many instances, we also have the problem of language and cultural barriers. Because of this, it is so important that we have knowledgeable people from the beginning who will provide the guidance and support that is so necessary.

In one case that I am familiar with, a child was born with multiple disabilities to an undocumented couple. The fears, language and cultural barriers caused these parents to wander for months without any real understanding of their child's disability or of services that were automatically available to that child as a citizen of the United States.

In another case involving a 1.5-year-old child born with Downs Syndrome to a young Hispanic girl, the child has many medical disadvantages which cause her to be ill 75 percent of the time. It has been determined that because of her illness, the most appropriate place for this child to receive service at this time is within her home.

Except that because the child's parent is Spanish-dominant, the child must receive bilingual services. However, the child has received no service in the past eight months. Because of language barriers, the mother has been unable to be an advocate for her child. This child should be getting service regardless of what language her mother speaks.

As parents of children with disabilities, we must also stop shortchanging our children. In order for them to grow and be accepted as individuals in their communities, inclusion must begin from day one. A strong foundation will give our children the opportunities to participate in a typical environment. Inclusion will also create a community that is aware and sensitive to the needs of persons with disabilities. It is their right as individuals to be part of the community, regardless of their disabilities.

It is for these reasons that as you consider reauthorizing the Part H program for infants and toddlers, I ask that you pay close attention to the recommendations of the Consortium of Citizens with Disabilities so that all parents of infants and toddlers with disabilities have the opportunities to receive support and services they want and need from the very beginning of their child's life.

Thank you.

Dr. BRUDER. If you will, Mr. Chairman, I would like to take a few minutes to highlight some of the issues which were identified within the CCD testimony and in Mrs. Putz's statement. In particular, I would like to address four issues:

The critical need for cultural sensitivity within early intervention services; the use of natural environments for early intervention services; the need for training of all who will be involved in the provision of services; and the important role families play in the service system.

Hartford, Connecticut has the largest proportion of Puerto Ricans in the country. Forty-seven percent of the elementary school-age population is Hispanic, yet only 20 percent of 337 infants referred to the Early Intervention Coordination Center in the greater Hartford area were Hispanic, as were 27 percent of 189 infants receiving early intervention services through the Department of Mental Retardation in the same geographic area.

This small number is even more surprising considering that 95 percent of the pediatric caseload in Hartford Hospital is Hispanic. The primary problem seems to be a shortage of bilingual staff and a lack of awareness about the unique cultural values of the Puerto Rican families.

From 1986 to 1989, I directed a model demonstration early intervention project, the Ninos Especialles Program, in Hartford, Connecticut. During the three years, we provided services to 34 infants with severe disabilities and their families of Puerto Rican heritage.

Unfortunately, many of these families encountered the same barriers to services described by Mrs. Putz. The families were eventually referred to our project through a variety of sources, all of whom had received a personal contact by a member of our bilingual staff.

One-third of these infants were born on the Island of Puerto Rico and only one of the families had an employed parent. The rest received public assistance. Yet, when provided with services which were directed at the parents' perceived needs in their preferred language, the families thrived. The families were able to identify and receive individualized services which met their expectations and family system.

In fact, most of the initial IFSP goals developed by the families focused on support needs: Finding housing, coordinating medical appointments, learning to understand English, et cetera. After 18 months of services, these families were able to design goals that primarily reflected their child's intervention needs. It should also be noted that our project was family-directed. That is, we supported the rights of the families to refuse services, providing the refusal did not constitute abuse or neglect.

We have subsequently been funded to provide outreach training to service providers and families in Connecticut and New York. We have offered over 30 workshops and long-term trainings to early intervention programs in the past year. We have found a great need for training. Most of this training encompasses sensitivity and respect to all cultures; that is, explaining cultural values, customs and beliefs and their effects on the provision of early intervention.

I urge you to recognize the need for cultural sensitivity within the reauthorization of Part H by including the CCD recommendations to require that States recognize the individual service needs of families through training on cultural sensitivity within the Comprehensive System of Personnel Development, CSPD.

I also urge you to require the use of culturally emblased assessments conducted in a family's preferred language within the evaluation phase of Part H services.

The natural environment for an infant is the family. The Ninos Especialles Program I previously referred to provided services to families in their home. The natural group environment for infants and toddlers in today's society is community early childhood programs, child care programs, nursery schools, toddler play groups, and other settings in which typical infants and toddlers participate.

Over the past 15 years, I have always been fortunate to be able to design, provide and evaluate early intervention services in settings having both infants and children without disabilities.

In my first professional position as a preschool special education teacher in Vermont, I was able to learn from the beginning that the segregation of your children with disabilities into specialized programs does not make sense.

As we strive for a community-based system of integrated services for persons with disabilities across the life span, we must start at the beginning.

Most recently, I have been directing a number of federally funded projects which focus on the design, provision and evaluation of early intervention services within community early childhood programs for children age birth to five with disabilities.

Unfortunately, this service model is not routinely provided to all eligible children and families. Though research and evaluation data strongly support the provision of integrated services, State regulations and funding sources can prove to be disincentives to achieving this goal.

In 1988, we conducted a survey in Connecticut to assess the attitudes of both school superintendents and special education directors on the integration of preschool age children with special needs into programs with preschool age children not having special needs.

The respondents overwhelmingly supported integration. In particular, though, and of most importance, was the fact that 82 percent of the superintendents and 90 percent of the special education directors felt that discretionary financial resources needed to be allocated in order for them to provide the integrated services.

In the same State of Connecticut, over 200 infants and toddlers who have moderate to severe disabilities are receiving early intervention within community early childhood settings under the auspices of the Department of Mental Retardation.

This is due to administrative recommendations which were formulated from a deinstitutionalization court order.

The Department's newly developed philosophy supports community participation at all levels and for the past three years infants and toddlers have been receiving early intervention services within their homes or in community settings in which typical children participate.

This model has proven so successful that New York State is proposing this type of placement option under its proposed Early Care Legislation.

I join with CCD to strongly recommend that language be inserted into Part H to recognize the importance of including infants and toddlers with disabilities in community environments.

Both Connecticut and New York are beginning to move toward providing early intervention services in integrated settings, and I would like to see this continue.

I would also like to insure that infants and toddlers without disabilities have the benefit of playing and learning beside infants and toddlers who have disabilities.

I direct a number of preservice and inservice training programs in both New York and Connecticut. I am able to report that in these two States, the need for personnel to meet the needs of infants, toddlers and their families clearly parallels the National needs.

In New York, as part of the development of the CSPD, we have just completed a series of five needs assessments with pediatricians, day care providers, early intervention program directors, early intervention service providers and preservice training programs.

The surveys focused on the existing need for training on issues related to Public Law 99-457. I would like to highlight the fact that out of a limited sample of 39 colleges and universities in New York

State, only five are providing a training program specific to infants and toddlers with disabilities and their families.

Clearly, preservice programs will not meet the personnel needs of Part H without financial incentives.

Of those surveys distributed to personnel, the results overwhelmingly supported the need for additional training across a variety of topics integrally related to the provision of Part H services. For example, 75 percent of 395 day care providers identified a need to learn about caring for children with special needs.

Likewise, in Connecticut, where I direct a training project for day care providers, we had over 128 requests for training about children with disabilities during the month of March.

These data must be highlighted because most States are not proposing to create new licensing or certification systems with training requirements specific to the provision of early intervention services.

In fact, the New York State Child Care Coordinating Council has just issued recommended standards for child care programs and providers. The needs of children with disabilities are not addressed.

I would also like to support the need for training opportunities for families who will receive Part H services. In Connecticut, we convened a group of parents of children with disabilities to assist us in developing recommendations for Part H.

These families participated with representative groups of the ten professions addressed by the law. The families identified a number of skills they felt were needed in order for parents to fully participate in Part H services.

These included such skills as the ability to: access information; participate in the team process; communicate effectively; utilize family supports; utilize professional expertise; and most importantly, build partnerships.

Most parents are not born with these skills, and some may not even want to acquire all of them. However, I feel that parents are asking for the option of becoming better skilled at negotiating the service delivery system created by Part H.

I would like to join CCD in requesting that the committee examine the provision for inservice training under Part H for professionals and paraprofessionals and provide recommended funding levels to States so that they may develop a coordinated and comprehensive system of personnel development.

In addition, I support CCD's recommendation that the reauthorization recognize the training needs of families and support State level efforts to address these needs in a systematic and organized way.

I join CCD in recommending that Congress increase funding for the Parent Training and Information Centers under Part D so that parents of the youngest group of children with disabilities will be prepared to participate fully in the provision of early intervention services.

Part H services were developed to encompass the entire family system. Recognizing the principles of family-centered care, I would like to recommend that the committee continue to refine a number of areas directly related to family participation within early intervention services.

First, and foremost, is the fact that many families do not want to be managed as cases. Therefore, service coordination seems to be a logical replacement for the process currently referred to as case management.

Second, most parents currently fill this role. As one parent who coordinates a project for me recently said, "For 13 years I have been looking for the elusive case manager who can organize the system for Marie. I would love to find one."

Unfortunately, Marie's multiple needs preclude any one provider being able to negotiate the medical, educational, social service and equipment agencies as well as the parents have been able to.

As recommended by CCD, I feel that Part H should recognize the competence of those families who choose to coordinate their own services by allowing them to be their own service coordinator. Going along with this notion is the belief of "equal pay for equal work."

I would also request a careful examination of sliding fee scales to fund Part H services. Such fees can severely limit a family's ability to access services, and such financial assessments are invasive to the integrity of the family unit.

Also, such assessments do not take into account the kinds of expenses families incur in day-to-day living. A project we have in Connecticut which provides technical assistance to families with children with complex medical needs received 146 requests within a three-month period, of which 70 percent had to do with funding and family support issues.

Additionally, another of our family projects identified "out of pocket" expenses incurred by a family as a result of having a child with a disability. These costs included such effects on a family as the loss of job or career opportunity, loss of leisure/family time and loss of time for basic household tasks.

Expenditures included the purchase or rental of medical equipment, supplies, special adaptations to the home, higher utility bills, the purchase of adaptive equipment, special transportation, dietary supplements, diapers or special clothing, special soaps, lotions, eyeglasses, hearing aids, braces, adaptive toys, child care and respite expenses, mileage to medical appointments, additional therapy costs including family therapy, higher insurance premiums, and copay amounts on other medical bills not covered by insurance.

Although some of these would be funded by the Part H, I join with CCD to strongly recommend that the subcommittee carefully examine the use of a sliding fee system as it relates to the Part H. system.

Such a system could be construed as discriminatory, especially in light of the fact that the regulations of Public Law 89-313 prohibit the billing of families to fund early intervention services.

This could result in a funding dilemma in that many States, such as Connecticut, are using Public Law 89-313 dollars to fund early intervention services.

The implementation of sliding fees may result in services being delayed or denied to families, and most importantly, it may undermine a family's ability to control the services their child may need. Please examine the funding provision carefully to avoid any additional cost burdens to families.

In closing, I would like to thank you for the opportunity to speak before you. I urge you to consider the recommendations from CCD. There are many others in addition to those I have mentioned, and they are just as important to the continued implementation of law.

For example, I join with CCD in recommending that the Secretary be authorized to grant time limited waivers of specific fourth-year requirements to States which have certified they have had significant hardships in meeting implementation timelines.

This is even more crucial in light of the budget situations in many States, such as New York and Connecticut. In addition, I join with CCD in recommending that the reauthorization of Part H require a funding formula based on child count.

I feel that this will provide the incentive States need to develop an aggressive child find system so that those families that both Mrs. Putz and I have dealt with will have easier access to services.

I would like to close by thanking Mrs. Putz and Jonathan for accompanying me today. I feel that Mrs. Putz was able to illustrate the importance of families to the overall success of the law.

I feel that she and every other family who has participated in early intervention must be given the opportunity to fulfill their dreams for their child. Public Law 99-457 has begun to allow families to do that.

Early intervention has also been responsible for enabling the children who have participated in such services to fulfill their dreams. Mitchell Levitz is a 20 year old young man who is fulfilling his dream of working in politics. He is currently interning with New York State Assemblyman George Pataki of Peekskill. Mitchell happens to have Down Syndrome, and he was the first child enrolled in the infant intervention program sponsored by the UNP at MRI.

This occurred when he was 15 months old. Mitchell feels that if he had been enrolled sooner, he could probably be running for office by now.

Mitchell is truly a special young man who, because of his family's tenacity, has been able to attend neighborhood schools and has even passed his Regents Competence Exams and coursework to be able to receive a regular Regents High School Diploma.

This is no small feat as those of us from New York are well aware. Mitchell's mother, Barbara, now coordinates a New York State Health Department funded Regional Planning Group for early intervention at MRI.

On behalf of Mitchell and Jonathan and their families, and all the others who have benefited from early intervention, I would like to thank you for your continued commitment to strengthening early intervention services.

I would like to have Mrs. Putz introduce her family at this time.

[The prepared statements of Dr. Mary Beth Bruder and Lourdes Putz follow:]

Consortium for Citizens with Disabilities

Statement of Dr. Mary Beth Bruder

to

The Subcommittee on Select Education

of the

United States House of Representatives
on
The Reauthorization of Part H

of the

Individuals with Disabilities Education Act

April 12, 1991

Good morning Mr. Chairman, Members of the Subcommittee. My name is Dr. ary Beth Bruder and I am the director of Family Support/Early Intervention services at he Mental Retardation Institute which is a University Affiliated Program in Valhalla, New York and I am also an Associate Professor of Pediatrics at the University of Connecticut School of Medicine. I have been involved in the provision of early intervention services for children age birth to five and their families for the past fifteen years. While I was born and raised in New York, I have only been back a year. My fifteen years of experience has been within four states, all of which provided some level of early intervention to children and their families.

I am happy to be here today to represent the Education Task Force of the Consortium for Citizens with Disabilities (CCD) and testify on the reauthorization of Part H of the Individuals with Disabilities Education Act. The Education Task Force of CCD has identified a number of issues that they recommend be included in your reauthorization legislation. I request that the written CCD testimony, which I believe you have before you, be included in the record.

During my training and career, I have always learned the most about the value of early intervention from the families I have been fortunate to meet. I am happy to introduce to you one such parent, Mrs. Lourdes Putz and her son Jonathan. As a parent, she represents the reason Part H of IDEA was designed. I would like her to share with you some of the issues she feels are extremely important to the continued success of Part H legislation.

I would like to take a few minutes to highlight some of the issues which were identified within the CCD testimony and in Mrs. Putz' statement. In particular I would like to address four issues: the critical need for cultural sensitivity within early intervention services; the use of natural environments for early intervention services; the need for training of all who will be involved in the provision of services; and the important role families play in the service system.

Cultural Sensitivity

Hartford, Connecticut has the largest proportion of Puerto Ricans in the country. Forty-seven percent of the elementary school age population is Hispanic, yet only 20% of 337 infants referred to the Early Intervention Service Coordination Center in the greater Hartford area (encompassing 37 towns and the city of Hartford) were Hispanic, as were 27% of 189 infants receiving early intervention services through the Department of Mental Retardation in the same geographic area. This small number is even more surprising considering that 95% of the pediatric caseload at Hartford Hospital is Hispanic. The primary problem seems to be a shortage of bilingual staff and a lack of awareness about the unique cultural values of Puerto Rican families.

It is important to realize that twenty-six separate nationalities are called Hispanic, and while certain characteristics may be found in each, there is considerable variation among groups. Spanish speaking populations span all socioeconomic classes and educational backgrounds. Differing degrees of acculturation, socioeconomic class, education, occupation, geographical and racial origins will affect beliefs and behaviors. For example, Puerto Ricans are different from other Hispanic cultures because of a number of factors: they are U.S. citizens, therefore, they can work legally in the U.S. and be eligible public assistance; they are only three hours from their home, therefore, they can "try ings out" and return home; and most importantly, they usually do not achieve improved conomic status after migration. Unfortunately, most of these cultural issues don't get addressed by early intervention programs because the most important aspect of the Hispanic culture, language, becomes a barrier to services.

From 1983-1986, I directed a model demonstration early intervention project, the Ninos Especialles Program in Hartford, Connecticut. During the three years, we provided services to thirty-four infants with severe disabilities and their families of Puerto Rican heritage. Unfortunately, many of these families encountered the same barriers to services described by Mrs. Putz. The families were eventually referred to our project through a variety of sources, all of whom had received a personal contact by a member of our bilingual staff. One third of these infants were born on the island of Puerto Rico and only one of the families had an employed parent. The rest received public assistance. Yet, when provided with services which were directed at the parents' perceived needs in their preferred language, the families thrived. The families were able to identify and receive individualized services which met their expectations and family system. In fact, most of the initial IFSP goals developed by the families focused on support needs: finding housing, coordinating medical appointments, learning to understand English, etc. After 18 months of services, these families were able to design goals that primarily reflected their child's intervention needs. It should also be noted that our project was family directed. That is, we supported the right of the families to refuse services (providing the refusal did not constitute abuse or neglect).

We have subsequently been funded to provide outreach training to service providers and families in Connecticut and New York. We have offered over 30 workshops and long term trainings to early intervention programs in the past year. We have found a great need for training. Most of this training encompasses sensitivity and respect to all cultures, that is, explaining cultural values, customs and beliefs and their effects on the provision of early intervention.

I urge you to recognize the need for cultural sensitivity within the reauthorization of Part H by including the CCD recommendations to require that states recognize the individual service needs of families through training on cultural sensitivity within the Comprehensive System of Personnel Development (CSPD). I also urge you to require the use of culturally unbiased assessments conducted in a family's preferred language within the evaluation phase of Part H services.

Inclusion in Natural Environments

The natural environment for an infant is the family. The Ninos Especialles Program I previously referred to provided services to families in their home. The natural group environment for infants and toddlers in today's society is community early childhood programs: child care programs; nursery schools; toddler play groups; and other settings in which typical infants and toddlers participate.

Over the past 15 years, I have always been fortunate to be able to design, provide and evaluate early intervention services in settings having both infants and children with disabilities and infants and children without disabilities. In my first professional position as a preschool special education teacher in Vermont, I was able to learn from the beginning that the segregation of young children with disabilities into specialized programs does not make sense. As we strive for a community based system of integrated services for ing project for day care providers, we had over 128 requests for training about children th disabilities during the month of March. These data must be highlighted because most tes are not proposing to create new licensing or certification systems with training equirements specific to the provision of early intervention services. In fact, the New York State Child Care Coordinating Council has just issued recommended standards for child care programs and providers. The needs of children with disabilities are not addressed.

I would also like to support the need for training opportunities for families who will receive Part H services. In Connecticut, we convened a group of parents of children with disabilities to assist us in developing recommendations for Part H. These families participated with representative groups of the ten professions addressed by the law. The families identified a number of skills they felt were needed in order for parents to fully participate in Part H services. There included such skills as the ability to: access information; participate in the team process; communication effectively; utilize family supports; utilize professional expertise; and most importantly, build partnerships. Most parents are not born with these skills, and some may not even want to acquire all of them. However, i . . that parents are asking for the option of becoming better skilled at negotiating the service delivery system created by Part H.

I would like to join CCD in requesting that the Committee examine the provision for inservice training under Part H for professionals and paraprofessionals and provide recommended funding levels to states so that they may develop a coordinated and comprehensive system of personnel development. In addition, I support CCD's recommendation that the reauthorization recognize the training needs of families and support state level efforts to address these needs in a systematic and organized way. I join

CCD in recommending that Congress increase funding for the Parent Training and Information Centers under Part D so that parents of the youngest group of children with disabilities will be prepared to participate fully in the provision of early intervention services.

Family Participation

Part H services were developed to encompass the entire family system. Recognizing the principles of family centered care, I would like to recommend that the committee continue to refine a number of areas directly related to family participation within early intervention services.

First, and foremost, is the fact that many families do not want to be managed as cases. Therefore, service coordination seems to be a logical replacement for the process currently referred to as case management. Second, most parents currently fill this role. As one parent who coordinates a project for me recently said "For thirteen years I've been looking for the elusive case manager who can organize the system for Marie. I'd love to find one". Unfortunately, Marie's multiple needs precludes any one provider being able to negotiate the medical, educational, social service and equipment agencies as well as the parents have been able to. As recommended by CCD, I feel that Part H should recognize the competence of those families who choose to coordinate their own services by allowing them to be their own service coordinator. Going along with this notion is the belief of "equal pay for equal work".

I would also request a careful examination of sliding fee scales to fund Part H services. Such fees can severely limit a family's ability to access services, and such financial assessments are invasive to the integrity of the family unit. Also, such assessments do not sons with disabilities across the life span, we must start at the beginning.

Most recently, I have been directing a number of federally funded projects which focus on the design, provision and evaluation of early intervention services within community early childhood programs for children age birth to five with disabilities. Unfortunately, this service model is not routinely provided to all eligible children and families. Though research and evaluation data strongly support the provision of integrated services, state regulations and funding sources can prove to be disincentives to achieving this goal.

In 1988, we conducted a survey in Connecticut to assess the attitudes of both school superintendents and special education directors on the integration of preschool age children with special needs into programs with preschool age children not having special needs. The respondents overwhelmingly supported integration. In particular, though, and of most importance, was the fact that 82% of the superintendents and 90% of the special education directors felt that discretionary financial resources needed to be allocated in order for them to provide the integrated services.

In the same state of Connecticut, over 200 infants and toddlers who have moderate to severe disabilities are receiving early intervention within community early childhood settings under the auspices of the Department of Mental Retardation. This is due to administrative recommendations which were formulated from a deinstitutionalization court order. The Department's newly developed philosophy supports community participation at all levels and for the past three years infants and toddlers have been receiving early intervention services within their homes or in community settings in which typical children participate. This model has proven so successful that New York State is proposing this type of placement option under its proposed EarlyCare Legislation.

I join with CCD to strongly recommend that language be inserted into Part H to recognize the importance of including infants and toddlers with disabilities in community environments. Both Connecticut and New York are beginning to move toward providing early intervention services in integrated settings and I would like to see this continue. I would also like to insure that infants and toddlers without disabilities have the benefit of playing and learning beside infants and toddlers who have disabilities.

Training Needs

I direct a number of preservice and inservice training programs in both New York and Connecticut. I am able to report that in these two states the need for personnel to meet the needs of infants, toddlers and their families clearly parallels the national needs. In New York, as part of the development of the CSPD, we have just completed a series of five needs assessments with pediatricians, day care providers, early intervention program directors, early intervention service providers and preservice training programs. The surveys focused on the existing need for training on issues related to P.L. 99-457. I would like to highlight the fact that out of a limited sample of 39 colleges and universities in New York State, only five are providing a training program specific to infants and toddler with disabilities and their families. Clearly, preservice programs will not meet the personnel needs of Part H without financial incentives.

Of those surveys distributed to personnel, the results overwhelmingly supported the need for additional training across a variety of topics integrally related to the provision of Part H services. For example, 75% of 395 day care providers identified a need to learn about caring for children with special needs. Likewise, in Connecticut, where I direct a a into account the kinds of expenses families incur in day to day living. A project we ave in Connecticut which provides technical assistance to families with children with omplex medical needs received 146 requests within a 3 month period, of which 70% had o do with funding and family support issues. Additionally, another of our family projects identified "out of pocket" expenses incurred by a family as a result of having a child with a disability. These costs included such effects on a family as the loss of job or career opportunity, loss of leisure/family time and loss of time for basic household tasks. Expenditures included the purchase or rental of medical equipment, supplies (such as rubber gloves, K-Y Jelly, waterproof pads, thermometers, tubing, gauze, catheters, etc.), special adaptations to the home (such as ramps, electrical re-wiring, air conditioners, humidifiers), higher utility bills, the purchase of adaptive equipment (such as wheelchairs, special beds, bath sets), special transportation (such as wheelchair vans), dietary supplements, diapers or special clothing, special soaps, lotions, eyeglasses, hearing aids, braces, adaptive toys, child care and respite expenses, mileage to medical appointments, additional therapy costs including family therapy, higher insurance premiums, and co-pay amounts on other medical bills not covered by insurance.

Although some of these would be funded by the Part H system, I join with CCD to strongly recommend that the sub-committee carefully examine the use of a sliding fee system as it relates to the Part H system. Such a system could be construed as discriminating, especially in light of the fact that the regulations of P.L. 89-313 prohibit the billing of families to fund early intervention services. This could result in a funding dilemma in that many states, such as Connecticut, are using 89-313 dollars to fund early intervention services. The implementation of sliding fees may result in services being delayed or denied to families, and most importantly, it may undermine a family's ability to control the services their child may need. Please examine the funding provision carefully to avoid any additional cost burdens to families.

In closing, I'd like to thank you for the opportunity to speak before you. I urge you to consider the recommendations from CCD. There are many others in addition to those I've mentioned, and they are just as important to the continued implementation of law. For example, I join with CCD in recommending that the secretary be authorized to grant time limited waivers of specific fourth-year requirements to states which have certified they have had "significant hardships" in meeting implementation timelines. This is even more crucial in light of the budget situations in many states, such New York and Connecticut. In addition, I join with CCD in recommending that the reauthorization of Part H require a funding formula based on child count. I feel that this will provide the incentive states need to develop an aggressive child find system.

I'd also like to close by thanking Mrs. Putz and Jonathan for accompanying me today. I feel that Mrs. Putz was able to illustrate the importance of families to the overall success of the law. I feel that she and every other family who has participated in early intervention must be given the opportunity to fulfill their dreams for their child. P.L. 99-457 has begun to allow families to do that.

Early intervention has also been responsible for enabling the children who have participated in such services to fulfill their dreams. Mitchell Levitz is a 20 year young man who is fulfilling his dream of working in politics. He is currently interning with New York State Assemblyman George Pataki of Peekskill. Mitchell happens to have Down Syndrome and he was the first child enrolled in the infant intervention program sponsored by the [illegible]P at MRI. This occurred when he was 15 months old. Mitchell feels that if he had been able to be enrolled sooner he could probably be running for office by now! Mitchell is truly a special young man, who, because of his family's tenacity, has been able to attend neighborhood schools and has even passed his Regents Competency Exams and coursework to be able to receive a regular Regents High School Diploma. This is no small feat as those of us from New York are well aware. Mitchell's mother Barbara now coordinates a New York State Health Department funded Regional Planning Group for early intervention at MRI.

On behalf of Mitchell and Jonathan and their families, and all the others who have benefitted from early intervention, I'd like to thank you for your continued commitment to strengthening early intervention services.

Consortium for Citizens with Disabilities

Statement of Lourdes Putz
Parent Advocate

to

The Subcommittee on Select Education
of the
United States House of Representatives

on

The Reauthorization of Part H
of the
Individuals with Disabilities Education Act

April 12, 1991

Good morning. My name is Lourdes Putz. I am the proud parent of six children. I guess this qualifies me to say that every child has special needs. Some require more attention than others, but they all require attention.

The youngest of my children is Jonathan. He will soon turn five years old. He was born with Downs Syndrome. We were very fortunate in that from the very first day we received much support and directional assistance from many resources. As a result of this, Jon began an early intervention program at six weeks old, where he received educational services, and speech, physical and occupational therapies.

Unfortunately most parents are thrown for a loop once they've been made aware that their child has a disability. They may go day to day floating in a cloud without really being in touch with the world around them. **In many instances we also have the problem of language and cultural barriers.** Because of this it is so important that we have knowledgeable people from the beginning who will provide the guidance and support that is so necessary.

In one case that I am familiar with a child was born with multiple disabilities to an undocumented couple. The fears, language and cultural barriers caused these parents to wander for months without any real understanding of their child's disability or of services that were automatically available to that child as a citizen of the United States.

In another case involving a 1 1/2 year old child born with Downs Syndrome to a young hispanic girl, the child has many medical disadvantages which cause her to be ill 75 % of the time. It has been determined that because of her illness, the most appropriate place for this child to receive service at this time is within her home. Except that because the child's parent is spanish dominant, the child must receive bilingual services. However, **the child has received no service in the past eight months. Because of language barriers the mother has been unable to be an advocate for her**

child. This child should be getting service regardless of what language her mother speaks.

As parents of children with disabilities we must also stop short-changing our children. In order for them to grow and be accepted as individuals in their communities, inclusion must begin from day one. A strong foundation will give our children the opportunities to participate in a typical environment. Inclusion will also create a community that is aware and sensitive to the needs of persons with disabilities. **It is their right as individuals to be part of the community, regardless of their disabilities.**

It is for these reasons that as you consider reauthorizing the Part H program for infants and toddlers, I ask that you pay close attention to the recommendations of the Consortium of Citizens with Disabilities so that **all** parents of infants and toddlers with disabilities have the opportunities to **receive support and services they want and need from the very beginning of their child's life.**

Thank you.

Chairman OWENS. Both the father and the son, welcome to the committee.

Mrs. PUTZ. This is Jonathan, and this is my husband, Frank.

Chairman OWENS. Welcome to the committee.

That ends our first panel. I want to thank Dr. Bruder for ending on an upbeat note. We like to get a little inspiration up here. Of course, Dr. Gallagher started that way.

Before I go into the questions, I just want to note that all of your written testimony will be entered into the record. We have also been given an additional document—related to the needs of military families—from the Consortium for Citizens with Disabilities that also will be entered into the record, if there are no objections.

Let me congratulate all of you for bringing a rich supply of material for the committee to ponder. Although we have limited time here, I assure you that staff will certainly go over your testimony in great detail as we move through the process of finalizing the legislation.

Dr. Gallagher, as I said before, you started on an upbeat note. We are happy to hear that the States are making a good-faith effort, despite the fact that this law calls for major reform and despite the fact that finances are a major problem as you pointed out.

I don't want to discuss finance. I think that that should be discussed in some other place, a larger arena; but I do want to discuss a few points that you made.

The authority of lead agency. Now, if the State designates the lead agency, don't they confer upon them the authority to do what has to be done?

What is the problem?

Mr. GALLAGHER. Well, on a practical matter, if the Department of Education in the State is given the lead agency responsibility, they still have to deal with a variety of other State agencies, the Department of Human Resources and health areas, and these other agencies also have their responsibilities and particular concerns.

And it was proven to be a little difficult to get full coordination and cooperation that the lead agency is one of equals under those circumstances.

And what we are asking for here is that it be placed at a somewhat higher level in order to give the true authority of the State to accomplish that coordination.

Chairman OWENS. Do you think that we need to do legislation; that common sense wouldn't prevail?

Mr. GALLAGHER. Common sense?

Chairman OWENS. It hasn't so far.

Mr. GALLAGHER. Mr. Chairman, I think that the structural aspects of this law, as it is being implemented in the States, have impressed us very much, and we think that it is very important to place the authority where it can actually be functional. And that is why we are asking for—to move it up at the State level and let the State decide where the authority should rest.

But it should not rest in one of equal agencies but should be at some higher level so that that coordination can be, in fact, drawn together and enforced by a higher level of authority.

Chairman OWENS. You mentioned the need for responsibility in offering comprehensive services. Did I understand you correctly that the State should be encouraged to more aggressively pursue diagnostic procedures and go ahead; not be inhibited by what they discover?

They may not be able to handle properly—we should make it clear that they don't have to handle it properly; just making the diagnosis in some cases is more desirable than neglecting them for fear of having to take care of them.

Would you clarify that?

Mr. GALLAGHER. Yes. I appreciate what you are saying, Mr. Chairman. What we are impressed with, first of all, was that the provision for at-risk children and dealing with them is a very wise provision and one that should be followed through on.

The practical matter of what has happened in the States, however, is that the States have looked at their financial condition. They have also looked at at-risk children and see a population of, perhaps, four or five times that of the youngsters with developmental delay and established conditions, and they have become frightened, and have backed off.

And it is very clear that they want to do something in this area. But the notion that they will be forced to provide comprehensive services for everyone of these children, and in the three different categories, including at-risk, has dampened their enthusiasm somewhat.

What we are suggesting is that they should still do consistent diagnosis and monitoring and follow up on these youngsters, so that if the youngster, in fact, becomes not at-risk any more, but actually developmentally delayed, then they should be given to direct services immediately.

But not all of these youngsters will have that. Fortunately, many youngsters who are at-risk in our terminology will turn out to be not developmentally delayed, and therefore would not need an enormous number of services at this time.

So what we are suggesting is a program of monitoring, of screening, of making sure that if the youngster really does have a serious problem, that they get services, but not to put the burden on the States for comprehensive services for all youngsters that would fall into that category.

If you do do that, then we think the States will back off and will not serve these youngsters.

Chairman OWENS. Thank you.

Dr. Odom, we discuss and debate least restrictive environment so thoroughly and repeatedly around here until we may be taking some things for granted.

You say we don't make it clear in the law that LRE also applies in the case of preschool children, and we need to clarify that.

Did I understand you correctly?

Dr. ODOM. I believe it does, because my experience has been that States interpret that law differently, and maybe that is their leeway.

But for elementary and high school age children, there is access within public education, public school systems, to a normalized setting within the school building even, that is class rules for children without disabilities.

For preschool aged children, there often are not—there is not that same vehicle for accomplishing a normalized or main stream setting. So the interpretation is that since it doesn't exist within the public education system, then efforts to provide the least restrictive and normalized environment doesn't apply.

So my feeling is that States do need more clarification about providing services within the least restrictive environment, which is actually a range of options, but one of which is inclusion and programs for children without disabilities.

And that is not only for the Part B kids, but as Dr. Bruder said, for infants and toddlers, too, who qualify under Part H.

Chairman **Owens**. We are also interested in the set of research requests that you think are still—we still need to wrestle with an answer. We would be happy to hear from you in more detail about those at a later date.

Lt. Colonel Sautter, we apologize for misspelling your name. I have it correctly here.

You said that you are involved at this point in a court case, and I suppose you don't want to discuss that in detail, essentially information you provided that DOD has the eighth largest school system in the countries; is that right?

Lt. Colonel **Sautter**. When you consider the number of students that DOD is responsible for educating, that is true, Mr. Chairman. It is 185,000-some students.

Chairman **Owens**. Is it the contention of the military that just as the adults who enlist surrender certain rights by implication, they surrender certain rights?

Lt. Colonel **Sautter**. You are making the skin on the back of my head crawl up and down. I think when we all raise our right hand in the military and agree to defend the constitution, we at the time probably don't realize it, but with a little bit of maturity, we realize there are certain things within the military that may be a little bit different than our civilian counterparts. And I think that we all understand that.

What grieves us or some of us is that sometimes we apply those same criterion to families. As hard as my wife works, she ain't wearing combat boots today. She is a dear, sweet lady and taking care of my two children.

She is, has been, and always will be, a civilian, as my two children are; and I think it was the issue—the shock that came to me when I asked for the same privilege that occurred to a child who lived a half a mile away outside the gate and I found that I could not have that.

And so as a parent who, I think Lourdes Putz indicated, parents with disabled children have to learn, they have to be the advocate for their child.

I felt that I was an advocate for the child, and I understood with a layman's viewpoint the law, but then I found out that the law that I understand—that I understood did not apply to my child.

Chairman **Owens**. Well, it is an interesting and important issue—one on which I think we would like to see any material that you want to offer, not just for this committee but, I think, the Education and Labor Committee as a whole should be concerned.

Ms. View, during the reauthorization of discretionary programs under IDEA, the act last year, we focused on the problem of low representation of minority personnel, and took some steps to try to deal with it.

Of course, the first and greatest problem several people have mentioned already is the personnel shortage overall.

There is a great need for a more aggressive effort to recruit and to provide some incentives for people to go into the field in general. We addressed that in great detail in our reauthorization of discretionary programs.

And if you hadn't heard about that, you might want to consult with staff on the kinds of things that are being done now to try to deal with that problem.

Several of you have mentioned parents and parent participation. And you know, I smile, because I am a graduate of the community action program, including Head Start, where we put a great deal of emphasis on parent participation, citizen participation, and lay participation, providing some budgetary means for the achievement of those ends.

It requires some money, not much, but some outlay of funds to achieve that. I was just wondering for the record, do you think we should make some effort to make sure that parent participation is spelled out in greater detail, including requiring some percentages of the budget to be devoted to it?

Ms. VIEW. Yes. I think that that would represent the position that we take, and we certainly don't want to suggest that efforts have not been made and progress has not been made in terms of parent participation.

What is of concern to us is the indication that there is going to be an increasing percentage of parents of children who receive service who are in a population who don't normally access services anyway.

I think you, yourself, referred to the increasing numbers of babies being born to drug addicted and substance abusing parents, not to mention the increase in the number of single head of house—single parents who are a part of this population.

My observation is that the strategies that have traditionally worked in terms of bringing parents into the system as advocates and as active participants are not as successful with this particular group of parents that is indeed increasing.

So I think that States will have to become much more creative in strategies to, first of all, in terms of outreach, but once you have identified the potential recipients of the service, to really bring them into the system to ensure that their children will have full benefit of Part H program, and certainly financial incentives will be one way to encourage States to do that.

Chairman OWENS. Thank you very much.

To Mrs. Putz, what is your address? You are in Brooklyn. I just wanted to see whose district.

Mrs. PUTZ. I live in Williamsburg, Brooklyn.

Chairman OWENS. You said you received support and resources from the very beginning. You had good experiences, which is not the testimony we have been hear——

Mrs. PUTZ. Which was not in Brooklyn.

Chairman OWENS. Was that in Brooklyn?

Mrs. PUTZ. No, it wasn't.

Chairman OWENS. You had to go to Manhattan?

Mrs. PUTZ. It was in Queens. Jonathan was born at Brooks Memorial, and it just so happened that one of their registered nurses also had a child with Downs Syndrome, and she was very supportive and she directed us to many services.

And she spoke to us very openly and told us that as parents, we had the right of choice, and what—which is not what I have found through the years as I have met other parents, whereas most parents go to one preschool and that is it, and they are not even aware that there are other schools that they can go to to make the choice for their children.

And I did have that choice. Yes, we were very, very fortunate. Very.

Chairman OWENS. Dr. Bruder, you pointed out that several of the items you covered have been covered before in terms of personnel needs, and we certainly appreciate your testimony.

I have run out of time, but I do want you to know that the sliding fee scales are of great concern to me; I hope to other Members of the committee. We want to take a close look at some of the proposals that are being made in that direction.

Thank you all very much for your testimony. I want to turn you over to the Ranking Member of the committee, Mr. Ballenger.

Mr. BALLENGER. I will be very short, I think, Mr. Chairman. I just had a couple of questions.

Dr. Gallagher, you know, this whole program is talking about Federal funding and so forth, Federal programs. But being from North Carolina, it appears like on your little chart here that there are only four or five States that are planning on serving biologically and environmentally at-risk children.

Mr. GALLAGHER. Yes.

Mr. BALLENGER. What percentage of the State money funds early intervention? I don't know, probably North Carolina would be the easiest one to ask.

What percentage of the money is used to fund this program in the future in North Carolina State funds? What percentage Federal and what percentage to State? I mean, I have no idea how much this lead amount of money which as far as Federal money is concerned is not a real large amount of money, what it attracts in the way of State funds.

Mr. GALLAGHER. Well, I think that is part of what is bothering the States, that the Federal money is clearly stated as planning and development money.

What we were suggesting in our recommendations is that in addition, some implementation money go along to encourage and give incentives to the State to go into full services.

It is clear that the States are going to have to pick up a large amount of this money. On our study of the financial resources available to the States, we found about 15 different sources of funds, but in actuality, the States are using only two or three of those funds, and medicaid is a major source of funds.

Some States are even proposing that medicaid be available to all families, regardless of income level, for youngsters who are eligible for this program.

So there is a whole variety of sources that are being looked at by the States to try and—but certainly the funds here in this particular law are a small proportion of what is going to have to be expended.

Mr. BALLENGER. Of course, if you talk Medicaid, that is both State and Federal funds that would be used along those lines.

Mr. GALLAGHER. Of course, yes.

Mr. BALLENGER. And so in reality, then, just off the top of your head, do you have any idea what might have been attracted by our little lead funding from the Federal Government, say, in any particular State?

Mr. GALLAGHER. Well, because few of the States have actually gone into full implementation of this, it is hard to make that kind of estimate at this time.

Certainly, this fund that we are talking about right here in Public Law 99-457 shouldn't—couldn't be any more than 10 percent of the total and probably less than that.

I just wanted to say, if I could, that I want to reiterate that the States are making a good-faith effort.

Another part of the testimony, however, was they aren't going to meet these timed deadlines, and so that some kind of adaptation or adjustment is going to have to be made. And they are not making it; not because they don't want to or don't want to try, but because of all of these various complications that have arisen.

So we hope the committee will really take cognizance of this and give the States the additional opportunity to continue in the program.

Mr. BALLENGER. We heard that yesterday, and we are hearing it again today, and I think that obviously we will take cognizance of that fact.

Ms. Bruder, considering the thoroughness with which you have involved yourself in this issue, and sadly, I notice that neither Connecticut nor New York decided on serving at-risk children.

But the statement was made, and part of your statement was that—and I would like just a personal opinion as to how you would approach this, that disabled children be put in with children that are not disabled when playing and learning.

Once you add at-risk, and I just know, you have seen it on TV, and I have, when you talk about an HIV positive child, do you think such a thing is really possible?

Ms. BRUDER. In particular, children who are HIV positive, yes, it is, providing the program in which that child is has taken precautions and knows exactly the health status.

It has become tricky in that two of our State agencies have had to adopt confidentiality requirements that obviously protect the family's right, but also protect the day care providers' or child care providers' rights.

The issue of at-risk is a touchy one, and I would like to hold out and say New York hasn't definitely decided yet what they are doing; and Connecticut is still debating a number of issues.

And I think the major reasons the States have looked at not providing services for at-risk is, in my opinion, somewhat shortsighted.

It is a cost factor, the immediate need. However, all the programs in which I have been involved, in particular one in Richmond, Virginia where we monitored, similar to what Dr. Gallagher was suggesting, provided tracking and monitoring service to teenage moms who lived in Richmond who had babies born prematurely, we were able to find that about 25 percent of those moms eventually did, in fact, need intervention.

But the rest of them, about 75 percent, really did a wonderful job with their babies and, in fact, were able to given even a little bit of information, monitor their baby's own development.

The cost was a huge savings, as far as I was concerned, because we were able to get in there, did not do in-depth intervention.

We saw the families on a three-month basis, but we provided a lot of case coordination or service coordination and really looked at the long term of helping these various young moms learn about their babies and themselves, which I think had long-term savings.

I think the issue of Head Start, which the Chairman mentioned, is something else we have to take into account. Head Start has proved to be incredibly successful, especially in our cities.

Westchester County, which unless you are from New York you don't realize, has the highest per capita of homelessness in the country. One of the big savings we have been able to see is that Head Start, there is about 49 Head Start programs, has really provided the big bonus to these families who are homeless and have enabled these children to be maintained and actually returned to neighborhood schools once they get their homeless situation taken care of. Thin, unfortunately, is another whole issue.

But I really think we have to continue to allow States to make that decision about at-risk, because I really think that if in fact we are looking at something that helps all children, we want to have a variety of different services provided.

And clearly not all are going to be as intensively or as costly as those of our most severely disabled, but we don't want to leave kids out.

Mr. BALLENGER. All right. Thank you, Mr. Chairman.

Chairman OWENS. Thank you again. Dr. Bruder, I do have a note here from staff. We would like to have more information with respect to family coordination and case management.

Thank you again, all members of the panel.

Chairman OWENS. The next panel consists of Dr. Brian McNulty, the National Association of State Directors of Special Education; Mr. George Jesien, President of the Division for Early Childhood Council for Exceptional Children, Reston, Virginia; Mr. Robin McWilliams, Frank Porter Graham Child Development Center, University of North Carolina; and Mr. Gene Wilhoit, Executive Director, National Association of State Boards of Education, Alexandria, Virginia.

Dr. McNulty.

STATEMENTS OF DR. BRIAN McNULTY, NATIONAL ASSOCIATION OF STATE DIRECTORS OF SPECIAL EDUCATION, WASHINGTON, DC; GEORGE JESIEN, PRESIDENT, DIVISION FOR EARLY CHILDHOOD, COUNCIL FOR EXCEPTIONAL CHILDREN, RESTON, VIRGINIA: ROBIN McWILLIAMS, FRANK PORTER GRAHAM CHILD DEVELOPMENT CENTER, UNIVERSITY OF NORTH CAROLINA, CHAPEL HILL, NORTH CAROLINA; AND GENE WILHOIT, EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF STATE BOARDS OF EDUCATION, ALEXANDRIA, VIRGINIA

Dr. McNULTY. Mr. Chairman, Representative, I am pleased to be here today. I am Brian McNulty. I am State Director of Special Education from Colorado.

I am here representing the National Association of State Directors of Special Education. I am also the lead agency in our State for the Part H program and have extensive experience over the last four years managing the Part H program.

What I would like to do today is we have submitted rather extensive written testimony, and I won't go through all that. I will limit my testimony to only four components that I would like to quickly go through for you.

One is the family focus of the system. The second is interagency coordination. The third would be looking at the flexibility that was originally built into Part H. And the fourth is the funding of the Part H program.

Let me start with the family focus of this program because I think it is very important for us to note that in the last four years, you have seen a significant shift in the way that we look at and work with families who have very young children with disabilities.

That is a significant national achievement, and I think it can be attributed to the Part H program. Traditionally our infant programs and our early intervention programs were very clinically oriented kinds of program, very focused on intervention with the child, much more medically or clinically focused. That focus has shifted over the last four years, I believe, as a result of the Part H program, and that shift has been moved to much more of what we are calling family friendly programs or services.

We are now putting the family in charge of making decisions and trying to empower families, prior to work with families, and assist them and also, I guess, that the shift has been away from a disability model and into an ability model.

I think that the feedback—we spent the first 18 months hearing from families in our State. Our interagency council is a very active council. It is very pro-family/child council and filled with advocates.

The focus that they took for the first 18 months was to listen to families and get a very clear articulation of the values that we wanted to bring forth to our State in terms of families.

Very clearly again, the shift moved away from seeing families in a deficit model and perceiving families in a competency model. That doesn't sound like a lot, but when you start to articulate that into programs and services, it is a significant change in the way the States are doing business.

And I think that everyone should feel very good about the change that has happened because of the Part H program. When we heard from families, what we heard oftentimes was an unintended result of intervention, and especially early intervention in infancy and preschool, resulting in isolating the families from their natural support systems.

In addition, families oftentimes left overwhelmed by the kind of intervention services that they were getting, and they felt like they lost control of their own interactions with their own child.

I think it was all done for the right reasons but with unintended consequences on the family. The model now has been shifted, and it is much more of a natural support system, keeps families linked to those supports and is linking families also with generic community resources and not just disability resources.

We heard story after story of families saying I got linked with the Y program to do infant swimming, but we couldn't go to that program. Instead, we had to go to an infant handicapped swimming program. And the list goes on and on.

Families want regular community resources. They want their kids to be a part of their neighborhood. They want them to go to regular schools. They want them to be seen as children first, and I think they have a right to have their children be seen as children, not as a label, not as a disability.

The second part of that, I think, is that when we asked—and we started to look at those families. I heard from a mom after one presentation, who came in and said, I will tell you, what we really need is babysitting services, and all we can seem to get are respite care services.

We don't need respite care services at $27 an hour. I just need a babysitter.

Those are the kinds of things where we have tended to overspecialize our system in an attempt, I think, to meet the needs of kids and families, but inadvertently pushing them into a disability-oriented system.

The second issue, I think, that was brought up by parents was case management. We have our support of the change in language, but I think you want to be careful not to specialize case management, also.

In our State, again, parents were very clear about saying that the first interaction that they would like with the family would be with another family, and that that first-tiered response at least of case management or coordinated service delivery should be parent to parent.

It should be—it, again, should be very—a warm family, friendly support. That is the first contact with families. The services then need to be much more flexible; not fitting families into services, but adjusting services to families.

Traditionally, again, we said we have an infant intervention program. It meets four times a week. If you want the slot, fine; if you don't, there is another family waiting.

That is not what we would like to see for families. If a family wants to wait three months or six months, if they only need one service, they should be able to get the one service.

If they want to get the generic resources that are available in the community, they should be linked to those.

Those are the kinds of shifts that we are seeing in the system, and that is directly attributable, I believe, to the Part H program.

The second component is the interagency nature of Part H. We again need to feel, I think, that significant progress has been made in the interagency area, but at least based on some of your questions, I guess I would like to say that even though being the lead agency in our State, we do not—we have the responsibility but we do not have the authority to direct other agencies.

It is very similar to what happens here at the Federal level. We have various committees that work and oversee the Department of Health, developmental disabilities, social services, et cetera.

Those different committees in the legislature control their budget; we do not. And so it is very complex negotiations. Part of what I don't think ever went into the figuring of the Part H program was we also go through a reauthorization at the State level.

Our Part H program coordinating council has been very involved in monitoring the developmental disabilities language in our State because developmental disabilities is a primary provider of infant services.

They have spent the last year and a half looking at their legislation in preparation for reauthorization to make a major rewrite of the developmental disability State law language around infants and toddlers.

That only happens once every five years. We cannot control that reauthorization process. It is very similar, again, to what goes on at the Federal level. So the timetables that we have been faced with have been set prior to Part H, and we are having to live with some of those timetables.

But I can guarantee you that the Part H interagency council is monitoring very closely every piece of legislation that affects infants and toddlers and is having significant input when those pieces of legislation come up for reauthorization, but that takes much longer, I think, than we originally anticipated.

The third point, I guess I would like to make, is in relation to flexibility. The Part H program originally contained components to provide flexibility.

As the lead agency needs to coordinate services across agencies, we have to have that kind of flexibility in order to embrace all of those different programs that have different requirements, that have different funding mechanisms, they have different eligibilities, et cetera.

All of those take work to coordinate. The flexibility that was built into the program allowed us to do that to some degree, but I would caution us not to look at changing the flexibility that was built in. Specifically, sliding fee scales. We have some programs that require sliding fee scales. We have some that do not. Those are conflicting in the States.

We, however, have said that if the State or the Federal Government has mandated a sliding fee scale, we will continue to do that. However, if a program does not, that is okay, too.

A good example, I checked with our Department of Health before I left. They have a mandated sliding fee scale for their handicapped children's program, for instance. It is a $2.5 million program, and I guess one of the questions that I know people have is how much money do you really recoup.

They recouped $30,000 last year in their sliding fee scales. That was prior to their administrative costs. So one of the things that we need to look at is oftentimes these look more rewarding than they actually are. And it is very difficult to get that money.

And I think Dr. Bruder's statement about the costs to families who have children with disabilities are incredible costs for a variety of kinds of services. I would say that there was wisdom in allowing for sliding fee scales originally in Part H because some programs do charge them.

There are others, however, again, RDD program and developmental disabilities, cannot charge a sliding fee scale because they receive Chapter 1 dollars; and therefore, they are precluded from charging a sliding fee scale.

We as the lead agency have to have a mechanism that embraces both of those programs if we are really to coordinate them. So I would caution you to allow that to continue to happen, but leave that the way it is.

The second issue in relation, I guess, to the at-risk, I think again that there was wisdom on the part of the Congress to allow States to use at-risk, but not to mandate them to do that. I think that Dr. Gallagher's statement is if you want to see more States moving into serving at-risk, then you need to look at the requirements that are associated with that.

There is a caution, however, around at-risk. At the same time, the disability community, is trying to say, we want kids to be perceived of as children first and then if they happen to have a disability, and we are trying to move them more and more into the generic community resources. If we attract children who are at-risk into the disability system, I am not sure that that is an appropriate avenue to come in for intervention.

And again, we all believe that the at-risk kids need services, and I think you are seeing at the State level a variety of programs to serve at-risk. And we again work in coordination with those programs.

In our State we have a major agenda on at-risk. We are part of that agenda as Part H lead agency.

Finally, under flexibility, the technical age of three, I think you have heard some testimony on this before. What we would say is just allow some flexibility on that technical age of three because again, part of the Part H program said we want to allow for a good, smooth, logical transition of kids out of infant programs into preschool programs.

Preschool programs are now being offered or coordinated through the public schools. Infant programs are offered by a variety of providers: health, education, developmental disabilities, et cetera, and we want the transition to be smooth.

And in order to do that we in our States have to be able to work out when that transition will occur because we don't want to stop services to a child just because their third birthday happens to be April 12th.

We want them to finish this year and then go the next year. And so that kind of flexibility is very important if we are truly concerned about transition.

Lastly, I would like to just spend a couple of minutes talking about funding. We are very supportive of the concept of differential participation and differential funding for States.

Again, the States have had real difficulties in coordinating resources and policies. It has been very difficult for us to do.

We would recommend that the Part H program reauthorization schedule, however, may be lined up with the rest of the Part C through G programs under Public Law 94-142 to bring those two programs a little more into sinc rather than doing one at one period of time and one at another.

It seems to make more sense to do the reauthorization at the same time because all of those programs are integrally linked.

Finally, the last statement I guess I would like to make is there is a concern on the part of the States regarding the reauthorization, at least a significant number of States are in their fourth year.

We would like to recommend that States be able to apply for the differential funding beginning this next fiscal year, similar to what we did when Part H was passed and not wait for the rules and regulations to come out.

The rules and regulations process from last year's reauthorization still are not out. And I am afraid that there will be a significant reduction in services under Part H unless we allow for applications under the new funding to occur beginning this next fiscal year.

I would appreciate answering any questions that you have. Thank you.

[The prepared statement of Dr. Brian McNulty follows:]

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Statement of

The National Association of State Directors of Special Education

to

The House Subcommittee on Select Education

on

The Reauthorization of Part H
of the Individuals with Disabilities Education Act

April 12, 1991

Presented by:

Dr. Brian McNulty
Executive Director
Special Education Services Unit
Colorado Department of Education

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Recommendations

Mr. Chairman and members of the Subcommittee. The National Association of State Directors of Special Education (NASDSE) appreciates the opportunity to present the following statement regarding the reauthorization of the Part H program for infants and toddlers with disabilities of the Individuals with Disabilities Education Act (IDEA). Our membership includes the administrators of education programs for children with disabilities in the Departments of Education in the 50 States, the District of Columbia, and the jurisdictions. At present, in 18 States and three jurisdictions the Department of Education serves as the designated lead agency for implementation of the Part H program.

Over the last year, NASDSE has surveyed its membership in preparation for this reauthorization, conducted seminars and discussions with our members and others involved in Part H implementation, and reviewed the results of the studies being conducted by the Carolina Policy Studies Program on States' implementation efforts and experiences. This statement and our recommendations for improving the program are based on these activities.

NASDSE was a major supporter in 1986 when Congress passed PL 99-457, creating the new Part H program of early intervention services for young children with disabilities and their families. Those amendments to the Education of the Handicapped Act authorized a new formula grant program to assist States in establishing "... a statewide, comprehensive, coordinated, multidisciplinary, interagency system to provide early intervention services for infants and toddlers with disabilities and their families."

The Part H legislation did more that authorize a new federal program. The statute relied heavily on what had been learned over the years from research examining the effectiveness of early intervention and from previous efforts to address the human service needs of young children. Part H created a vision that we can now say may serve as a model for future initiatives in the area of human service delivery, even beyond early childhood. Key to this vision are:

> **Family Focus.** Part H acknowledged as central to the program the critical role of the family in the development of young children, and was constructed to ensure that parents would have the opportunities they desired in the design and delivery of early intervention services. It further recognized that in order to enhance the child's development, the system of services would need to support and assist families in their unique and on-going role of primary caregivers for their children. In contrast to other efforts in early childhood service delivery, Part H envisioned a system which would be responsive to the needs of children within the context of the family instead of asking them to adapt to the system.
>
> **Interagency System of Service Delivery.** Congress designed in Part H a system of early intervention services that fully recognizes that children with disabilities and their families have needs that extend beyond the boundaries of individual agencies

and disciplines providing services. The system is to be interagency in nature, with respect to service delivery as well as to financing. First, to be effective from the family's perspective and cost efficient from the public's perspective, coordination of the diverse aspects of the service delivery system was imperative. Part H envisioned that parents would be able to access needed services through a single process. Rather than asking parents to search for available services and contend with the sometimes overwhelming obstacles associated with differing program policies and requirements, services available from diverse public and private providers could be coordinated and delivered in a way that would reduce burdens on the individual and avoid unnecessary duplication of effort. Second, the system is to take advantage of multiple public and private resources at the Federal, State and local levels to finance early intervention services through the coordination of existing programs and services and elimination of barriers to cooperative financing. In contrast to past emphasis on single agency approaches to service delivery and financing, when implemented Part H was to represent a comprehensive, multi-agency and coordinated approach responsive to the needs of the target population.

Community Based Service Delivery. To be responsive to the ongoing needs of infants and toddlers with disabilities, the system of services is to be community based to ensure access to services in a timely and consistent manner. By building upon existing services and further expanding local capacity, a greater diversity of services would be available thus promoting more typical patterns of living for children and their families.

Status of States' Implementation of Part

When Congress established Part H, it was anticipated that all States would be at or on the verge of implementation of the 14 required components during the 1991 reauthorization process. It was believed that 5 years would be sufficient time for States to achieve the policy directives established in the statute. It was the goal that by this summer all infants and toddlers with disabilities were to have evaluations, Individualized Family Service Plans (IFSPs), case management services and that the system would be established to meet the other required components. By next year, all eligible children and their families were expected to be receiving all the services identified in their IFSPs.

As you are well aware, some but not all States have been able to keep to this schedule for the Part H planning and development process. It appears that 17 States are pretty much on schedule, making remarkable progress towards achieving Congressional goals and preparing to provide services to all eligible infants and toddlers and their families at the beginning of their fifth year of participation in Part H. Even in most States which have had to delay entry into the fourth year of the program, there is convincing evidence of substantial progress towards putting in place a statewide, comprehensive, coordinated, interagency system of early intervention services. However, it is now becoming clear that the endeavor States have undertaken is far more complex and challenging than originally envisioned. We believe there are at least two major reasons for differences in the status of policy development and implementation in the States.

First, implementing the Part H requirements has not been business as usual for the States. Policy development, approval and implementation have been both complicated and time consuming. Part H, in effect, asked States to do something that had not been done before, for which there were no models or established rules: to coordinate activities across different State and Federal programs and across disciplines into a statewide system; to eliminate barriers to and generate new policies for the financing of services across agencies; to generate new fiscal support for early intervention services; to establish or change policies and procedures in different programs within multiple agencies. Further, "since, within each State, no one person or agency has the authority to direct or command the required action, lead agencies and Interagency Coordinating Councils have had to operate through compromise, consensus and negotiation to achieve a final result" (Carolina Policy Studies Program, 1991).

Second, it is evident now, based on research on Part H implementation and surveys conducted by national organizations, that existing resources may to be insufficient to make services available on a full entitlement basis. When Part H was passed, there was an assumption that sufficient resources were available in States or could be generated to finance comprehensive early intervention services for all infants and toddlers with disabilities. The Federal funds were, in large part, viewed as "glue money" to help facilitate the coordination and cooperation necessary to bring State and local resources to bear on meeting the needs of very young children with disabilities. This assumption has not been born out in some States. Prior to 1986, investments in early intervention services in some States had been considerable. Yet, even where this was true and especially where little or no service infrastructure or experience predated Part H, there is considerable concern over program financing.

Further complicating the funding situation is the deteriorating condition of State budgets, an unanticipated factor back in 1986. There is no doubt that this is having a significant and sometimes negative effect on efforts of lead agencies, ICCs, and advocates to gain the support necessary within States to move into full implementation. According to the National Governors Association, at least 30 States are experiencing severe financial troubles. States are seeking funds for expansion of Part H services at a time when other basic human services are being cut, and in some cases cut substantially. Funding for early intervention services for infants and toddlers with disabilities is competing with equally compelling needs for prenatal and maternity care, and other forms of basic health, medical and social services. Further, in those States which have enacted mandatory special education services for preschool age youngsters over the last four years to meet next year's Part B requirement, it has been particularly difficult to secure from legislatures sufficient funds to adequately support both early intervention and preschool services. Against this backdrop, we believe we will continue to see a reluctance on the part of some State legislatures to favor new mandatory spending programs.

In the face of very difficult budget situations and competing demands for vital human services, advocacy for the funds needed to support full implementation of the Part H program is still strong and will be important in efforts to maximize existing resources and to secure additional fiscal support in the future. However, during this reauthorization process we believe Congress must consider the fiscal and programmatic realities some states are facing in their efforts to implement comprehensive, interagency, statewide systems of early intervention services.

Despite these challenges, however, the goals Congress set out in 1986 are still appropriate. Four years later, the States now know more about what it may take to ensure that the original vision is realized. NASDSE continues to strongly suupport the development and operation of statewide systems of early intervention services for infants and toddlers with disabilities and their families. Part H has already been instrumental in assisting States to establish a stronger foundation for achieving that goal.

We also believe that this reauthorization provides an opportunity to develop a first set of adjustments in the program to strengthen it in ways that will assure that all States continue to participate. This reauthorization was originally scheduled to coincide with the fourth year of the five year phase-in period. At this point it was expected that at a minimum all States would have adopted policies incorporating all 14 components of the statewide system, be providing multidisciplinary assessments and case management services, and would have developed IFSPs for all eligible children. However, at this point the reality is that not all States have achieved the requirements necessary to apply for fourth year funding. We believe the next 18 to 24 months will be particularly critical to the overall success of the program as States complete the planning process and attempt to secure the resources necessary to move into full service delivery. How successful they are in maximizing available resources and securing additional financial support will undoubtedly be affected to some degree by the budget problems they have unfortunately run up against.

Our recommendations which follow are based upon principles which have been articulated previously by the Subcommittee and which we believe will provide the support necessary for States' continued progress towards full implementation. First, to maximize the investments made to date and support the continued development of statewide comprehensive systems of early intervention in all States, it is important to institute measures that will enable States to continue in the program. States have made more than a good faith effort but, as described earlier, have encountered obstacles in implementing on schedule the large agenda set out for them in the statute.

Second, the program was originally designed to enable States to build upon existing policies and early intervention services unique to each State and to promote development of a statewide system that would be consistent with each State's service history and unique organizational and governance structures. A comprehensive system of early intervention was expected to look different from one State to another, for example in the definition of the eligible population as well as in service and finance configurations and agency participation. The experiences of States over the last four years confirm the critical importance of maintaining the flexibility necessary for States to fit program requirements to their special circumstances.

Third, it will be important to minimize changes in the statute that may further impede States' progress in reaching full implementation. Major policy changes at this critical point that place new obligations on States or substantially change existing requirements will make it difficult for States to sustain the momentum they have achieved and, for some, may erode support for continued participation in the program.

RECOMMENDATIONS

PART H PROGRAM FOR INFANTS AND TODDLERS

This section presents NASDSE's recommendations regarding Part H reauthorization. Whenever appropriate, we have addressed issues that have been raised and recommendations that have been made by others, such as the Council for Exceptional Children and its Division for Early Childhood, the Carolina Policy Studies Program, and State ICCs, and described in their own statements regarding reauthorization.

Differential Participation and Funding

Our recommendations for amendments that will permit, for a period of time, differential participation and funding are intended to enable all States to continue participation in the program, to support continued development and system enhancement efforts, and to provide differentially more funds to States which implement full services for infants and toddlers with disabilities.

(1) NASDSE strongly recommends that Part H be amended to allow those States which have not been able to meet the requirements of the fourth or fifth year applications, but have demonstrated good faith efforts, to continue participation in the Part H program until the program is again reauthorized (rather than for just two years). We further recommend that Part H be reauthorized during FY 1994, putting it the same schedule for reauthorization as Parts C through G of the Act. This additional time will enable States to continue efforts to plan for and gain support for full implementation. During

this additional time, States would be expected to complete the implementation of the minimum components of the statewide system, and to meet the application requirements for each year of participation. In their applications for funding, States should be required to document the progress made to date in the implementation of the required components of a statewide system, identify the barriers that have impeded their progress, and describe a plan and schedule for meeting the requirements for full implementation.

(2) If a period of differential participation is enacted, it will be imperative that States have the opportunity to submit applications as soon as possible in 1991 in order to facilitate continued activity under the program. For this to occur, application requirements would have to be based on the statutory language resulting from this reauthorization, as was the case when Part H was first enacted in 1986. This approach is necessitated by the lengthy period required to develop program regulations which could not be completed in time for the FY 1992 application process.

(3) Until all participating States have reached full implementation of Part H, NASDSE recommends that funds should continue to be allocated on the basis of census.

(4) We recommend that a substantially greater share of Part H appropriations should be allocated to States which are providing required services to infants and toddlers, consistent with application requirements governing a State's participation, during the period of differential participation. We concur in principle with the recommendations of DEC/CEC for the allocation of funds in FY 1992 and thereafter to States which have met fifth year application requirements after July 1, 1991, and to States not able to meet fourth or fifth year application requirements after that same date.

(5) Moving to an allocation of funds based on child count rather than census has strong support from many State directors of special education. However, we believe the complex arrangements and possibility of unforseen consequences of moving to a formula driven funding mechanism during the proposed period of differential participation weigh against such a shift at this time. As we have examined at what point in time such an approach should be implemented, several issues requiring careful consideration have emerged. During your deliberations, we strongly encourage the Subcommittee to avoid measures that would allocate funds to States based on an estimate of the number of infants and toddlers a State anticipates serving during the year. States' experience with the estimating procedures of several years ago under the bonus provisions of the Preschool Grant Program (i.e., funding in one year was based on State projections of the number of children to be served, then adjusted the next either up or down depending upon the accuracy of the original projections) seemed like a good idea at the time, but proved to be an administrative nightmare for the Department of Education, and State and local education agencies as well. We recommend that the issue of how to allocate Part H funds in the long term (e.g., on the basis of child count) be addressed, preferably, in the next reauthorization of Part H, during FY 1994, at which time all States have reached full implementation.

(6) NASDSE believes continued Congressional support of increased appropriations for the program as States move into full implementation is vital, particularly in recognition of the serious recessionary and budget conditions in the States. For FY 1991, Congress nearly doubled the appropriations for the Part H program. The support members of this Subcommittee and others in the House provided for this increase has been greatly appreciated by the States. This significant increase was important, both as a signal of Congressional commitment to assist States in achieving the goals of Part H and as a source of revenue to assist States in providing required services to infants and toddlers with disabilities.

Long Term Financing for Part H

As we suggested earlier in this statement, Part H represents a different vision from those of the past with respect to its requirements for interagency service delivery and coordinated funding across multiple sources. Reports from administrators from different State agencies involved in the implementation of Part H coupled with the findings of research by the CPSP indicate that some States will face a gap between available resources and the funds necessary to pay for services, even with significantly higher Federal financial support. It appears that States are having the most difficulty in assuring the necessary level of resources to finance Part H services. Further, achieving coordination across funding sources is not a simple process, nor one that is static (CPSP, 1991). The current approach for financing the system needs to be carefully studied over the next several years as States attempt to take full advantage of the multiple funding options available through private, State and Federal programs. NASDSE believes there is insufficient information available at this time to know whether the current approach to financing early intervention services or other approaches will be most successful in assuring full services for all infants and toddlers with disabilities.

(1) A Part H seminar sponsored by NASDSE in August, 1990 identified as one option to facilitate coordinated financing the need to specifically name in the Part H statute all relevant agencies governed by Federal law and to require them to maintain current programmatic and fiscal responsibility related to comprehensive systems of early intervention services. We recommend such an amendment be made. Further, we agree with the recommendations of DEC/CEC and others to assign to the State, rather than to the lead agency under Sec. 676(b)(9)(C), the responsibility for assigning fiscal responsibility among appropriate agencies that provide or support early intervention services. However, we are concerned that these actions may be insufficient for resolving the long term financing of the program.

(2) We strongly recommend that technical assistance be made available to States in the area of financing statewide systems of early intervention services for infants and toddlers with disabilities to enhance the ability of States to reach full implementation as soon as possible. The purpose of such assistance would be to provide expert help and support to

States in their on-going efforts to access and maintain the financing necessary to implement a statewide system. Assistance should be sufficient to assist individual States in addressing their specific needs as well as to develop resources that will be of use across States. Assistance could be provided through a variety of mechanisms, including consultation, information development, and topical meetings. Such technical assistance could include, but not be limited to, help in the design of analyses and models for projecting costs for different levels of services, and for different populations (including at-risk children), as well as in developing strategic plans for accessing needed resources available from State, Federal and local sources and from private insurance.

(3) NASDSE recommends that consideration be given to directing the Secretary of Education to conduct a study or studies to track and investigate issues related to program financing experienced by States as they approach and move beyond the fifth year of program implementation. Such inquiries should identify obstacles to fully funding statewide systems, most importantly those barriers resulting from policies in Federal programs, and determine whether and under what conditions adequate financing can be achieved. Coupled with the ICC annual reports, we believe this type of systematic inquiry, conducted over the period of time when States are moving into full implementation, would provide highly valuable information to Congress and the Department of Education for determining whether and what type of future actions or support are needed to assist States in effectively serving all infants and toddlers with disabilities.

Services to At-Risk Children

For a variety of reasons, it appears that approximately half the States have decided not to include at-risk children in their definition of eligible children under Part H (CPSP, 1991 Draft Report). In addition to issues related to developing operational definitions for this population, a major reason appears to be financial. Of primary concern to the States is, first, how they will finance full services to all infants and toddlers with disabilities. It is difficult to project the service costs for an unknown number but apparently growing population of children at-risk for having substantial developmental delays if early intervention services are not provided. However, it is clear that most States are, understandably, opting to limit the eligible population for the time being to youngsters with disabilities and focusing their efforts on getting in place the necessary fiscal arrangements before expanding the scope of the eligible population to include children who are at-risk.

(1) The potential for States to use Part H as one means of addressing issues associated with the prevention of later problems can, we believe, be strengthened by allowing States to provide a more limited set of services to at-risk children who are not included in eligibility definitions. We concur with the recommendation of DEC/CEC and others to permit States to conduct activities for the purpose of identifying, screening, tracking or

referring at-risk children. However, States should not be required to do so as this would constitute a major change in the program and, further, would jeopardize continued participation by States.

(2) The Education of the Handicapped Act Amendments of 1990 authorized the Secretary to support activities under the Handicapped Children's Early Education Program (Sec. 623) to improve the early identification of at-risk children and their transition from medical care to early intervention services and from early intervention services to preschool programs. At this time, NASDSE does not support the establishment of further priorities focusing on at-risk children within the Sec. 623 program. We believe that resources provided by this program should continue to be directed primarily at efforts focusing on children with disabilities as defined under the Act.

Technical Age of Three

(1) NASDSE strongly supports the position articulated in a letter to the Office of Special Education Programs from the Utah SEA (1990) that States should be allowed to determine the definition of the "technical" age of three. We believe amendments to the statute are required affirming States authority to do so in order to facilitate a child's transition from the Part H to the Sec. 619 preschool program and assure that services are not unnecessarily terminated or delayed. This approach would enable agencies and families to decide at what point transition from early intervention to preschool services is most appropriate.

(2) In order to provide flexibility to States in financing services during the period of transition around the age of three, Part H should be amended so that funds can be spent on services up to the technical age of three; similarly, Sec. 619 should be amended to permit use of funds on services down to the technical age of three. As necessary, States should be required in their applications for Part H and Sec. 619 funding to address how coordination between the programs for the purpose of transition is to be accomplished (e.g., through interagency agreements).

State Interagency Coordinating Council

The State ICCs are playing a critical advisory and leadership role in Part H implementation. In order to enhance ICC effectiveness over the next phase of implementation, NASDSE believes that certain changes in the statute are advisable.

(1) We concur with the recommendation of DEC/CEC, CPSP, some State ICCs and others that the current limit of 15 members on the ICC should be removed. For some States, this limit is too restrictive, resulting in key persons not being included in ICC

membership. To enable States to determine the appropriate size of the ICC, the statute should be amended to set 15 members as the minimum, thus allowing States the option to tailor ICC membership size to the particular circumstances of their State.

(2) We recommend that a representative of the SEA and the State health agency be required members of the ICC, subject as are all ICC members to the conflict of interest provisions detailed in CFR 303.604. We believe there would be greater potential for coordination within the State with representation of these key agencies required. Further, one of the parent members of the ICC should be the parent of a child with disabilities in the birth through six age range. We believe no other age limits on the children of other parent representatives should be specified in order to permit the Governor to identify qualified parent representatives who are knowledgable about early intervention service delivery. We do not believe additional statutory changes regarding ICC composition should be made so that States can retain the flexibility to design ICC composition to best meet their particular circumstances. However, we would support report language encouraging appropriate proportional representation by parents when the ICC membership exceeds the 15 person minimum.

(3) NASDSE recommends that the ICC be required to address the transition issues between the Part H and preschool special education program. Further, to enhance planning for children from birth through age five, we support the DEC/CEC recommendation that the ICC advisory functions (under Sec. 682(e)), at State discretion, address planning for services for children from birth through age five. In some States, such as Illinois and Oregon, the ICC advises on services for children birth through age five. Alternatively, States may want to have overlapping membership on their ICC and State Advisory Council under Part B to facilitate birth through five planning efforts.

(4) We agree with the CEC/DEC recommendation that compensation be provided to parent representatives on the ICC for time and allowable costs associated with their membership. NASDSE believes it is particularly important to recognize the support that may be necessary in order to enable parents to carry out their responsibilities as ICC members. We would also support report language recommending that, whenever possible, resources necessary to facilitate parental participation on the ICC should be made available in such a manner that minimizes the need for parent members to finance their participation from their personal resources and be later reimbursed.

Federal Interagency Coordinating Council

NASDSE believes that improvements in Federal coordination of programs authorizing services for infants and toddlers with disabilities and their families need to be achieved in order to facilitate States' efforts to fully implement Part H. Further, we view the Federal Interagency Coordinating Council as having the potential to contribute to such improvements.

(1) NASDSE members support an amendment that would require in statute the Federal Interagency Coordinating Council (FICC). We also concur with the DEC/CEC recommendation regarding FICC membership, with adequate staff and resources for its activities to be provided by the participating programs or through some other appropriate means.

(2) We envision the FICC role to be largely advisory, rather than coordinative, in nature. In the absence of complementary requirements on the full range of Federal programs regarding support and services for early intervention, we believe the FICC ability to act as a coordinator of Federal policies and activities will be highly limited. The goal of FICC efforts should be to facilitate achieving coordination across Federal policy and programs to enhance the delivery of services to infants and toddlers with disabilities and their families by the States. The major responsibilities of the FICC should, then, be (a) to review relevant policy and programs across Federal agencies (e.g., in such areas as technical assistance, eligibility, interagency agreements, financing, etc.); (b) to review State ICC annual reports and identify issues relevant to Federal policy and programs; (c) make recommendations to Federal agencies to improve collaborative and effective programming at the Federal level and to eliminate interagency barriers; and (d) report to Congress on issues which require statutory consideration.

(3) We agree with the DEC/CEC recommendation that the statute require a policy analysis be conducted of other relevant Federal programs to determine areas of conflict and overlap with Part H, so that necessary coordination might occur at the Federal level. Such a study should examine the purpose and goals of these programs as well as their policies and procedures. We believe such study should be conducted by the U.S. Department of Education as the program's administering agency (see recommendation under Long Term Financing of Part H).

Early Intervention Services

Expanding the list of early intervention services included in the Part H statute has been recommended by various organizations providing input to this reauthorization process. NASDSE views the listing of early intervention services in the law as necessarily less than exhaustive. In other words, services other than those listed at Sec. 672(2)(E) can be considered early intervention services by the States (e.g., vision services and transporation are named in regulations but not in statute) as appropriate to the needs of infants, toddlers and their families and identified through the assessment process. NASDSE, therefore, does not believe a statutory change is required to assure that needed services are provided to infants, toddlers and their families.

Other Recommendations Related to Part H

(1) DEC/CEC, CCD and others have recommended several additional changes we want to comment on here. We fully support their recommendations that would substitute in the statute certain terminology that represents the preferred usage of service consumers and providers. Specifically, we concur with the recommendations for revising language related to IFSPs (i.e., substituting "families' concerns, priorities, and resources" for "families' strengths and needs"); case management (i.e., substituting "service coordination" for "case management"); and developmental domains under the definition of "developmental delay" (i.e., substituting "communication development" for "language and speech development," substituting "social/emotional development" for "psychosocial," and substituting "adaptive development" for "self help skills").

(2) NASDSE concurs with the DEC/CEC and CCD recommendations for other changes related to case management (e.g., service coordination means case management for purposes of Medicaid or other billing for services; elimination of terminology "from the profession most immediately relevant to the infant's and toddler's or family's needs").

PART B STATE GRANT PROGRAM AND SEC. 619 PRESCHOOL GRANT PROGRAM

When Part H was passed, Congress recognized that special efforts would be needed to assist young children make the transition from early intervention services to preschool special education programs around the age of three years. One of the recommendations for changes in the IDEA that would facilitate transition between Part H and Part B programs, addressed earlier in this statement, concerns the "technical" age of three. This section of our statement addresses issues that have been raised to further facilitate children's transition, and to effect a more comprehensive approach in services to children from birth through the preschool years.

Developmental Delay

A growing number of States have elected to permit the use of alternative or non-categorical terminology for the identification of preschool age children with disabilities under the Part B program. The purpose of such an approach is to more appropriately reflect the special developmental characteristics of young children, and, in some cases, to minimize the practice of assigning to children particular disability labels. At present, it appears that over one-half of the States employ such alternative terminology, most often as an adjunct or supplement to the categories of disability included in the Part B regulations at CFR 300.5. Among the terms States use are "significant developmental delay" and "pre-primary disabled." In taking such actions, States have neither restricted nor expanded the population eligible for Part B services as defined in the IDEA.

NASDSE believes that sufficient latitude exists in the statute for States to employ alternative, developmentally appropriate terminology and approaches for the identification of preschool age youngsters under Part B. However, we are also aware that some States will not do so because they believe the IDEA restricts such actions and/or because of concern they may later be found out of compliance or be subject to audit exceptions because their approach for determining the eligibility of these children appears to differ in some respects from their approach to children at later stages of development. This should not be a concern where States have conducted the study and analysis necessary to assure that children identified under Part B through such an approach represent the same children intended to be identified under the categorical definitions of the regulations. Models for such study exist in a number of States. In the 1986 amendments to the Education of the Handicapped, Congress lifted the requirement that States report preschool age children served under Part B according to disability category. That action now appears to have been insufficient to provide support to States that wish to take what they might consider to be a more developmentally appropriate approach for the identification of preschool age children with significant development delays. To ensure that States which desire to employ alternative terminology, including developmentally appropriate criteria, for determining eligibility for preschool special education services may do so, NASDSE believes that Part B of the IDEA should be amended to give States the authority to utilize the category "developmental delay" (as defined in Part H) for children in the three through five age group only. Use of such a category should be optional for States, and they should be permitted to develop eligibility criteria which are developmentally appropriate for children in the three through five age group.

Definition of Related Services for Children Ages 3-5 Years

It has been recommended that the definition of related services under Part B be amended to include "service coordination" (or case management services) and "family services" for children ages three through five if they are needed for the child to fully benefit from the preschool program.

(1) With regard to service coordination, NASDSE believes that the activities to coordinate services provided to children ages three through five can already be provided under Part B to all children, ages three through 21, under the regulatory definition of "social work services" (CFR 300.13(b)(11)). This definition authorizes such services as "group and family counseling with the child and family; working with those problems in a child's living situation (home, school, and community) that affect the child's adjustment to school; and mobilizing school and community resources to enable the child to recieve maximum benefit from his or her educational program."

We understand that some preschool age children with disabilities may require and receive services that are beyond the school program and not part of the IEP, and that in some cases coordination of such services with those provided by the schools would be desirable. However, while schools have the responsibility to coordinate the services included in a child's IEP, schools do not have the authority to coordinate the services of other agencies that are not part of the child's IEP. While we do not at this time recommend amending Part B to include as a related service "service coordination," we are interested in exploring ways in which coordinative activities which would enhance children's participation in preschool programs might be addressed.

(2) Regarding the proposal to include "family services" as a Part B related service for children ages three through five, we believe that Part B already authorizes certain types of services (e.g., home visits, social work and counseling) for the families of children with disabilities served under the program. In addition to services specifically named in the law, a wide variety of parent and family support services and initiatives are also being provided at the local level through the schools. Further, we are concerned that family services which appropriately are provided by agencies other than education (e.g., social services and health) should not be made a school responsibility. Here again, we are interested in exploring ways in which the child's program can be enhanced through services for parents or families, and whether statutory revisions are appropriate. At a minimum, NASDSE would support report language regarding the importance of designing and providing appropriate opportunities in the schools for meaningful parent involvement that contribute to the effectiveness of the educational program for all children with disabilities, with particular emphasis on the special considerations to be given to such involvement as children transition from early intervention programs and during their preschool years.

IFSPs as IEPs

It has been recommended by DEC/CEC that States be encouraged, but not required, to use Individualized Family Service Plans (IFSPs) instead of Individualized Education Programs (IEPs) for children with disabilities in the three through five age group. NASDSE believes the flexibility to do so already exists in the law. In fact, some States, such as Minnesota and Maine, are now proposing to use IFSPs for children from birth to age six. NASDSE believes report language discussing the reasons for States to consider this approach might be considered.

ICC Responsibility for Meeting SAC Requirements for Children 3-5

The DEC/CEC have recommended that IDEA be amended to permit the ICC, at State discretion, to meet the requirements of a State advisory council under Part B for children ages three through five, in order to facilitate planning for children with disabilities from birth. NASDSE supports this recommendation in order to permit States to use this approach as one means of facilitating comprehensive and coordinated planning for children with disabilities from birth through age five. In some States, the State advisory council already advises on matters pertaining to children from birth through 21, and, as noted earlier in this statement, in some States the ICC already advises on children from birth through five. Because the SEA is responsible for children with disabilities for children from age three through 21, it is important that this approach be at State discretion, and not required for all States.

Sec. 619 Funding

(1) NASDSE believes there is continued need for differential support for three through five year old year children under Part B. This is because of the relatively higher program costs associated with services to this age group and the scarcity of preschool programs for nondisabled children with which schools can share certain program overhead costs to achieve economies in service provision. The per child allocation under the Part B, Sec. 619 preschool grant program appropriation is nearing the $1000 limit currently in statute. NASDSE recommends that the cap on the per child allocation under Sec. 619 be raised to $1500, to enable funding under this program to rise over the next several years.

(2) In order to facilitate transition of children from the Part H program to preschool services under Part B and consistent with the recommendation earlier in this statement regarding the "technical" age of three, NASDSE recommends that Sec. 619 be amended to assure tht States are able to fund services to children starting at the "technical" age of three.

Concluding Comments

We appreciate the opportunity to provide input to you on the reauthorization of this important program. Over the next months, please feel free to call on NASDSE for information you may require to assist in your considerations regarding the early intervention program.

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Chairman OWENS. Thank you very much.

We are going to break the order a little bit here because Mr. Ballenger has to catch a plane. I would like to have Mr. McWilliams go next.

Mr. McWilliams.

Mr. MCWILLIAMS. Thank you, Mr. Chairman. Thank you for this opportunity and thank you, Mr. Ballenger, for flattering me enough to want to stay to hear my part.

I would like to recognize Mr. Ballenger and his wife, Donna, who have done a lot for the well-being of children in North Carolina for many, many years.

I come from an institution that has a veritable troika of institutions that are involved with this legislation; the Carolina Institute for Research on Infant Personnel Preparation, which is the main topic I will cover today; Dr. Gallagher's Policy Studies Program, and the headquarters of National Early Childhood Technical Assistance system, which as you know is funded through Public Law 99-457.

My primary comments are on personnel preparation. You already have my written testimony, so I will simply highlight some particular areas of concern.

The concerns are in the areas of shortages, inadequacies in preservice training, some content areas that still need attention, and the need for inservice opportunities.

I am delighted to see that most of my colleagues are more eloquent than I am on these needs and preservice, and that is because they are older than me.

But the shortage issue is of paramount concern. The dilemma that we are faced with is an apparent conflict between trying to get enough people to serve the infants, toddlers and preschoolers with disabilities and their families and making sure that the people that we get are well enough trained.

In many areas, in many disciplines, special education, speech and language pathology, occupational therapy, physical therapy and so on, we are adopting people who are trained to work with school aged children, and hiring them to work in our early intervention and preschool programs.

I think that you have heard that there is a good argument for making the preschool services more like the infant and toddler services and the applicability in terms of how we train personnel would be quite obvious, in that people who are trained to work with school age children are not necessarily equipped to work with infants, toddlers and preschoolers and their families.

So we do, however, need to have enough people in the programs, and we are anticipating shortages in all of the major disciplines that are related to this law, some very, very severe shortages indeed.

Numbers are hard to predict, but we are talking about thousands of professionals that aren't going to be available but needed by the year 2000 and even projecting only the next five years.

There simply are not going to be enough people. Related to that are some inadequacies in preservice training; that is, training at the university level.

About half of the schools of education in this country do not have any early childhood special education programs, and that is only talking about one of the ten disciplines involved in this law.

And when, in our research and other people's research we have asked people, how much would you add to your existing programs for training on how to work with infants and toddlers and families, they say, we might be able to squeeze in one lecture, or we can add three to six clock hours of instruction. Surely, that is not going to train people enough.

The other problem with preservice training is that it is weak on training to work with infants and in family-centered approaches to early intervention.

The content areas I have just mentioned—family issues, and working with professionals from other disciplines—are generally not well enough attended to in the preservice or inservice programs for that matter, and that is an essential component of this legislation.

It is one of the major strengths, is that we are charged to serve these families by collaborating amongst disciplines, but university programs generally are not structured to really facilitate that. They need incentives to have more interdisciplinary training programs.

The good news is that since Public Law 99-457 came out, a number of universities have really developed some very nice models for it. We just need more of it.

And then the need for inservice opportunities. If we are going to be taking on people who are already trained in their professions, and we need to make sure that they have the specific skills and strategies and techniques for working with very, very young children and their families, they are going to need a lot of that training through inservice training.

And I have in my written testimony a number of quite specific recommendations that I would respectfully ask you to consider as you make your decisions. All in all, I think that we have operated on the principles that any professional is better than no professional, and that may have to be the case for a while.

But I would like to suggest that you put the States, the professional associations who are very important in this, and the university systems, on notice that this situation will not be able to go on indefinitely.

At some point in the future, we need to have standards that specify what it takes to work well with this population, and through this law.

And you might want to consider a study commission or task force that is charged with looking at personnel preparations, standards and shortages, because there is this conflict right now, and States definitely need help with this.

Some additional comments that I would like to make are to support the idea of differential funding, because that is very much related to the time that is needed to prepare people.

The concept of adding developmental delay to the preschool categories, which I believe might be mentioned some more, and Section 619 Part B needs to be rewritten to be more compatible with Part H.

I know, Mr. Chairman you would like people to end on a good, positive note, and I will say that when I was trained beginning 15 years ago, I was trained t^ do things, really I was trained wrong, and people are being trained right now.

People are being trained to do the kinds of things that Dr. Odom and Dr. McNulty have recommended; the modern approach to early intervention, if you will. So, on behalf of all of us who are working to ensure that there are enough people working in early intervention and trying to work on making sure that they are well enough trained, I do thank you for this opportunity and respectfully ask you to consider the recommendations.

[The prepared statement of Robin McWilliams follows:]

STATEMENT TO THE
SUBCOMMITTEE ON SELECT EDUCATION
OF THE
UNITED STATES HOUSE
COMMITTEE ON LABOR AND EDUCATION

WITH RESPECT TO REAUTHORIZATION OF THE
EARLY INTERVENTION PROGRAM (PART H)
AND THE
PRESCHOOL PROGRAM (PART B, SECTION 619)
OF THE
INDIVIDUALS WITH DISABILITIES EDUCATION ACT

APRIL 12, 1991

By R. A. McWilliam

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STATEMENT BY

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The success of young children with disabilities and their families is largely contingent on the quality of services they receive, and the quality of services is largely contingent on the caliber of the personnel working in this area. There appears to be somewhat of a discrepancy between the goals of quickly ensuring enough personnel and ensuring their excellence. For example, in order to meet the numeric demands in early intervention, many programs are hiring professionals who are only trained to work with children *over* the age of five. Because of the chronic shortages of personnel in early intervention, most of my recommendations are for Federal-level encouragement and support rather than regulatory policy. The stricter the requirements, the fewer people will be available to serve the children and their families. As the supply of personnel increases, however, Congress, the Office of Special Education Programs, and states should develop policies regarding the amount and quality of training of professionals from all disciplines relative to working with infants, toddlers, and preschoolers with disabilities and their families. *Although it is too early to impose regulations that will curtail the number of professionals available to work in this area, Congress should put training programs, professional associations, and states on notice that these safeguards will be put in place, perhaps by 1996.*

A major policy decision will need to be made regarding the authority source (i.e., Congress, OSEP, professional associations, states) for improved standards. The existing research shows that neither professional organizations with licensure power nor state licensing boards are likely to adopt early intervention standards. *A Study Commission on Personnel Preparation, Standards, and Shortages should be formed.* The tasks of this commission would be (a) to recommend policy direction, including the question of authority source, (b) to recommend hiring or licensure standards in early intervention for all disciplines listed in PL 99-457, (c) to determine the personnel to which these standards would apply (e.g., those working over half-time in early intervention; those paid through PL 99-457), (d) to recommend curricular content and methods for preservice and inservice training, and (e) to recommend recruitment processes (e.g., lateral entry programs, high school recruitment) that would address shortages. The overall charge of the commission would be to improve standards without compromising the number of personnel available. The commission would need to include representatives of each of the professional organizations, Federal and state policy-makers, consumer parents, academics, and researchers. It would have the work of two current Federally funded institutes at the University of North Carolina on which to draw, the Carolina Institute for Research on Infant Personnel Preparation and the Carolina Policy Studies Program. The commission should conclude its work by 1996, but Congress should act now to support what we already know can improve the preparation of early intervention personnel. In order to act now, Congress should be aware of the current and anticipated shortages, inadequacies in preservice training, content areas needing attention, and the need for inservice opportunities.

Shortages

The current and anticipated demand for trained professionals by far exceeds personnel now available or projected to be available by the year 2000. Speech and language pathologists, occupational therapists, and physical therapists are in particularly short supply[1]. Exact numbers are impossible to determine because of (a) different service delivery models, (b) unknown numbers of projected eligible children, (c) professionals' working only part-time with infants, toddlers, or preschoolers, and (d) calculation models based on a range from current vacancies to full implementation of best practice.

The average number of students graduating each year from schools of education offering programs in early childhood special education have been reported from 9 undergraduates, 5 masters level students, and less than one doctoral student[2] to 21 undergraduates and 36 masters level students[3].

The staff attrition rate of the early intervention staff in North Carolina was estimated to be 19% per year[4].

Severe shortages of personnel with proficiency in working with infants and families have been projected[5]. Eighty-one percent of the states anticipate shortages in the Part H program, and 65% anticipate shortages in the Section 619 program.

Opportunities for OSEP grant support for personnel training under Part D have diminished. only 20 out of 165 projects announced this year w for Training in infant, toddler, and preschool intervention, accounting for only 1.5 o e 13 million dollars allocated.

Recommendations

1. As recommended by the Carolina Policy Studies Program, set aside 5-10% of Part H funds for each state to develop a coordinated and comprehensive system of personnel development or reserve Office of Special Education Programs funds for states needing help in developing its comprehensive system.
2. Encourage and support training in consultant and transdisciplinary service delivery models.
3. Subsidize students and training programs.
4. Encourage professional associations to set standards for working with infants, toddlers, and preschoolers.
5. Encourage higher education institutions to plan comprehensive and coordinated training programs.
6. Support a major recruitment effort, including the establishment of a national job bank.
7. Support continuous inservice efforts in response to the staff turnover rate.
8. Encourage and support states' establishment of career ladder opportunities for different levels of personnel.

9. Expand the early intervention and preschool competition for training personnel for the Individuals with Disabilities Education Act (formerly EHA), Part D. Applicants should not be excluded from other appropriate priorities. The early intervention and preschool competition should have clearly stated priorities and OSEP leadership.

Inadequacies in Preservice Training

Over half the respondents to a survey of schools of education reported no existing program in early childhood special education[2].

Typical special education students receive little exposure to information about working with infants with disabilities and their families, and these programs indicate they are only likely to add either a 1-hour lecture or 3-6 clock hours of instruction[5].

The average student in eight of the early intervention disciplines receives little specialized information--practical knowledge--relative to infancy or working with families[6].

University training programs and state licensing boards tend not to exceed the requirements of the professionals organizations' licensure criteria. Only one professional organization, the Division for Early Childhood of CEC, which does not have licensure power, has recommended standards for the early intervention professional (early childhood special educator). Five organizations (American Nurses Association, American Occupational Therapy Association, American Physical Therapy Association, American Speech Language and Hearing Association, National Association of Social Workers) have developed or are in the process of developing nonbinding guidelines for working with infants and toddlers. Four associations (American Dietetic Association, American Psychological Association, Council on Social Work Education, National Association of School Psychologists) are not adding any infant and family requirements or guidelines[7].

Recommendations

1. Support universities' efforts to increase enrollments and establish undergraduate programs.
2. Encourage and support training programs to provide students with exposure to real programs and to use reality-based training methods (e.g., case method of instruction).
3. Encourage and support faculty training opportunities.
4. Encourage and support professional organizations to develop standards for working with children 0-5 years of age and their families.
5. Fund the dissemination and replication of model training programs and research institutes on personnel preparation.
6. Add statutory language to the role of the Federal Interagency Coordinating Council, making it responsible for coordination of national preservice opportunities.
7. Encourage states to use ICCs to coordinate state preservice efforts.

Content Areas Needing Attention

Training is needed in **family issues, IFSP development and implementation,** and **service coordination** (case management)[6].

Not enough students are trained adequately in **working with infants** or with families[3,6].

Training is needed in **working with personnel from other disciplines,** including regular early childhood education or child development[5].

Training is needed in using **"best practices"** as identified by research and model demonstration. In addition to the content areas listed above, both preservice and inservice trainees need more training in such areas as instructional methods, environmental arrangements, working in diverse settings, cultural diversity and sensitivity, program management, classroom organization, integrated (nondisciplinary) programming, and data collection.

Recommendations

1. Encourage and support targeted training (preservice, inservice, technical assistance) in the content areas listed above.
2. Encourage and support practical training in working with families and with other professionals from other disciplines.
3. Encourage and support model demonstration sites to be used for training in the family-centered approach.
4. Encourage and support interdisciplinary training in the universities, both among the disciplines listed in PL 99-457 and including regular education/early childhood.
5. Include families in the planning, delivery, and evaluation of training.
6. Encourage and support training in legislative mandates relative to early intervention and in available services; when appropriate, this training should be coordinated with states' public awareness efforts.

The Need for Inservice Opportunities

Many professionals entering the field of early intervention are already trained in their profession to work with older children.

Some of the most effective training methods are those that can be provided on the job.

In many instances, university programs will provide only basic (nonspecialized) training[6].

Experts in personnel preparation have consistently noted the need for a priority on inservice training[6].

Some professional associations (e.g., DEC, AOTA, ASLHA) have developed extensive inservice opportunities in early intervention.

Recommendations

1. Make inservice training, including outreach projects, a priority for OSEP funds.
2. (a) Encourage and support interdisciplinary training (including regular education/child development), and (b) include the professional associations (including regular education associations, the National Association for the Education of Young Children, etc.).
3. Encourage and support inservice programs that incorporate adult learning principles and effective training practices (needs assessment, planning with trainees, multiple contacts between trainers and trainees, efficacy data collection, etc.).
4. Encourage and support the inclusion of families in the planning, delivery, and evaluation of inservice training.
5. Encourage and support the use of team-based training to reduce administrative barriers to implementation of the training content and increase ownership and endorsement.
6. Give funding priority to training projects that have developed their procedures and materials under Federal support. through model demonstration projects, outreach projects, inservice projects, research projects, and research institutes.
7. Fund dissemination and replication activities as extensions of model demonstration projects, outreach projects, inservice projects, research projects, and research institutes.
8. Add statutory language to the role of the Federal Interagency Coordinating Council, making it responsible for coordination of national inservice opportunities.
9. Encourage states to coordinate inservice efforts through the ICCs.

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Chairman OWENS. Thank you. Mr. Ballenger.

Mr. BALLENGER. Mr. Chairman, I am happy to see Mr. McWilliams here and hear Dr. McNulty, and I am very embarrassed to say I will not hear the next two gentlemen.

There is an airplane waiting. I have to go. I greatly appreciate what you are saying. I am quite sure our Chairman will listen and advise me what other knowledge we may have picked up for the rest of the day.

Chairman OWENS. Thank you, Mr. Ballenger.

We will continue now with Mr. George Jesien.

Mr. JESIEN. Thank you, Chairman Owens. I would like to thank you also for the pleasure and opportunity of being here and making comments on the reauthorization of Public Law 99-457. I would also like to take this opportunity to thank you and this committee for the leadership and the attention they have paid to infants and toddlers with special needs and their families across the country.

I am here representing the Division for Early Childhood, an organization of 7,000 members, who are dedicated to the provision of the highest quality of services to young children and families.

The written testimony which you have is also endorsed by the International Council for Exceptional Children, an organization of approximately 60,000 members throughout the United States. We have worked very closely with International CEC in the development of our recommendations that I will be talking about this morning.

What I would like to do is three things: Make some general comments on some of the outcome of this law; two, highlight some of the recommendations you have before you; and three, close with some comments as a father and as a person who has been involved in early intervention for close to 17 years.

DEC and its 7,000 members see Public Law 99-457 as a historical marker which has put us on a new path in terms of the way we conceive and design and plan services for families.

Public Law 99-457. in fact, is a promise to families across this country. The way you deal with the reauthorization will determine when this promise is fulfilled or when it is regrettably, as in previous promises, not quite met as they come down to full implementation.

Public Law 99-457 has the promise of not only opening up access for parents to the system, but in fact, making them integral to the planning, the design, and the implementation of—truly establishing a partnership of equals of parents and professionals of community planners and State government bureaucrats—what is needed for their young children and their family.

This committee, I am sure, knows there are parents, service providers and State officials across this country that with great expectation are looking forward to the work of this committee and the Senate in the reauthorization of Public Law 99-457.

Much has already been accomplished. Let me give you a couple of examples. In Ohio, for example, 88 counties in the State have now developed local inner-agency coordinating councils that meet on a regular basis that include parents, professionals from a wide array of disciplines, and State and local government people to discuss how they can improve the system to more adequately meet the needs of children and families.

I think paraphrasing Winston Churchill here is appropriate, Never have so many done so much with so little in these counties in Ohio.

A recent meeting had over 140 individuals meeting to talk in a local office on how they can better serve young children and families.

Another example is in my State of Wisconsin where faculty from each of the 10 disciplines and from the 16 State campuses of the University of Wisconsin system met with parents to talk about the needs of new and future professionals in terms of adequately meeting the needs of young children and families.

In our State, this was the first time that not only did the disciplines get together to talk to each other, but included parents as both participants and lecturers in the discussion of what early intervention needs to look like in the next decade and into the next century.

With this law, I believe Congress has harnessed some of the fundamental resources in this country. You have harnessed the resources of the family, of local communities, and the daily workers that work with young children and families throughout this country.

This law has given them a chance and empowered them to work together in trying to make the system work to adequately address the needs of young children and their families.

Let me move on to some of the recommendations that DEC has developed, working with its own members and with other organizations for the reauthorization.

DEC is very proud of these recommendations because we feel that they reflect a broad base of input from principal stakeholders in early intervention across the country.

DEC held a series of regional hearings conducted across the country. Over 140 individuals provided testimony from 29 States. Participants included parents, service providers, program managers and State level lead agency personnel. Our full set of recommendations are before you. Let me highlight some of them.

First—and it has been mentioned frequently this morning—the concept of differential funding. Each State has its own history of services; each State is in a different place in terms of its capacity to provide full coordinated family-focused services. The law, I think, needs to recognize those differences and allow that some States will need more time to move into full implementation.

Second, States need incentives and encouragement for them to plan across the age range of birth through five.

The division of services in birth to three and three to five was more the result of historical dissent and political expediency, rather than clinical best practice or research that tells us we need to divide up services by those ages.

Third, at-risk children and families.

We have under Public Law 99-457 a significant opportunity to serve some of the most vulnerable children and families in our country. As Dr. Gallagher stated earlier, many States initially indicated a great deal of interest in serving these children and families.

Right now, as we see future year applications coming in, a very small handful of States have maintained that interest from a legal perspective. States have actually stepped back from this commitment worried about the entitlement issues and the unknown costs for serving this population.

DEC recommends that States be allowed to use their Part H dollars to at least identify, screen, and track at-risk children, even if they are not named within their eligible criteria.

Secondly, DEC recommends that States be offered flexible incentives and encouragement to serve at-risk children and their families.

The family-focused, coordinated services that are provided for in Part H may in fact provide all of us the best model for services to these families and children, and we encourage this committee to study ways in which Part H may directly apply to at-risk families.

The one caution that we would suggest is in order to do this, States will need flexibility and encouragement.

Next, that States be allowed to define the technical age of three, allowing Part B dollars to serve children before they are three and Part H dollars to serve children older than three, so that families and children experience no cessation of services and have the possibilities of a smooth transition into their next program.

DEC has also been working with Section 619 provisions for preschool programs in Part B. As you know, most States have merely extended Part B provisions for children down to age of three. Part H, on the other hand, embodies some of the latest research practice and thinking in best practice for serving young children and families.

DEC recommends that the provisions of Part H at least be allowed to be reflected in Part B or at least to remove any obstacles for States which would wish to include Part H provisions within their Section 619 programs.

Accordingly, DEC recommends that States be allowed to use the category of developmental delay within their three to five program.

Adding this category will not increase the total number of children served, but rather will recognize the differences associated with diagnosis and labeling children at such an early age.

To facilitate this, we have presented to the committee some additional information on developmental delay questions and answers and I respectfully request that additional information to be entered into the record.

Secondly, allow States to provide case management or as we have suggested, service coordination as a related service for three to five year olds.

Also, to allow children or to allow States to provide family services if the child needs those services to benefit from the preschool program.

And, lastly, to encourage States to use the individualized family service plan in lieu of the individualized educational plan for children three to five.

These recommendations are made in the spirit of recognizing that the needs of a four year old are much more akin to those of a two year old than those of a middle or secondary student who may be in special education.

These recommendations will allow States or assist the States in recognizing those similarities.

Lastly, I would like to move to some of our recommendations on the overall system. First, that the FICC and its existence be placed in statute and that the necessary resources be provided to the Federal inner-agency coordinating council so that it may serve as a model and do the necessary coordination in technical assistance and training to the States.

Secondly—and this topic has been mentioned frequently—is the personal preparation needs within this country; that sufficient resources be provided to train the necessary new professionals that we will need in the field to allow for the retraining of those professionals already in the field.

And, thirdly, to encourage the infusion of those from culturally-diversified backgrounds into the field so that the clients—that the partnership between those we serve and those providing services can more easily occur.

Lastly, as you move through the authorization process, we are asking in this law for providers to work collaboratively with families, to identify their strengths, their concerns, their priorities and resources, to enable and empower families.

We ask that as you reauthor this law, you use this same model in working with States; that we provide States models at the Federal level of inner-agency coordination; that we ask States to identify their resources, their priorities and concerns, and that we enable and empower States to meet the needs of the families within their boundaries.

As a father of a six year old and a four year old, my daughter came into the world about six months old through an emergency Cesarean. I saw her come into this world not breathing and weighing two pounds, 12 ounces. She stayed in the hospital for eight weeks before she came home, and this gave me a glimpse of some of the challenges that families face on a daily basis across this country. This law has the potential for truly addressing those challenges for families now and well into the future.

I applaud and DEC applauds the work of this committee and encourages it to continue so someday we might look on the 1990s as the decade that began our true placement of families in a high priority within this country.

We do not skimp on Defense. We do not skimp on our savings and loan industry; let us not skimp on the families in this country.

Thank you and DEC looks forward to working with this committee in its future work in the reauthorization of this bill.

[The prepared statement of George Jesien follows:]

STATEMENT TO THE
HOUSE OF REPRESENTATIVES
SUBCOMMITTEE ON SELECT EDUCATION

WITH RESPECT TO
REAUTHORIZATION OF PART H
AND
AMENDMENTS TO PART B
OF THE
INDIVIDUALS WITH DISABILITIES EDUCATION ACT
REGARDING SERVICES TO CHILDREN
FROM BIRTH TO AGE SIX YEARS AND THEIR FAMILIES

APRIL 12, 1991

From the International Division for Early Childhood
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and
Endorsed by the Council for Exceptional Children

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INTRODUCTION

In September, 1990, DEC issued a set of recommendations regarding Part H and Part B to facilitate discussion in the field prior to reauthorization activities in the Congress. As hoped, the document generated widespread comment and consensus building. Based upon the response to the September recommendations, DEC has refined some of the original options. These include:

- Amendment recommendation #1: combines the ideas originally formatted as the first two recommendations and now refers to "differential participation and funding" and suggests that while differential participation is needed for states, it is premature to change the funding formula, i.e., census-based, to some other, i.e., child-count. However, DEC is recommending that the Department of Education study what formula is most appropriate for full service.

- Amendment recommendation #2: maintains the goal of facilitating birth-5 planning and services to at-risk children but through different mechanisms than originally proposed. Based upon comments received, DEC is now recommending that the planning responsibility for ICCs include birth-5 system planning. We received much comment about needing to do more than just "encourage" birth-5 activities. The current fragmented system (birth-2, 3-5) is causing a great deal of confusion at the local level and for parents.

  Secondly, we are recommending that Part C - the Handicapped Children's Early Education Program - be the vehicle for further study and incentives for serving at-risk populations, just as it has been related to services for children with disabilities for over 20 years. However, we are also recommending that, at state discretion, Part H funds be allowed to be used for identifying, screening and tracking at-risk infants/toddlers even if they are not "eligible" for early intervention services.

- Amendment #3: has been expanded to recommend flexibility in the use of Part H and Part B funds as it relates to states' "technical" age of three policies.

Other than these refinements, the document stands as it did in September because of the widespread support of the original recommendations.

The Division for Early Childhood and its 7,000 members nationwide represent a rich and unique source of information and expertise in early intervention and preschool services for children with special needs and their families. We trust these recommendations will be helpful during the reauthorization process. Please contact us if we can be of any further assistance in this important endeavor.

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DIVISION FOR EARLY CHILDHOOD STATEMENT and RECOMMENDATIONS

In 1986, Congress passed P.L. 99-457, The Education of the Handicapped Act Amendments of 1986. Through amendments to Part B and the establishment of a new Part H of the Act, the Congress dramatically advanced nationwide efforts to provide appropriate services to infants, toddlers, and preschoolers with special needs and their families. The Division for Early Childhood (DEC) worked closely with the Congress in the development of this landmark legislation and has been involved with state and local efforts in its implementation through our 7,000 members nationwide. Every state has expanded or improved services to eligible preschoolers under Part B and has engaged in new or expanded planning and service provision for eligible infants and toddlers under Part H. Now, a full four years of implementation later, families, professionals, communities and states express their support for the mission of P.L. 99-457 but now based on experience offer many recommendations for improvements to both Part B and Part H in order to fully realize that mission.

From October, 1989 to April, 1990, the Division for Early Childhood sponsored hearings on recommendations for improving Part H and Part B services for very young children and their families. These hearings resulted in testimonies from 122 people from 29 states. This endeavor produced an enormous amount of information and expert recommendations. This rich resource has been summarized by the Division and has served as a basis from which to develop our own recommendations for amendments to Part H and Part B. Supplementing the national testimonies, the Division has drawn on its experiences of the past 20 years in state and federal policy development in early intervention and preschool services as well as the wealth of research findings on best practice and quality services for young children and their families.

With the benefit of these unique resources, we feel the following recommendations represent informed, practical and necessary adjustments to the current federal efforts. As the largest membership organization in the country dedicated solely to the provision of quality services to young children with special needs and their families, DEC is in a unique position to offer recommendations. Our 7,000 members are parents, direct service providers, researchers, personnel trainers, policy makers and administrators. Our conclusions and recommendations are balanced as well as progressive. Our goal is to advance the quantity and quality of current efforts while recognizing the enormous task facing states and localities as they attempt to engage in widespread, interagency planning and provide high quality and effective early intervention and preschool services to all eligible children and families. 1991 and 1992 represent hallmark years for these programs, children and families because if states choose to continue to participate in these federal programs, they will have to ensure that they are making appropriate services available to all eligible children, birth to age six. DEC's recommendations are focused on: 1) providing the necessary support and incentives so that all states will continue to participate in Part H and Part B, 2) amending current provisions of both programs based upon four years of experiences in order to ensure that services are in fact provided and that those services are of high quality and appropriate to individual needs, 3) clarifying current provisions to ensure nationwide uniformity in implementation where appropriate, and 4) providing guidance in the way federal training and technical assistance should be delivered to ensure the advancement of the Part H and Part B missions as well as best practices for services for children and families. Therefore, our recommendations are grouped in the following categories:

- Statutory Amendments
  - Part H
  - Part B

- Clarifying Language - no statutory change
- Recommendations for Nationwide Training and Technical Assistance for Implementation

STATUTORY AMENDMENTS

PART H - THE INFANTS AND TODDLERS PROGRAM

Amendment #1: Differential Participation and Funding

Purpose: To develop funding mechanisms that:

- encourage states' continued participation;
- encourage states' progress toward full service;
- provide an adequate and stable federal contribution to fill in the current gaps in the provision of direct services.

Amendment: States not able to meet the requirements of the 4th or 5th year application for funding under the Part H Program may continue to participate and receive an annual allocation equal to their FY '90 (calendar year '90-'91) allocation except that no state shall receive less than $500,000. States may receive up to a total of two years of such additional funding. The Secretary shall develop criteria and guidelines for such differential participation.

Amendment: Amend the current funding mechanism under Part H to provide for a differential funding formula of:

1) Beginning in Fiscal Year 1992:

a) States meeting fifth year application requirements and for each succeeding year after July 1, 1991, shall receive a census-based allocation from the appropriation for that year.

b) Participating states not able to meet 4th or 5th year application requirements after July 1, 1991, shall receive from the appropriation for that year, an allocation equal to their FY '90 (calendar year '90-'91) allocation except that no state shall receive less than $500,000. States may be eligible for such additional funding for up to two additional years.

c) For any year in which any participating state is unable to meet application requirements but receives differential funding at the FY '90 (calendar year '90-'91) level, and if the appropriation for that year exceeds the total of all states' allocations, the unobligated funds shall remain available for obligation for two succeeding fiscal years.

2) The Congress shall authorize such sums as necessary for each appropriation to hold harmless state allocations at the FY '92 level. Part H should be reauthorized no later than 1995 at which time Congress should construct an appropriate funding formula and level for full implementation of the Part H Program nationwide. Congress should direct

the Secretary to report within three years on recommendations for such funding formula and level for full service.

3) Finally, Part H appropriations should be of sufficient levels to compensate for any reduction of Chapter I (P.L. 89-313) funding. Such a reduction in early intervention resources (in 1989 37,000 infants and toddlers were served under Chapter I) cannot be sustained without a complimentary and proportional increase in Part H.

Amendment #2: Incentives for Birth-5 Planning and Services to At-Risk Children

Purpose: To facilitate birth-5 planning and to provide incentives to serve at-risk children.

Amendment:

1) Part H and Part B (Sec. 619) should authorize the expenditure of Part H and Part B (flow-through and set-aside) funds for birth-5 planning efforts. The Interagency Coordinating Council functions should be amended to include birth-5 planning activities (see amendment #9) in order to prevent abrupt and clinically unsound changes in programming for children at the time they reach three years of age. Several states including Maine and Pennsylvania are conducting successful birth-5 planning. However, there are additional costs to this approach and, therefore, both programs need to authorize funding for such planning efforts. Applications for funding under both programs should require information on birth-5 planning activities and the use of funds for those activities.

2) Part H should be amended to:

   a) include language expressing congressional intent that states serve at-risk children; and

   b) allow Part H funds to be used for the purpose of identifying, screening, tracking and referring at-risk children even though the state does not include them in its definition as an eligible population for early intervention services. Therefore, while not eligible for early intervention services, these children could receive the less costly service of periodic screening and tracking to ensure that if an at-risk child should begin to display delays that would deem him/her eligible for early intervention services, he/she could be referred to those services at the earliest possible time. The screening and tracking systems should be developed under the same guidelines as the statewide early intervention system, e.g., by the ICC, payor of last resort, and as a cooperative, interagency activity.

3) Part C (Sec. 623) should be amended to require the Secretary to target the needs of at risk infants, toddlers and preschoolers (birth-5) for funding in all activities of the Early Education Program including: Model/demonstration, experimental, outreach and research. Such activities should address identification of risk factors, service needs effective intervention strategies, incidence and prevalence and system planning including the coordination of all available resources for each at-risk population

Amendment #3: "Technical" Age of Three

Purpose: To ensure continuity of services as a child and family move from the Part H program to the Section 619 Preschool Program under Part B.

Amendment: In order to ensure that services to an eligible child and family are not terminated or delayed unnecessarily, allow states to decide the definition of the "technical" age of three to facilitate a smooth and nondisruptive transition from the Part H funded program to the Part B, Sec. 619 funded program. This flexibility would allow states to decide what is the best age at which to transition children for both the child and family and the agencies, e.g., 2 years 7 months by September 1, etc. However, this amendment should in no way revise the absolute right to a free appropriate public education under Part B for eligible children upon their 3rd birthday. In other words, an eligible child should be receiving services according to an IFSP or IEP either under Part H or Part B by the age of three.

Part H should be amended to authorize the expenditure of Part H funds on services to children older than two years if they have not yet reached the "technical" age of three established by the state for entry into the preschool program. Sec. 619 should also be amended to allow expenditure of preschool funds on children less than three years of age who are the "technical" age of three including flow-through funds and state set-aside funds.

Applications for funding under both programs shall include documentation on how both programs are coordinating transition including pertinent interagency agreements. Part B would need complimentary legislative action as well, in order to implement this provision.

Amendment #4: Developmental Domains

Purpose: To use more widely accepted terminology for the developmental domains under the definition of "developmental delays" (Sec. 672 (1) (A):

Amendment: The developmental domains should be:

- cognitive development
- physical development
- communication development (vs. language and speech)
- social/emotional development (vs. psychosocial)
- adaptive development (vs. self help)

The last three are being recommended for revision because the proposed language is the preferred usage in the field, more appropriate to this age group, and reflects more standard terminology related to assessment and curriculum materials in use.

Amendment #5: IFSP

Purpose: To more accurately reflect the appropriate role of the family in the Individualized Family Service Plan procedures and the delivery of services:

Amendment: Substitute the terms "families' concerns, priorities, and resources" for "families' strengths and needs" throughout the Act (e.g., Sec. 677 (d) (2)). The substitute terms reflect less pejorative language as well as the role the family should play in providing this information at their discretion.

Amendment #6: Services

Purpose: To ensure a comprehensive array of services under the definition of "early intervention services":

Amendment: Add to the list of early intervention services (Sec. 672 ((2) (E)):

- vision services
- transportation services

Amendment #7: Case Management

Purpose: To ensure that a system is in place for coordination of services to all Part H eligible children and families:

Amendment: Change the name of "case manager" to "service coordinator." Families report that they do not like the inference that they are "cases" to be "managed."

- Change the term of "case management" to "service coordination."

- Service coordination shall be defined as "case management" for the purpose of Medicaid billing or other public or private reimbursement systems.

- Remove the terminology "from the profession most immediately relevant to the infant's and toddler's or family's needs" as included under IFSP content (Sec. 677 (d) (6)). This is creating confusion and unnecessary red tape at the local level.

- A service coordinator and service coordination be available to families and they shall have the option to accept or reject the person and/or the service.

- Parents may serve as co-service coordinator.

- States must have a policy in place for assuring that service coordination matches the changing needs and preferences of the family and child.

Amendment #8: FICC

Purpose: To assure a continued and expanded role of the Federal Interagency Coordinating Council as a federal collaborative force to assist states in developing a comprehensive community based system of services for children with special needs and their families:

Amendment: The Federal Interagency Coordinating Council (FICC) should be a requirement of Part H with adequate staff and resources for its activities provided by the participating programs. The purview of its activities should continue to be birth through five.

- The FICC should have specific responsibilities outlined in Part H including: the coordination of early intervention policies and activities including interagency agreements across federal programs; the coordination of all federal technical assistance activities across all participating agencies and programs; advisement of the lead agency (the Department of Education); dissemination of information; facilitation and support of states' efforts; the receipt of all state ICC annual reports and the requirement that it address any concerns and issues raised in the reports that specifically relate to developing collaborative and effective systems across federal programs and the elimination of federal interagency barriers.

- The FICC membership should include current programs as well as parents and may include: a state ICC representative, a Part H lead agency representation, and a state Preschool Program lead agency SEA representative. The FICC meetings should be publicly announced and to the extent appropriate, open and accessible to the general public.

Amendment #9: ICC

Purpose: To assure the efficient and effective operation of state Interagency Coordinating Councils (ICC's) to meet the goals of P.L. 99-457:

Amendment: Part H should be amended to achieve the following:

- The selection of a chair of the ICC by election of the members of the Council.

- At least one parent on the ICC must have a child with disabilities in the age range of 0-6. Other parents must be those of children with disabilities of no more than 12 years of age who have knowledge or experience with programs for infants and toddlers with disabilities.

- The ICC must develop a schedule of terms of member service which would include a provision for reappointment and recommend it to the Governor.

- The ICC will be composed of a minimum of 15 members and a maximum of 25 members with the following representation:

    - at least 20 percent of the members shall be parents as defined above;
    - at least 20 percent of the members shall be public or private service providers of early intervention services;
    - at least two members shall be from the State legislature, one from each house except in unicameral states;
    - at least one member shall be involved in personnel preparation;
    - at least one member shall represent the State Education (SEA) Preschool Program and at least one member shall represent the Part H lead agency;
    - the Council shall include members representing each of the agencies involved in the provision of, or payment for, early intervention services for infants and toddlers with disabilities and their families; and
    - Council may include other members selected by the Governor. (Head Start; American Academy of Pediatrics, the Division for Early Childhood, and other relevant professional organizations).
    - State agency representatives appointed by the governor must be of sufficient authority to engage in policy planning and implementation on behalf of the agency.

- Amend Sec. 682(d) to read as follows: "Management authority - subject to the approval of the Governor, the Council shall prepare and approve a budget that provides for the compensation of parent representatives for time and allowable costs. The Council may approve a budget using funds under this part to have staff....."
- The focus of the ICC shall be on children birth through five years of age, or, at a minimum, be required to address the transition issues between the birth through two program and the preschool program.
- The ICC must report to the FICC in its annual report to their Governor and the Secretary any concerns and issues that specifically relate to developing collaborative systems across federal programs.

Amendment #10: Participation of Other Programs

Purpose: To assure a programatic and fiscal role and responsibility of all relevant agencies to develop and implement a comprehensive community based system of services for children with special needs and their families:

Amendment:

1) All relevant agencies governed by federal statute, shall be named in the Part H statute and be required to maintain current programatic and fiscal responsibility to develop and implement a comprehensive community based system of services for children with special needs and their families as designated by Part H.

- Agencies shall include but not be limited to:
  - Department of Education
  - Office of Human Development Services
  - National Institute of Mental Health
  - Office of Maternal and Child Health
  - Administration on Developmental Disabilities
  - Administration on Children, Youth and Families
  - Health Care Financing Administration

2) The Division for Early Childhood recommends that Sec. 676(b)(9)(C) be deleted and, instead, a new component be added to Sec. 676 to read as follows: "(15) The state shall assign financial responsibility among the appropriate agencies that provide or support early intervention services." We recommend the "state" have this requirement, not the "lead agency." We also recommend that Sec. 676(b)(9)(F) be revised to read: "....for early intervention services (consistent with state law and Sec. 676(b)(15)) and procedures for resolving......"

PART B - THE STATE GRANT PROGRAM AS IT RELATES TO CHILDREN 3-5 YEARS OF AGE

Amendment #1: Coordination of Part H and Part B

Purpose: To assure a comprehensive and coordinated delivery system for infants and toddlers and preschoolers with disabilities and their families:

Amendment(s):

- The term "developmental delays" as defined in Part H (as recommended by DEC in the previous section) should be added to the list of handicapping conditions under Part B for children in the age range of three through five years only. Children found eligible under this term would be eligible for all the rights and protections under Part B. As noted below the recommendation is not intended to expand the eligible group of children, but rather facilitate the most appropriate diagnostic procedures for young children because of the many difficulties in assessing the etiology of the delays at this young age.

- Service coordination (our recommended term for case management) be defined as a related service under Part B for children 3-5 years of age only.

- Language should be added to Part B that expressly authorizes services to be provided to the family if they are needed for the child to fully benefit from the preschool program and are in the child's individualized plan.

- Language should be added to the statute that encourages states to use Individualized Family Service Plans in lieu of Individualized Education Programs for children 3-5 years of age only.

- Part B should be amended to authorize that at state discretion a state's ICC may meet the requirements of a state advisory council under P.L. 94-142 for children 3-5 years of age only. This would facilitate birth-5 coordinated planning. In such case the SEA would delineate in its state's plan under P.L. 94-142 that its special education advisory council's purview is 6 through 21 and the ICC's purview is birth through 5

- As recommended earlier under Part H recommendations, the "technical" age of three years should be defined by states as necessary to ensure smooth and efficient transitions from Part H services to Part B services. Such policies should ensure that: 1) there is no unnecessary delay or termination of services when a child transitions from Part H funded services to Part B funded services, and, 2) all Part B eligible children have services available to them by their third birthday either under Part H funded services or Part B funded services. The length of the "school year" for a preschooler should be governed by the individualized plan not "extended school year" (ESY) policies. The "tests" used for ESY eligibility have not been validated for preschoolers and may in fact be overly restrictive However, DEC does not endorse the use of special education and related services resources for child care. Procedures need to be in place to distinguish a child's need for special education and related services to be continued in the summer from child care needs. Resources should be found to assist families with child care and respite care where needed

Currently, the effect of separating the policies and planning by the arbitrary age of three years is creating havoc in many states. Most states that had extensive services for children from birth prior to P.L. 99-457, had services that appeared more similar in nature between the birth-2 and 3-5 age groups than Part H and B are. The arbitrary decision to construct state-of-the-art policy in Part H for infants and toddlers, but simply apply the school age policies of Part B to preschoolers was a political one, not one based on best practice or in the best interest of children. Clearly, services for a three year old should be more similar to those for a one year old, than those for a 10 or 15 year old And yet, in many instances, schools are now simply lowering the school age requirements to preschoolers in order to meet the minimum letter of the law. These policies are not developmentally appropriate to preschoolers - they are in some cases - developmentally inappropriate. What we have are three, four and five year olds. While they are "handicapped" it is unclear why (or what label is the correct etiology) and hopefully, many of their problems will be remediated by early intervention so, why stigmatize them with an inappropriate and premature label of one of the 11 etiology categories under P.L. 94-142? And secondly, we have a near total neglect of the critical role that parents play in the success of the preschool child's intervention and the important role of service coordination for this age group as well as for birth-2 year olds.

Even those states that would prefer to construct developmentally appropriate policies for preschoolers feel constrained by the current limitations of Part B. This is not an appropriate role for federal legislation - federal policy should lay a broad foundation that reflects state-of-the-art knowledge - not constrain state activities to a narrow and archaic framework. For instance, a couple of states are currently studying policy options that would provide for a coordinated and consistent system for children birth-six years of age including:

- the same eligibility criteria, i.e., Part H criteria, so that children and families do not lose services at the arbitrary age of three years when they still need them. While the reporting requirements in Part B were amended to not require a count by handicapping conditions for 3-5 year olds as an acknowledgement of the need to not label children prematurely, the Congress now needs to complete the policy and add a more appropriate category like "developmentally delayed." Even though there is no intent to expand eligibility, states are reticent to use categories other than those expressly authorized by Congress for fear of being found out of compliance.

- providing for case management or service coordination for 3-5 year olds. Again, because a child reaches the arbitrary age of three, his/her needs do not necessarily change. The necessity for a case manager or service coordinator to coordinate the vast array of services needed by the young child and his/her family continues.

- providing the child and family with an Individualized Family Service Plan (IFSP) rather than an Individualized Education Program (IEP) for the same reasons as listed above and in addition to encourage schools to address the family's role in the child's development. One of the consistent factors in the most successful preschool programs is family support and involvement. If a program helps a family address the particular needs of their child and to access services, it is much more likely that the child will make significant gains. It also stands to reason that the family will continue those activities long after the child has left the particular program. We also point out that the term "IEP" never appears in P.L. 94-142. Instead the words "individualized education program": are used - with lower case letters implying a generic term for written individualized plans. Secondly, the IFSP requirements meet the requirements of the individualized education program under P.L. 94-142 and then exceed them in a couple of areas. Thus, the IFSP would meet the requirements of Part B. OSEP has clarified that IFSPs may be used under Part B. However, because of the critical importance of this practice, it should be in statute.

In other words, what Congress saw as good for the infant and toddler, is good for the preschooler as well! And Part B should reflect this state-of-the-art knowledge.

Amendment #2: Funding Mechanisms

Purpose: To develop a funding formula that would:

- encourage states continued participation,
- provide adequate and stable contribution to the provision of direct services:
- ensure smooth transitions for children from Part H to Part B preschool services and from the Part B preschool services to first grade

Amendment: Amend the authorization for appropriations to remove the cap of $1,000/child to a minimum of $2,000/child which would represent a more adequate federal contribution to the total average cost of serving a preschool-aged handicapped child.

- The Preschool Program funds should be allowed to be used for services for all eligible children from the time the children reach the state's "technical age" of three years and the state's definition of the age of eligibility for first grade (e.g., "technical age" of 6 years); i.e., preschool funds should be available for preschool programs that may include children that are younger than age three, but not younger than two, and older than five, but not older than six.

CLARIFYING LANGUAGE - NO STATUTORY CHANGE

Report language or another mechanism is needed to clarify or underscore a few provisions that are either confusing to states or are being neglected in implementation. It is important that the Congress clarify/amplify the intent of these provisions.

Part H

- Language is needed to encourage states to include in their comprehensive planning efforts primary referral sources especially neonatologists, pediatricians, and other hospital and clinical personnel.

- Language is needed to encourage states to consider serving children who are at-risk of developing delays. This critical prevention provision of Part H is considered valid and important by states but, simply due to fiscal constraints, is in very serious jeopardy of not being implemented. DEC feels that this preventative approach to developmental delays deserves to be retained as a discretionary provision, but should be facilitated by congressional language encouraging states to implement this provision and by the incentive funding proposed earlier in this statement.

- Language is needed to clarify that eligible children and families are entitled to all the "early intervention" services as defined in Sec. 672 (2) of the Act that are included on their IFSP by the time a state is eligible for funding under the fifth year application requirements of Sec. 675. However, services not defined as "early intervention" (e.g., income maintenance, surgery, etc.) may be added to the IFSP in order to attempt to coordinate the full array of services needed by the child and family. These non-early intervention services, while on the IFSP, are not the responsibility of the early intervention service system.

- Language is needed to amplify the fact that if a state implements a system of payments as is allowable under Sec. 672 (2) (B), children and families may not be denied any early intervention services in their IFSP due to inability to pay, nor can services be delayed due to inability to pay.

RECOMMENDATIONS FOR NATIONWIDE TRAINING AND TECHNICAL ASSISTANCE NEEDED FOR FULL AND EFFECTIVE IMPLEMENTATION OF PART H AND PART B - PRESCHOOL PROGRAM

Recommendation #1:

The Federal Interagency Coordinating Council (FICC) should be directed to facilitate the coordinated planning of all technical assistance (T.A.) and training programs and activities under the purview of its participating agencies, e.g., OSEP, MCH, Head Start, UAP's, etc., that are related to services for eligible children and families birth to age six years.

Currently, there is a wealth of inservice training and T.A. activities available, e.g., NEC-TAS, MCH, SPRANS, HCEEP Outreach, RRCs, UAPs, etc. However, there is no coordinating effort or oversight to ensure that: 1) there is minimal duplicative or conflicting efforts, 2) there are no gaps, and 3) that there is no barrier to getting needed T.A. to the appropriate consumer. Indeed, there are duplicative efforts, gaps in areas that are of great need, and some T.A. groups are restricted from including some appropriate recipients in their services.

Recommendation #2:

The FICC, in addition to facilitating the coordination of national T.A. and inservice activities, should target priority areas of training and T.A. based upon public input. The public input shall be gained through the use of proposed priorities published in the Federal Register; from the State ICC Annual Report; or specific information requests to ICCs, lead agencies, service providers, parents and groups such as DEC. Through the national hearings, our extensive state and local membership activities and other research and program and policy efforts, DEC is keenly aware of critical areas of need for T.A. and inservice training. These areas are:

- **Systems Planning**
  - State and local planning procedures;
  - birth to six planning -- policies and programs;
  - requirements under P.L. 99-457, P.L. 94-142 and other relevant federal programs-ranging from basic training (many new people have never had training on P.L. 94-142 or haven't had any in 10-15 years, as to how to coordinate requirements);
  - assistance in establishing eligibility requirements that will facilitate national uniformity;
  - developing procedures and training for effective primary referrals, child find and tracking.
- **Implementation**
  - Family issues, family participation, IFSP development and implementation, case management (service coordination);
  - Best Practice, e.g., how to ensure that all early intervention and preschool services are the most effective possible: quality assurance, program evaluation, integration, intervention methods, etc.;
  - Meeting the needs of culturally diverse families.
- **Personnel Qualifications and Skills**
  - Development of Personnel standards that require that personnel possess the skills that ensure effective services;

• Development of pre- and in-service training programs that will produce personnel who will possess the above skills including leadership development (the development of leadership skills - not just degrees) and faculty training (ensuring that faculty can indeed produce the personnel that can meet the above standards);

• Development of T.A. and training that is interdisciplinary and combines and coordinates "specialized" or "special education" knowledge and skills with non-specialized or "regular early childhood" knowledge and skills.

• Interdisciplinary teaming skills that are in support of direct services which are responsive to the unique nature and context of early development;

• Recruitment training and maintaining professionals from minority backgrounds in the field of early intervention.

Recommendation #3:

The national technical assistance and training activities should be based upon certain characteristics or criteria. These characteristics should include:

- state and local entities of all relevant groups - schools' health care, providers, parents, administrators, etc., - should be given the opportunity to assess and report their T.A. and training needs;

- T.A. and training should be on practices that are based upon effectiveness data where possible;

- T.A. and training should recognize and promote cultural diversity of both the families receiving the services and the professionals providing the services;

- Product development, e.g., T.A. materials and documents, should be a high priority because all states and localities can benefit from them and they are cost effective. However, they should be based upon banks of state data and policies, data-based practices, etc., to ensure the broadest applicability;

- T.A. and training should incorporate best practices in adult training technology, e.g., personalized, repeated, etc.;

- Inservice training and T.A. activities should become the vehicles for utilization of the techniques and materials developed over the last 20 years with federal research and development monies, i.e., providers and trainers using validated information developed under federal endeavors such as OSEP research, institutes, and demonstration projects should be given priority for T.A. and training monies;

- Dissemination and utilization of current and future research and demonstration projects should be funded as part of the project or as an extension of the project where the project has validated effective practices.

Recommendation #4:

The FICC should include in its annual report (recommended earlier) all T.A. and training activities of its member agencies, how the efforts are being coordinated, and what the T.A. and training priorities are and how those priorities were developed.

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Developmental Delay: Questions and Answers

The International Division for Early Childhood and its "parent" organization, The Council for Exceptional Children, have made the recommendation that a category of "developmental delay" be added to the list of eligible disabilities under Part B of IDEA for 3-5 year old children. This recommendation, while reflective of best practice in the field of early childhood special education, has generated several questions from other arenas. Answers to those questions follows.

What are the parameters of the DEC/CEC recommendation?

DEC/CEC recommend that this category be: 1) used at state discretion and could be used in addition to some or all of the existing eleven Part B categories; 2) used for 3-5 year old children only; and 3) states could develop different diagnostic criteria for 3-5 year olds than used to determine developmental delay in birth-2 year olds under Part H; i.e., more stringent criteria, if they so chose.

Do children who would be determined to be "developmentally delayed" have a disability or are they simply "at-risk" of a disability? How many children might fall under this new category?

"Developmental delay refers to a condition which represents a significant delay in the process of development. It *does not* refer to a condition in which a child is slightly or momentarily lagging in development or is "at-risk' of a delay. The presence of a developmental delay is an indication that the process of development is significantly effected and that without special intervention, it is likely that educational performance at school age will be effected.

Over the past 20 years several states have identified preschool children with disabilities by a variety of non-etiological (e.g. referring to *cause* of the delay like mental retardation, autism, etc.) definitions like "developmental delay" (Maine, Iowa, Connecticut, Massachusetts, Wisconsin, Colorado, etc.). These states report serving a percentage of the population well within the average percentage that all other states report. Using such categories *does not* "let the flood gates down". Indeed, most states employ diagnostic measures for this category that are more stringent than their procedures for the Part B categories.

Typically, states and professionals have recommended a criteria of 1.5 or 2.0 standard deviations (SD) below the mean on a standardized measurement. If development in the domains is assumed to be normally distributed, a 1.5 SD below the mean would result in a 7% prevalence rate and a 2.0 SD below the mean would result in a 3% prevalence rate. Currently, states using the existing Part B etiological categories report serving approximately 4% of all preschoolers; and IDEA has a 12% cap. *Clearly, there are no data to support the argument that the addition of the term "developmental delay" might significantly increase the number of eligible children.*

If significantly more children would not be identified, why add "developmental delay"?

The intent of DEC and CEC is not to expand the population under Part B, but rather to ensure: 1) that all preschoolers eligible to be served *are* served, and 2) that they are served *appropriately*. Adding "developmental delay" is critical

A DIVISION OF THE COUNCIL FOR EXCEPTIONAL CHILDREN to achieving these goals because:

- because 3,4, and 5, year old chilrens' development is uneven and difficult to measure, the cause (category) of the delay is not apparent even though the delay itself is;
- currently some significantly delayed children are not being served because the etiology of the delay is unclear, thus, the Part B label is not readily apparent;
- it is important to state 3-5 year old childrens' eligibility in terms of development rather than "educational performance" (Part B criteria) because most preschoolers have not had previous educational experiences at the time of diagnosis;
- a premature and/or inaccurate etiological label can result in changing etiologies later in the child's life causing the family to readjust to a new set of implications;
- high quality preschool services can have a remedial effect resulting in a child exiting from special education by first grade - but being hounded by the etiological label such as mental retardation or autism. If a label is to have lingering effects, one such as "delayed" may have less serious consequences.
- while it is unfortunate, but absolutely true, specific special education services, more often than not, are determined by the label a child gets - a child labeled as having mental retardation, gets the "M.R. Program", a child with autism gets the "autism program", etc. a category such as developmental delay would help prevent an inappropriate "program" based on an inaccurate label; and would facilitate services based on a childs' actual strengths and needs.
- such a category may facilitate placement in community mainstream programs because the term recognizes a continuum of developmental status rather than assigning a handicapping condition.

In 1985-86, during the development of P.L. 99-457, the early intervention field and parents convinced Congress of this inappropriateness of the Part B categories for many 3-5 year olds. The Senate version of the bill created a new Part B category of "developmentally delayed". However, the final bill addressed the issue by only amending the child count requirements and removing the count-by-disability for 3-5 year olds. Thus, in 1986, Congress acknowledged the need, but stopped short of an effective remedy. The solution has only created confusion and most states are reluctant to use a non-Part B category for fear of being found out of compliance. It is time to accept the fact that Part B was not written with 3-5 year old children in mind, and now with the expansion of Part B to age three, and to make the modifications necessary to ensure appropriate services for these very young children.

Chairman OWENS. Thank you. Without objection, your additional material will be entered into the record.

Mr. Gene Wilhoit.

Mr. WILHOIT. Chairman Owens and members of the subcommittee, my name is Gene Wilhoit and I am the Executive Director of the National Association of State Boards of Education.

On behalf of those State board members who are the lay leadership who set public education policy for elementary and secondary education, who develop the criteria for learning in those States and set the general climate for teacher training and preparation, we appreciate the opportunity to testify today.

You have my testimony. I am not going to read that. What I would like to do is talk in three general areas. First, I would like to present what I see as a central dilemma facing this subcommittee. Secondly, I would like to talk about some State policymaker concerns. Concerns of generalists, not of specialists, in the field, but people who look at the general development of education for all children.

And, third, I would like to talk about some broader issues that seem to be emerging that we feel are under the purview of this committee and could result in some positive response of this committee if undertaken.

First, the dilemma. I think I, as a person, am in a similar dilemma as you as chair of a subcommittee. Let me explain that a bit. I am—15 years ago, my son, Jason, contracted spinal meningitis at 10 months of age. Jason was at that time, our most advanced child for that age, walking around, causing us what at that time we though were horrible pains, that is getting his fingers in everything and roaming the home.

Unfortunately, the spinal meningitis was a very rare strand. It penetrated the menges of Jason's brain and left him mentally retarded. You can imagine the impact on the family. We were fortunate as a group of people entered our lives as professional resources and as friends.

They walked the halls with us in the immediate time. They helped us put together a family that was torn apart. They sat on the floor with us during those days and months and years working with Jason to rehabilitate this your person's life.

They helped us in ways that brought us very close to each other as a family and helped us reestablish a positive relationship with each other.

I want every parent in that circumstance to have the advantage of those kinds of programs. Unfortunately, 15 years ago, that wasn't the case. This happened to be a private institution. I happened to have the resources to avail myself of those services, and I [illegible] a very aggressive spouse.

All of those things allowed us to rebuild a family and to provide the beginning point for our son. I think from a parent's point of view, and from the view of this subcommittee, the central challenge is to keep that purpose alive. That is, every family, every child in every State should have access to these kinds of services during infant and toddler years.

I also come to you today having worked 14 years, either directly or for State policymakers. I have witnessed in those 14 years a transition. Fourteen years ago, States needed prodding. They needed prodding from the Federal Government and they got that prodding.

I have seen them mature and develop in their outlook toward education and I see today States willing to openly address these issues. I see States willingly pushing for reform in public education and I see States willing to move ahead to bring about the kind of society our children are going to have to survive in.

I come to you with what I think is a central dilemma. That is how do you maintain a program where all States have quality services for infants and toddlers, yet do so in a way that assures that we address the realities of States today, which leads me, I think, to my second set of comments; that is some of the realities that States are facing.

First, the issue of collaboration, and it has been addressed by other people on the panel. It is a very different enterprise. Although lead agencies have been established, although people have signed contracts to work together, collaboration is a new concept within State agencies. It is a new concept at local levels.

We have been accustomed to establishing funds for specific purposes and aligning those specific agencies for specific delivery. This collaborative effort is very difficult for some people. It requires a lot of very strong leadership on the part of those in positions at State level to do so. It requires people giving up turf, it requires systems to be realigned and it requires a professional from a lot of different people.

I met with people in Virginia who are now very proud that they now have in place a quality program to move ahead for infants and toddlers. They began that program two year before your initiatives.

So the have been at it for seven years and are proud now at the point they have the systems in place to move ahead. Not what we like to hear in a lot of cases, particularly for those who are inpatient, but I think a reality and I think something that needs to be considered as we move ahead.

Secondly, we made some assumptions five years ago about what we were doing that I think were incorrect. We have assumed that what we needed was some glue to hold systems together, that what was missing out there was not programs of quality, but the kind of ingredients that could be put in place to hold these programs together and make them work more effectively.

As States have begun to more effectively identify children and more effectively develop needs assessments and interactive programs, what we are finding is all those programs were, in fact, not in place.

So, as we have begun to collaborate, we have also had to begin to identify programs for those holes in the comprehensive program delivery system. That has been difficult at a time when we have also expanded commitments to education, generally, as we moved to restructure and reform education, as we have added the early childhood component to elementary schools, we have also begun to pull on systems for increased programming services for infants and toddlers, which leads me, I think, to the third major concern I see from a State perspective and that is the State fiscal climate that now exists was not in existence five years ago.

When we established this system, we were on a boom; States were expanding; they were making commitments to programs beginning two years ago and last year and this year more and more States are beginning to see pressures placed on State budgets.

Many of those States are in deficit and are cutting back programs at a time when they look at these provisions and see the mandate providing services for all children and get a little bit scared about the kind of commitments they need to make in a tough economic situation.

I think in the written testimony, there are a number of suggestions, but I think these concerns lead me to three specific considerations I would ask you to consider.

First, the issue of differential treatment is one others have mentioned, but we would advocate also.

We think you ought to recognize those States that have moved ahead, those 15 to 17 States that are at a point of implementation. We think they ought to be rewarded for that implementation, but we also think at some level, we ought to continue to hold on to as many of those States as we can through those planning grants.

We are not saying they should receive equal treatment, but some assistance from the Federal Government in helping them to continue to process of moving ahead, realizing it well may be there, but the economic condition at the moment may prohibit advancement that we would want with the legislation.

Secondly, we feel that the at-risk provision is one where you each allowed a discretion for identification. We would urge that that continue to be a State option. We feel that some States, given some financial incentives, would take advantage of that from the Federal Government and begin to move ahead in some of these areas.

We agree that identification of these populations is critical, but the issue for States is looking at that five-year plan date for service for all children and they are beginning to shy away. They are, frankly, afraid they will not be able to make the commitment as they move into these areas. We are faced with a tremendous problem. A desire for identification and for as much treatment as possible, but of fear for limited service.

Finally, on the recommendations, we are optimistic about what is printed in Part H. We feel States are moving towards these concepts. The family-oriented delivery systems are catching on in States and we see them mirrored in programs like Parents as Partners in Missouri, the Kentucky programs. States are looking at those in a very positive light. What we would ask you to look at is how can you move Part H into the other parts of the programs. We think that is the way to go in the future. We think with Federal guidelines, more States will begin to consider this kind of approach.

My final set of concerns are broader issues that we think this committee could assist the country in addressing. We, as an organization, NASBE, have undertaken a two-year project now because in the area of special education, handicapped education, individuals with disabilities there are so many concerns that are going to impact on the future.

We have begun to work on this issue and we have seen issues emerge that could benefit from your wisdom. We would encourage you, through study groups or special studies or hearings, to address some of these issues. We think we could enter into partnerships that would be productive in the future.

First, the whole issue of coordination. There are a number of State programs that are mirroring Federal programs that are coordinated with Federal programs that are addressing the same clients. We think we need to step back as States and you as a Federal Government begin to look at how we can better coordinate the multitude of programs.

People have bought the concept that prevention is a better strategy than remediation. States are beginning to put more funds into early childhood education programs, and we are seeing a proliferation of those at the State level and merging those with Federal programs is creating a sense of a multitude of programs without the kind of coordinated efforts we need.

Secondly, we would encourage you to look at some of the research that is coming out on the effects of all special education programs, and I noted in written testimony the report coming out of the City University of New York, what I think is one of the better articles about some of the concerns that policymakers are facing, that is State boards of education are facing, as we move forward.

First of all, we are very concerned about separate programs for children. We are very concerned that by separating them into these programs, they are being tracked, that they are being lost in the system, that the expectation level for those students are not what they are for other students.

We want that to stop. We think there are ways we could devise programs for special education for handicapped disabilities that would help that. We are concerned about the number of boys being placed in those programs. We are concerned about the number of minorities, particularly African-Americans, who are placed in these programs over a period of time.

We are also concerned about personnel. We are concerned about the disincentives in the system for people who want to enter early education, both in terms of extended training that is not there for other teachers, and in terms of salaries that are not there for those working in early years. We have got to begin to address that.

We are concerned about the burn out of those people in those positions over a period of time and the inability to hold those people in those positions over two to three or four to five years. We are concerned about the new categories, about the splintering of new categories and about the effect of new populations that are being identified and what impact that is going to have on the overall system and what we might do in a partnership to work in the next few years.

I thank you for listening to the testimony and we would be glad to answer any question.

[The prepared statement of Gene Wilhoit follows:]

NATIONAL ASSOCIATION OF STATE BOARDS OF EDUCATION

TESTIMONY ON THE REAUTHORIZATION OF PART H OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

GENE WILHOIT, EXECUTIVE DIRECTOR

FRIDAY, APRIL 12, 1991

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Chairman Owens and members of the Subcommittee:

My name is Gene Wilhoit and I am the Executive Director of the National Association of State Boards of Education (NASBE). I feel uniquely qualified to testify before you today, because in addition to my work in education, I am the father of two handicapped children. My son Jason, who is 15, contracted spinal meningitis as an infant and now has multiple handicaps. My son Christopher, who is 20, was born with Down's syndrome. Thus, on the one hand I bring to this discussion the perspective of a policymaker who works with states -- states that are at all phases of implementation, that are struggling to provide financial support for a quality education for all children, and that are attempting to redesign systems to support education reform. But I also bring to this discussion the perspective of a parent with deep love and concern for his children: a parent who has participated in infant stimulation, and who has worked in partnership with public and private schools; a parent who has advocated educational opportunities for these special citizens, and who has pushed for change within the institutions serving our children.

NASBE was a major supporter of P.L. 99-457 when it was passed by Congress in 1986; we testified in support of the new Part H program of early intervention services for young children with disabilities and their families. Those amendments to the Education of the Handicapped Act authorized a new formula grant program to assist states in establishing a statewide, comprehensive, coordinated, multidisciplinary, interagency system to provide early intervention services for infants and toddlers with disabilities and their families. One of the reasons we feel this legislation is so important is because research has shown that early intervention dramatically improves children's physical, cognitive and social abilities, thus minimizing the effect of existing and potential handicaps. Given the remarkable capacity to improve children's potential, it is critically important to evaluate at-risk infants as early as possible with an eye to sophisticated preventive and therapeutic measures. We know that the earlier intervention is started, the greater the ultimate dollar savings and the higher rate of educational attainment.

When Congress established the early intervention Part H program, it was anticipated that all states would be at or on the verge of implementation of the 14 required components during the 1991 reauthorization process. It was believed that five years would be a sufficient time for states to achieve the policy directives established in the statute. As you are aware, some -- but not all -- states have been able to keep to this schedule for the Part H planning and development process. Seventeen states are basically on schedule. They have made remarkable progress towards achieving the congressional goals, and they are now preparing to provide services to all eligible infants and toddlers and their families. Indeed, in most states there is convincing evidence of efforts towards implementing a statewide, comprehensive, coordinated, interagency system of early intervention program.

However, it has also become clear that the endeavor states have undertaken is far more complex and challenging than originally envisioned. That is why we support the suggestion, made by the Division of Early Childhood within the Council for Exceptional Children, that a provision be included in the law enabling states that are not able to meet the requirements of 4th or 5th year application for funding under the Part H program to continue to participate and receive an annual allocation equal to their FY'90 allocation. However, we feel it is important to reward those states with the dedication and resources that have demonstrated full commitment. Therefore, we also support the suggested amendment that the current funding mechanism under Part H be amended to provide for a differential funding formula.

We feel very strongly about this. Many of the requirements of implementing Part H, including the policy development, approval and implementation, have been very complicated and time consuming. Part H asked the states to do something the federal government has been unable to do -- in essence, to coordinate activities across different state and federal programs and across disciplines, creating a statewide system that would eliminate barriers to financing of services across agencies while at the same time generating new policies to promote such coordination; it asked states to generate new fiscal support for early intervention services; and to establish or change policies and procedures in different programs within multiple agencies.

This implementation is made even more difficult by the fact that within states there is no one person or agency who has the authority to direct or command the required action. Lead agencies or Interagency Coordinating Councils have had to operate through compromise, consensus and negotiation to achieve the final result. Yet, there is evidence that these lead agencies or newly created children's councils are becoming successful tools for addressing comprehensive needs of children.

Another factor contributing to the delay in implementation is that P.L. 99-457 was based on an assumption that there were a lot of services for handicapped infants and toddlers, but that these services were not coordinated. The federal funds were meant to enable states to pull together and coordinate these programs. Yet it is now evident that existing resources are insufficient in most states to make services available on an entitlement basis, as is required by law in a state's fifth year of participation.

The deteriorating condition of state budgets also was not anticipated in 1986. This has had a significant effect on the ability of lead agencies. ICC's and advocates to gain the necessary support in states to move towards full implementation. States are being forced to seek funds for expansion of Part H services at a time when services for other basic human needs, such as prenatal and maternity care and other forms of basic health, medical and social services, are being cut. In addition, in states that have enacted the mandatory special education services for preschool age youngsters to meet the Part B requirement, it has been particulary difficult to secure enough funds to adequately support both early intervention and preschool services.

We hope that Congress will consider the fiscal and programmatic realities some states are facing in their efforts to implement this statewide system of early intervention services during this reauthorization.

Another important aspect of this legislation concerns services for infants and toddlers who are at risk of having substantial developmental delays. P.L. 99-457 gives states the option to serve these children if early intervention services are not otherwise provided. NASBE believes that states should be encouraged to serve this population. However, given the fiscal restraints states are facing, we urge that states continue to have the option to decide whether or not to include at-risk children in their state plan. We would, therefore, recommend that flexibility be maintained in the reauthorization amendments so that each state has the discretion to define its at-risk category for the purpose of this legislation.

Within this framework, it is still possible to provide incentives. Because the primary reason states have not included at-risk children in their definition of eligible children under Part H appears to be financial, we recommend that an allotment of discretionary incentive funds should be created and allocated to states that choose to identify at-risk infants and toddlers. Discretionary incentive grants would enable states to undertake expanded outreach to low-income and minority families in generally underserved populations. States would have to apply for the funds and specify how they would be used to reach the underserved population. The grants would be in addition to a state's allocation of service funds.

We also believe that the statute should be amended to facilitate a child's transition from the Part H to the Part B (Section 619) preschool program. The artificial separation of Part H and Part B programs has had an adverse effect on some states that have a more streamlined approach for providing programs for these children. We advocate that these programs be streamlined at the federal level and that states be encouraged to do the same. In addition, we recommend that the comprehensive, family-centered approach used for the Part H program should be extended to the Part B (section 619) program. All eligible children and their families should be entitled to ongoing assessment and case management, and to the development, implementation, review and evaluation of an Individualized Family Service Plan.

In addition to these recommendations, we have a few others not related to the reauthorization of Part H, but that pertain to goals of the Individuals with Disabilities Education Act.

First, we would like to recommend that there be improvements in the overall federal coordination of programs for preschool-aged children. There are many initiatives for targeted populations of preschool-aged children who may be at-risk of poor health or developmental outcomes. There is a need to examine the array of programs in order to determine areas of conflict and overlap with these programs. This is particulary important because of the mandate to provide appropriate education services to all handicapped disabled children aged 3-5. Programs that serve this age group, such as Head Start, state funded preschool programs and state child care programs, are competing to meet the needs of this population of children.

We would also recommend that the amended legislation authorize a study, such as a GAO report, on the implementation of Part B. The information obtained should include: data on who receives special education services and the quality of the education provided; how funds are actually being spent;

how many children are "graduating" from special education into regular education, with particular emphasis on borderline children; and what types of services and programs do these children move into when they enter a regular school program. The report should identify and highlight programs that support parent advocacy for locating and developing options for handicapped preschoolers, as well as listing sources of funds for services to handicapped children ages 3-5.

Moreover, we hope that the subcommittee will consider holding an oversight hearing to seek answers to some additional critical issues that are not tied to this reauthorization, but that are under this subcommittees's jurisdiction:

- Should Congress explore or fund research options to study the need to revamp the current system of special education? The current system model of a separate, special environment is not only expensive but research suggests that it is ineffective. (Gartner and Lipsky, The Yoke of Special Education: How to Break It).
- How should personnel issues be addressed? Currently, thirty percent of special education teachers nationwide are on emergency certification and the turnover rate for special education teachers is much greater than that of regular education teachers.
- A related question concerns the responsibilities of teachers who work with medically fragile children -- will Congress look at ways school systems can meet some of the medical and/or health costs associated with these children and provide more direction on this issue?
- The splintering of special education into an increasing number of categories of special education students is an important issue. As more categories of impairment come under consideration and are included in the federal law for special education, how will the quality of the program be affected? On the related issue of A.D.D., can a method of diagnosis be devised that is more objective than the current behavioral inventories and anecdotal reporting? Such subjective measures may lead to an even greater proportion o ̦oys and minority children and youth being labeled as handicapped rather than simply being in need of other considerations or help in the classroom.
- Finally, a sizable population of children are now entering school with severe emotional handicaps, many of which result from prenatal exposure to crack and other drugs. Others are emotionally scarred due to growing up in the destructive environment of the drug world. It is my understanding that these children are not covered under section 504 of the Rehabilitation Act unless they are drug addicted. Will Congress try to incorporate these children into special education policy? Is this financially feasible? Will the federal government explore other answers for educating these children?

Thank you for the opportunity to provide input into the reauthorization of this important program. I will be happy to answer any questions that you may have.

Chairman OWENS. Thank you.

I want to thank all of you for your testimony. You all have impressive credentials and qualifications. You can be very helpful to us as we reauthorize this legislation.

Let me ask a number of questions and address them to all of you. You may put them together as you see fit in terms of the answer.

First of all, cost. We asked Mr. Wilhoit, who is the Executive Director of the Association of State Boards of Education, and my friends who are policymakers at either the State level or the local level. The minute I mention my connection with special education and disabilities, they throw up their hands and talk about, oh, those programs are so expensive. We just can't take much more of your mandates, et cetera.

So cost, and that is not unrelated to differential funding; so differential funding.

We, in essence, let some States off the hook in terms of pressure. Does that mean that they will continue to pursue the slow—with all deliberate speed—progress toward reaching the goals that we had wanted them to reach in five years; or will they merely save money because of the pressure of the budget, and we will lessen the momentum of the effort by being too kind in our arrangements for differential funding?

Also, on the matter of parents and families being more involved, even in super-coordination and case management, et cetera, it was indicated this that might be a cost-saving factor.

On the other hand, there is a great concern about training personnel and how to train parents to report. Mr. Gallagher, the lead-off this morning, expressed a concern for personnel by saying we should have a set-aside; that from the money that States receive, we should set aside a certain percentage for personnel training.

Does such a mandate solve problems, or does it create more problems?

And, finally, the President and the Governors have set their goals. The first goal of the Governors is that every child should start school ready to learn.

How does all this relate to that goal and what do you think we can do behind the charge of the President and the Governors, what can we do to get the kind of program we need or show where we fit into this all-important every-child-should-start-school-ready-to-learn? Maybe we are on the cutting edge at this point in terms of doing that.

I have said a mouthful, and you can take two minutes each to answer it.

Mr. WILHOIT. First of all, on the issue of family involvement, my sense is that one of the problems has been that the system has not approached families in a way that is conducive to true partnership, and I am not sure the issue there is cost, but a rethinking of how schools operate and how their systems operate in relation to parents.

Often we ask them to approve a program that we have in place, or to work with their kids at home in a way that we have predetermined. We have not asked them to become truly involved in determining the education of their child. And I think here is where this program is way ahead of the thinking of education generally.

One of the problems is that this program has been segregated, both at infant and toddler stage, but also during early elementary ages, and during those—even through the high school ages in the schools. So one of the issues is going to be, how do you begin to pull these concepts and pull this community into the mainstream of thinking about education reform generally?

The second comment I would make on readiness is that I think it is, if the charge in that first goal of readiness, is every child ready for school, is every school ready for every child? And it seems to me that, again, this program is on the forefront of thinking about what we need to restructure in public education, particularly early childhood education.

Those ages are now becoming five-, even six-year-olds, all the way to the fourth graders, eight-year-olds, and so forth; it seems to me could benefit greatly from what has been done in this whole area and from the general thinking of those in early childhood education.

We, as a national organization, are advocating that the concepts—developmentally appropriate curriculum concepts—developed by the National Association for the Education of Young Children be pushed up into the elementary schools as opposed to the higher curriculum, high school curriculum, being pushed down and upper elementary curriculum being pushed down on these children; and we think that is a key concept and something that could be added dramatically to that goal of readiness.

Mr. McWILLIAMS. Mr. Chairman, on the issue of training parents, I would suggest that the higher priority is to train professionals to support families to do what they feel they need to do, and there is a difference between support and training of families.

Secondly, I would concur with Dr. Gallagher, my colleague, on the issue of a set-aside, or at least OSEP research funds to help those States that need help in the development of a comprehensive system of personnel development.

And thirdly, regarding the President's and Governors' first goal of readiness to learn, I would suggest that Public Law 99-457 is more concerned with a closely related issue, which is these children's and families' readiness to live in the most normalized manner possible.

Mr. JESIEN. You did have some very significant questions. Let me just touch on a couple of points.

Chairman OWENS. I wasn't serious about the two minutes, really.

Mr. JESIEN. On the position of States, I think without the differential participation, we in fact will lose some States and the planning activity; the staff that have been collaborating and working together will actually stop, and the system will slowly revert to where it may have been three to four years ago. And so the lead time to do some additional planning, I think, will not take the pressure off, because that is there and there is a momentum building up that I think conversely, without the differential participation, we will really lose the total momentum in some States.

Both in my State of Wisconsin and in others, there almost seems to be a velocity or a momentum that this law has generated by the very fact of families and professionals working together, that as you institute or institutionalize the participation of parents who have children, they will keep pushing that system to the best possible level that it can attain.

And I think that this additional time is absolutely necessary for some States, and DEC also, in its testimony also strongly recommends that those for States that have kept pace and are ready to move into the full implementation the Federal Government demonstrates its commitment by providing direct service or implementation dollars, once a State is ready to as[illegible] full comprehensive services to all eligible children.

And second, on parent participation, let me give a couple of examples that we have learned in Wisconsin. None of the grants that come through from Part H can have a staff that is not, or does not consist of parents also. One of the rules that we have established in our State is that the personnel training grants, that the demonstration sites, the learning programs that we have developed require that a parent be on there as a paid staff person.

What this has really done is change the complexion or the chemistry of the way the early intervention system is evolving, so that in any training program or workshop or conference, you will see parents integral on both sides of the podium, if you will, as participants listening to professionals, and also as providers of information, lecturing to other professionals and participants.

I think that one of the most exciting things that I have seen happening in our States is the recognition of the expertise that parents have because of the experiences that they have gone through.

And then third, in terms of success for learning, I think Part H holds within it the capacity to serve as a model for a whole range of social services that address the challenges that face our society. In some way, I think each child ready for learning or for school does not recognize that we don't need more programs for specific types of children. I think what we need are comprehensive services for the primary context of that child, which is the family, that if we support and enhance that family's capability, the children will be provided the most optimal, natural support that we have in our society.

I would like to see that program's goals or primary care objective be broadened so that each family is enabled to provide their children with the necessary support to make them ready for their future lives and educational years.

Dr. McNulty. Mr. Chairman, let me talk about the first issue of funding and time lines, because being one of the States that is trying to do that and one of the States that is in the fourth year, one of the 17 States, I guess I would like us to reflect on our history just a bit.

Somehow we seem to have skipped over the fact that, if we look at Public Law 94-142, which came out 15 or 16 years ago and looked at kids three to 21, with at least setting the expectation that we would begin to serve children who were age 3. Over the last 15 years, States have been moving towards that goal of serving children three to five. What is it that took so long for States to move even into the three to five?

I think that really what you found was that there were two major stumbling blocks, and they were, one, we didn't have enough programs in place to have enough of a constituency in place throughout our States to affect our own State policymakers. And that is what affects policy. And the second was, the reason we didn't have enough of those was, there wasn't sufficient funding to get programs and services out there to have parents participate in them.

And I don't recommend that we wait 15 years for infants and toddlers, but what we do look at, there is somewhat of a critical mass of services that we need to get out there, and in order to effect the change at the State level. That is what we are going through at this point in time with our infant programs, number one, trying to develop more programs; but number two, trying to link the programs that are out there; and three, trying to get the parents, as the consumers of those programs, to become involved in the political process, so that we can get statewide services to infants.

The dilemma, again, for that piece is oftentimes we are finding that families of very, very young children are somewhat overwhelmed by having a child in the family to begin with, and are not quite ready to become actively involved in the political process.

So all of that is taking a little more time than we had certainly hoped, also.

I don't think the extension is going to take any of the pressure off. I can guarantee you that the reason that we are in our fourth year is because of our interagency council that pushed every—that said, we will stay on the time line. We are going to go for the first year, the first year; the second year, the second year. And we kept pressure on, and kept pressure on the entire State that this was a commitment that we have made to kids and families.

So I don't see that that is going to at all take pressure off in terms of that commitment, because that ball is rolling and it is very, very powerful.

The second part, I think, is a lot like George. We made a commitment in our State that every project that was funded under Part H would have to demonstrate the parent/professional partnership. We have parents involved in every single initiative under Part H, and that is including all of our training, technical assistance; every project has parents involved in it. That is the kind of commitment, I think, that we are seeing.

So while we do want well-trained professionals, we also want to balance that somewhat with the needs of families and not get that out of kilter. And we want parents to assume leadership roles throughout that system. And if they can be case managers, we would like them to be case managers. They can be case managers for another parent, fine.

If we need a professional person to then go in and talk about how it is you apply for SSI, or whatever, fine; we will do that also. But we want that kind of partnership, so that is a balance that we want to find between supporting and empowering parents and having well-trained professionals.

The second part of that, I guess, is—one other thing that we have done in our State is to fund what we are calling "partners in leadership," which is to take parents and provide them with extensive amounts of training and awareness to assume leadership positions.

And this goes back to the first statement around how is it that we affect that political process.

We have made a very sincere commitment, and that partners in leadership project is targeted also towards low-income and minority partners, and it brought those parents in to be a part of the system and has empowered those parents to assume leadership positions, which is what we need to have happen in all of our States.

But the last part around the Governors' initiatives of all kids ready to learn, it is interesting for me, because my Governor is the head of the National Governors Association Education Task Force and has taken that position. However, in our State, what you also find is that the Governor and all of the agency heads started a policy academy about two years ago to look at, how is it that we look at State policy and how it affects children, and how is it that we empower families and children to all be ready for school? And that does include a major initiative in our State for at-risk kids. But it also includes issues like health.

I got a note that said, unless kids are healthy, we can't expect them to come to school ready also. We have a multiplicity of needs that families have, including health and social services and education and all kinds of supports. That is what Part H is all about—interlocking all of those initiatives. But, again, that has proven to be an incredibly complex endeavor.

I, again, have been in early childhood for, you know, almost 20 years, and I can say that this has been the most complex endeavor that we have ever undertaken, because of our trying to work with some agencies to try to get them all to buy into those outcomes. But I think we have that buy-in; now we are in the political arena of trying to get politics to work and to look at resources and to move the agenda down from remediation to prevention. And that is a major challenge to all of us.

Chairman OWENS. Thank you very much. And thank all of you. We like to believe that this very small program is definitely on the cutting edge and of vital importance to education in general. And I think your testimony certainly has reinforced that belief.

Thank you again for appearing.

The hearing of the subcommittee is now adjourned.

[Whereupon, at 11:45 a.m., the subcommittee was adjourned.]

[Additional material submitted for the record follows.]

Consortium for Citizens with Disabilities

April 12, 1991

RECOMMENDATIONS OF THE EDUCATION TASK FORCE OF THE CONSORTIUM FOR CITIZENS WITH DISABILITIES

ON THE

REAUTHORIZATION OF PART H OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

American Academy of Pediatrics
American Association for Marriage and Family Therapy
American Association on Mental Retardation
American Association of University Affiliated Programs
American Foundation for the Blind
American Speech-Language-Hearing Association
American Occupational Therapy Association
Association for Retarded Citizens, Inc.
Center for Law and Education
Child Welfare League of America
Children with Attention Deficit Disorders
Coalition of Representatives of Organizations Serving the Deaf and Hard of Hearing
Conference of Educational Administrators serving the Deaf
Convention of Instructors of the Deaf
Council of State Administrators of Vocational Rehabilitation
Epilepsy Foundation of America
Federation of Families for Children's Mental Health
Learning Disabilities Association
Mental Health Law Project
National Alliance for the Mentally Ill
National Association of Developmental Disabilities Councils
National Association of Music Therapy
National Association of Rehabilitation Facilities
National Association of Protection and Advocacy Systems
National Association of State Mental Retardation Program Directors
National Council on Education
National Easter Seal Society
National Head Injury Foundation
National Mental Health Association
National Recreation and Park Association
National Parent Network on Disabilities
Self-Help For the Hard of Hearing
Spina Bifida Association
The Association for Persons With Severe Handicaps
United Cerebral Palsy Associations, Inc.

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RECOMMENDATIONS OF THE EDUCATION TASK FORCE OF THE CONSORTIUM FOR CITIZENS WITH DISABILITIES ON THE REAUTHORIZATION OF PART H OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

The Education Task Force of the Consortium for Citizens With Disabilities (CCD) is pleased to offer the following recommendations for reauthorization of Part H of the Individuals With Disabilities Education Act. These recommendations were developed following extensive discussion and analysis of the current implementation of Part H. The CCD is a working coalition which is comprised of more than 65 national consumer, advocacy, provider and professional organizations which advocate on behalf of more than 43 million Americans with disabilities.

RECOMMENDATIONS

Extension of Timelines for Implementing Part H Requirements

The Education Task Force of the CCD supports the five years provided for planning and implementation of P.L. 99-457 as an adequate period of time for states to arrange the necessary financial, administrative and service delivery systems to carry out the mandates of the law. The full intent of the law must be achieved without further undue delay. The well-being of thousands of young children and their families would be damaged by a general extension of planning timelines. CCD is therefore opposed to any general extension of timelines for implementation of this important program.

However, in order to accommodate states that are having significant hardship, <u>CCD recommends addition of a provision permitting the Secretary to grant time-limited waivers of specific fourth-year requirements to states which have certified they have had "significant hardship" in meeting implementation timelines</u>. Any such waiver program should include the following criteria:

1. Significant hardship should be defined in terms of obstacles faced by the state in trying to meet the fourth year requirements, and should include such things as major economic difficulties (such as above average unemployment, or a

substantial drop in rate of state revenue increase); inadequate training programs of sufficient size and scope for training professional therapists, case managers, therapeutic aides, or other personnel needed, thereby resulting in severe personnel shortages; the inability to obtain meaningful inter-agency agreements; and the failure of state legislatures to pass critical enabling laws and appropriate funds.

2. The request for the waiver should be certified by the governor as a way of raising the problem to the highest political level in the state.
3. The waiver request should be part of the state's grant application thereby requiring public hearings.
4. The waiver would contain a plan for meeting the waived requirement(s), including specific timelines.
5. The Secretary would have to approve the plan and the timelines.
6. A state would be granted no more than two one-year waivers. The state would be expected to demonstrate that it has significantly met the first year's timelines before the waiver is renewed for a second year.
7. States granted a waiver would receive funding at their third-year "planning" (FY 1991) allocation level as long as the waiver is in effect.

Formula For Funding States in the Fifth Year and Beyond

CCD recognizes that the way funds are distributed to states will have a significant impact on the state's incentive to find and serve children. A census-based allocation formula is appropriate for the planning period and necessary because no reliable data have been available on numbers of infants and toddlers with developmental delays or disabilities. However, a continuation of the current census approach as the sole funding mechanism would reward the state serving fewer children, and would penalize the state that has a strong child find system and thus provides services to a larger number of children.

After considerable discussion, CCD recommends moving to a formula based on child count, which would provide essential incentives for states to develop an aggressive child find system. As a state finds more children, their Part H funding levels would increase.

However, CCD recognizes that since most states lack a track record for serving Part H children, they will need time to phase-in a child count system. We also recognize a state's need for flexible funds for continued planning, administration, personnel training and/or tracking "at risk" children. Therefore, CCD recommends that the Committee consider the following two-part funding formula:

1. Phase-in of Child-Count Formula

   States that have begun to coordinate the provision of services on a comprehensive, state-wide basis would receive significant additional funds based on the number of children the state anticipates it will serve each year, with an adjustment in the subsequent year for over-and under-counting of children actually served. For purposes of the child count allocation, the eligibility definition adopted by the state would control the allocation. The child count formula would not begin until the state is in its second year of providing services. Funds during the first year of services (or the fifth year of the planning period) would be census based. In other words, states that are "on track" would have the child-count formula phased-in during year six; states who receive two years of waivers, as recommended by CCD, would have the child-count formula phased-in during year 7 or 8.

2. Funding for Administration, Training, and Planning

   States would continue to receive a basic level of funding for their ongoing development of administrative structure, personnel training, and planning. States could also use the funds to identify, screen and track "at-risk" children (currently ineligible under the state's definition) to assure that if these children begin to display delays that would make them eligible, they could be referred for needed services at the earliest possible time. CCD suggests a minimum allotment of $350,000 per state with upward adjustments for size.

Discretionary Incentive Grant

Part H, like Part B, must be available to all low-income minority and hard-to-reach families with eligible children. However, for a variety of reasons ranging from physical distance to cultural factors, low-income, minority and rural families are less likely to participate fully in the program. While existing law requires an on-going outreach and child-find effort, CCD recognizes that attracting traditionally underserved families is a difficult challenge which is more likely to be met if states have funds specifically earmarked for that purpose. Therefore, CCD recommends amending Section 623 of IDEA, Early Education for Children with Disabilities, to specify a priority for states to undertake expanded outreach to low-income and minority families and other generally underserved populations under Part H (for example, in many states, rural families). We further recommend report language specifying that in implementing such a priority, states be required to apply for grants and specify how they would use the dollars to reach underserved populations.

Procedural Safeguards

The early intervention service system is an entitlement program. Infants and toddlers who meet the state's eligibility criteria, and their families, have a right, enforceable in law, to receive early intervention services and family support services in participating states.

While infants and toddlers with disabilities and their families are entitled to early intervention services, participation of families in the Part H system is voluntary and must remain so. Participating parents must be provided the information they need to make informed decisions about how their children (and they themselves) will receive services and supports, and states must respect parental wishes in this regard. While Part H regulations fill in a number of gaps in the procedural safeguards system, CCD has several recommendations for further fortifying parental protections, as follows:

1. Confidentiality of records: Public and private agencies should not be permitted to exchange information freely without parental consent.

2. Informed consent on IFSP: The IFSP should be fully explained to and signed by the parents as evidence of their informed consent to the provision of services in the plan. Parental consent is "informed" when:

   - the parent has had explained to him/her all information relevant to the activity (ies) for which consent is sought in the parent's native language or other mode of communication;

   - the parent understands and agrees to the carrying out of the activity (ies);

   - the parent understands and the IFSP specifies which records, including physical documents and recorded information, that will be released and to whom; and

- the parent understands that the granting of consent is voluntary and may be revoked at any time.

3. Parental right to refusal of some services: Parents may refuse a particular service recommended by the interdisciplinary team without jeopardizing their right to the remainder of services. The IFSP form should allow the parents to indicate refusal for some of the proposed services. The parents' refusal may be overridden only if such refusal constitutes child abuse or child neglect as determined by appropriate procedures.

4. Inclusion in Natural Environments: The natural environment for an infant is the family; the natural group environments for infants and toddlers in today's society are day care centers, preschools, and other group settings with age-mates. CCD feels strongly that infants and toddlers with disabilities should be included in these natural environments consistent with Title III, Public Accommodations, of P.L. 101-336, The Americans With Disabilities Act (ADA). We recommend that language be inserted in Part H to recognize the importance of including infants and toddlers with disabilities in these natural environments. We will work with the Subcommittee to identify statutory language that will operationalize these values.

Recommended Amendment to section on Findings

Section 671(a) of the Act lists four findings which set the tone for this legislation. CCD strongly supports the values embraced in these findings, with the exception of Sec. 671(a)(3), which states "to minimize the likelihood of institutionalization..." Since we hold fast to the belief that individuals (especially infants and toddlers) should be in communities, not in institutions, we strongly urge the Subcommittee to amend this finding to read: "to eliminate the likelihood of institutionalization..."

Inclusion of Assistive Technology Services and Devices Under the Definition of Early Intervention Services

CCD recognizes the critical importance of assistive technology in liberating many infants and toddlers with disabilities and their families from barriers encountered in all aspects of daily living, and in significantly enhancing learning and development. We have been made aware of many instances in which the provision of assistive technology has dramatically altered prospects for a child's future - where access to technology has resulted in labels being dropped, in the provision of opportunities in integrated environments, in increased confidence and ability of the child, and in changed perceptions of the child by the family and others.

Assistive technology is currently included in the regulations to the Part H program. CCD believes that adding it to the statute will clarify that these important supports are included as part of early intervention services for those infants and toddlers and their families who can benefit, and thus ensure their provision when appropriate. We therefore recommend that assistive technology services and devices be added to the definition of early intervention services under Section 672(2).

Recommended Amendments to Definition of Qualified Personnel

1. Inclusion of Marriage and Family Therapists

CCD recommends that marriage and family therapists be added to the list of qualified personnel under Sec. 672(2)(F). Marriage and family therapists are uniquely qualified to provide services within the Part H program. Not only do they provide important family assessment, counseling, and psychological services (all of which are already enumerated in the statute), but they do so from a family systems perspective. Marriage and family therapists utilize family systems theories and intervention techniques in providing effective service. As a matter of course, they recognize the family as central to the development of its own therapy plan. They therefore, like the Part H program, support rather than supplant the family through therapy.

2. Inclusion of Pediatricians and Other Physicians

Pediatricians, as the providers of primary health care services for infants and toddlers, often assume the responsibility to perform medical services for diagnostic or evaluation of developmental delays and related conditions. Pediatricians also provide early identification, screening and assessment services, and health services necessary to enable the infant or toddler to benefit from other early intervention services. Pediatricians are an integral part of the early intervention team, along with other physicians who might be involved in the screening, diagnosis and assessment of developmental delays and disabilities. CCD therefore recommends that "pediatricians and other physicians" be added to the definition of qualified personnel under Sec. 672(2)(F).

Consideration of Vision and Hearing Needs

In several places throughout the Act, by omission of references to hearing and vision services, infants and toddlers with vision and hearing disabilities could be in jeopardy of inadequate identification and service delivery. CCD recommends clarifying amendments be added throughout the Act to ensure that this does not occur. We will provide a list of specific references to address this issue.

Issues Relating to Case Management

CCD recommends that the term "case management" be replaced by "service coordination", and that family members be able to act in this capacity when they so choose.

1. Change in Terminology from Case Management to Service Coordination

Families consistently tell us that they do not want to be referred to as "cases" nor do they want their lives "managed." CCD recommends that the term 'case management', at the point of its initial insertion in the Act read "case management (hereafter referred to as 'service coordination')", and that succeeding references utilize the terminology "service coordination" in lieu of "case management," in order to clarify the original intent of the law -- that the family is the locus of control of services. The term service coordination is compatible with the current Part H regulatory definition of "case management." Because of concern over potential jeopardy to Medicaid financing for "integrated case management", we further suggest inclusion of report language to clarify that the Committee intends for the Secretary of HHS to continue to fund service coordination activities for Part H under Medicaid's state plan option for targeted case management.

2. Family Members as Service Coordinators

CCD recognizes that a second issue with respect to services to the family is the current regulation which precludes family members from serving as the case manager (service coordinator) for their child. Some families may wish to share the service coordination responsibility with a professional. Statutory changes are recommended to allow families who wish to serve as service coordinators to demonstrate necessary competencies in order to assume that responsibility for their family member, and to be paid commensurate with other qualified personnel. This can be accomplished by expanding the definition of the term "qualified personnel" to include "family members trained in the delivery of service coordination" (case management). The IFSP section should also be amended to include the possibility for a family member serving as service coordinator, with accompanying report language addressing the need for family training as a prerequisite for this role. Each state must indicate in their state plan how training will be accomplished, such as through use of the Parent Training and Information Center.

Minority and Cultural Issues

CCD believes that the statutory language in Part H should emphasize that early intervention professionals be sensitive and responsive to the needs of children and families from diverse cultural and language backgrounds. Families will have different cultural histories, values, and beliefs that must be recognized and acknowledged. Families may differ in their views of medical care, the meaning of a disability, and in childrearing practices. They may also differ in their willingness to seek help, in their communication style, in the amount and type of their participation, in their goals and in the involvement of family members. Professionals need to be sensitive to such cultural differences, and demonstrate a willingness to adapt to and respect the diverse needs of families and children from different racial and cultural groups. CCD recommends that language be added to the Act to reflect such sensitivity, including use of evaluations that are culturally unbiased, and addressing training needs in the service of a multicultural population in the comprehensive system of personnel development.

Clarification of the Family as Locus of Control of Services

Current "best practice" in family support suggests that family support is much more than a "program" -- it is an attitude. The legislative history and intent of the Part H program supports this approach by recognizing that primary care giving for infants and toddlers belongs to families -- not to systems, agencies and professionals. The legislation builds on the presumption that families have strengths, are competent, and know a lot about what they need. Unfortunately, language in the statute has been interpreted by some professionals in such a way as to allow them to approach families from a deficit/dysfunctional perspective, rather than a competency perspective, and does not clearly indicate that the family is responsible for directing the services and supports which they feel would be of greatest benefit.

Accordingly, CCD believes that the role of the family in this family-centered legislation should be more accurately reflected in statutory language. We will provide a list of specific references for inclusion as "clarifying" amendments to accomplish this goal.

Training

1. Parent Training and Support

CCD has identified a clear need to increase parental ability to participate knowledgeably in the determination of scope and intensity of service needed by their infants and toddlers. Under Part D of the IDEA, parent information and training activities are carried out through federally funded Parent Training and Information Centers (PTI) and the national Technical Assistance for Parent Programs (TAPP). Currently, each of the fifty states has a Parent Training Center. Although the language of the statute does not differentiate between the needs of parents of infants and toddlers and parents of older children, in practice the Centers emphasize training and information for Part B parents.

CCD recommends that Congress modify the current emphasis and increase funding for the Parent Training and Information Centers (PTI) under Part D so that parents of children of all ages can equally benefit from the information and training support they provide. Further, we recommend that each funded Parent Training and Information Center receive an additional $50,000 per year to serve parents of infants and toddlers, thus increasing the authorization levels for the PTI to $3 million.

2. Inservice Training

CCD recognizes that severe shortages of trained personnel are a significant barrier to implementation of the Part H program. CCD is currently working on recommended provisions for inservice training to be included in the reauthorization legislation. We anticipate that this will entail amendments to Part D, Section 632 of IDEA, with the addition of a separate authority for Part H inservice training.

I.C.C. Composition

CCD recognizes that one of the underlying principles in Part H is the inclusion of infants and toddlers with disabilities and their families in the mainstream of community life. Nevertheless, the usual practice in most communities and states is to exclude representatives of generic community resources from policy and program planning. This traditional practice often results in these generic resources being perceived as a part of the problem. By including individuals representing these resources in the planning process, we have the opportunity to let them become part of the solution. This value-based policy takes on further statutory importance as a result of the specific listing of day care centers and private preschools as entities required to be in compliance with the public accommodation mandate of Title III of the Americans With Disabilities Act.

Therefore, CCD recommends that statutory language regarding the I.C.C. specify that it's composition include at least one provider of generic day care or pre-school services, and that at least two of the other members be from "outside" the disability community. In addition, in view of the increasing role that third party private insurance is expected to play in the financing of Part H services, we recommend that the statute be amended to mandate that one of the Governor's appointments to the I.C.C. must be the state insurance commissioner. This person's presence on the I.C.C. will greatly enhance their understanding of the program and facilitate improved communication for families, providers and policy makers with insurance companies.

CCD further recommends that the Director of the Parent Training and Information Center in each state be included on the I.C.C. In addition, because of the importance of parental participation on this Committee, CCD recommends that as a state expands the I.C.C. composition to incorporate these recommendations, the overall percentage of parents be maintained.

F.I.C.C. Authorization

The Part H reauthorization legislation should provide a formal authorization for the Federal Interagency Coordinating Council (FICC) along with language focusing it's operations. CCD will provide additional recommendations on the composition of the FICC, and its recommended responsibilities for developing a formal plan outlining the specific role of each agency in facilitating implementation of Part H and interagency activities. CCD further recommends that the Secretary of Education be given the responsibility to ensure that the FICC is fully staffed and operational.

Schedule of Sliding Fees

The Findings in P.L.99-457 relative to the establishment of the Part H program strongly state the benefits to society, to taxpayers, and to state and federal government, as well as to the child and family, of the provision of family-centered early intervention and family support services in order to reduce educational costs to society, to minimize the likelihood of institutionalization, to maximize potential for independent living, and to enhance the capacity of families so that they will not seek out of home placement.

Current law allows the use of a sliding fee schedule in the implementation of the Part H program. CCD is concerned that a such a fee schedule becomes a significant barrier for some families, particularly low-income and minority families, to access the supports and services necessary to achieve the intended benefits of the program. We realize the critical importance of accessing Medicaid to fund some of the early intervention services authorized under Part H. We further recognize that ability to pay technically cannot be a reason to deny services. However, we question whether the reality of implementation of a schedule of sliding fees is in fact one of services delayed or denied. In addition, we are particularly concerned about the sliding fee schedule in light of the President's budget request, which emphasizes that the Department of Education intends to actively promote such a system. For many non-Medicaid services, the costs of administering a program of sliding fees essentially "washes out" any financial benefits gained from such a program.

CCD strongly recommends that the Subcommittee carefully examine this sliding fee system as it relates to the Part H program, in order to better understand it's practical effect on infants and toddlers with disabilities and their families. **CCD is strongly opposed to the addition of any provisions which would mandate, or in any way penalize or otherwise bias state's decision regarding whether to implement a schedule of sliding fees.**

Authorization Level

The Part H program is responsible for assuring that the eligible child and family obtains the services they need. It is not expected, however, to be the sole source for financing services. Other programs and resources, such as Medicaid Maternal and Child Health, private insurance, and designated state funds, are expected to finance services for which they are responsible. As the law is structured, the Federal authorization level for Part H is the remainder required after all other sources of financing are subtracted and a state share factored-in.

Very preliminary indications are that states have identified 200,000 children as eligible for Part H services. The average cost of service is unknown. The actual cost of implementation will vary from state to state, due to factors such as state eligibility criteria, method used for determining costs, prevalence and utilization rates, average length of time served, and scope and frequency of services provided. Preliminary cost-estimate surveys indicate that average per-child costs are substantially higher than the $1,000 per child formula CCD is recommending for consideration.

Therefore, given the case load and the provision that Part H is the payor of last resort, <u>we believe that authorization for fiscal year 1992 should be a minimum of $250 million</u>. That level would provide an average of $1,000 as the "residual" cost of per-child service, and a reasonable level of census-based funding for continued state planning and administration. Higher authorizations would be needed for each subsequent year as the number of eligible children increases.