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ABSTRACT

This hearing transcript presents testimony on the reauthorization of Part H (early intervention services for infants and toddlers) as well as a review of the preschool grants program of the Individuals with Disabilities Education Act. Statements of the following persons are included: Senator Paul Simon; Robert Davilla, Assistant Secretary for Special Education and Rehabilitative Services; Senator Dave Durenberger; individual parents; Tom Gillung of the Connecticut Department of Education on behalf of the National Association of State Directors of Special Education; Dr. Richard Nelson, University of Iowa, for the Association of Maternal and Child Health Programs; Jonathan Wilson, representing the National School Boards Association; Ruth Rucker, representing the Low-Income and Minority Parent Empowerment Task Force; and George Jesien, on behalf of the Division for Early Childhood, Council for Exceptional Children. Additional material includes articles, publications, and letters from such organizations as the Consortium for Citizens with Disabilities. (DB)

S. Hrg. 102-133

REAUTHORIZATION OF PART H OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

HEARING

BEFORE THE

SUBCOMMITTEE ON DISABILITY POLICY

OF THE

COMMITTEE ON
LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

ONE HUNDRED SECOND CONGRESS

FIRST SESSION

ON

EXAMINING PROPOSED LEGISLATION AUTHORIZING FUNDS FOR THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT, FOCUSING ON PART H, RELATING TO EARLY INTERVENTION SERVICES FOR INFANTS AND TODDLERS.

MARCH 15, 1991

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REAUTHORIZATION OF PART H OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

FRIDAY, MARCH 15, 1991

U.S. SENATE,
SUBCOMMITTEE ON DISABILITY POLICY,
OF THE COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, DC.

The subcommittee met, pursuant to notice, at 9:35 a.m., in room SD-430, Dirksen Senate Office Building, Senator Tom Harkin (chairman of the subcommittee) presiding.

Present: Senators Harkin, Simon, and Durenberger.

OPENING STATEMENT OF SENATOR HARKIN

Senator HARKIN. The Subcommittee on Disability Policy will come to order.

The Subcommittee on Disability Policy is meeting today to consider the reauthorization of Part H, Early intervention services for infants and toddlers, and to review section 619, the preschool grants program of the Individuals with Disabilities Education Act.

Before we begin this review, I would like to note that this past year was one of the most exciting years of my life. I had the honor of sponsoring the Americans with Disabilities Act (ADA). This was a profoundly moving experience for me and one that I will never forget.

Some of you may know that I dedicated the ADA to the next generation of children with disabilities and their parents.

But without appropriate intervention, preschool and special education services provided under the Individuals with Disabilities Education Act, the promise of ADA cannot be kept. Public Law 99-457 has created a new framework for the delivery of services. The statute declares that it is the policy of the United States to assist the States to develop and implement a statewide, comprehensive, coordinated, multidisciplinary Interagency program of early intervention services for infants and toddlers with disabilities and their families. This legislation has been referred to as the most important children's disability legislation of the decade, and I agree with that.

The programs created under this act provide early intervention and prevention services at the cutting edge, and more importantly, they maintain a focus on the family. Better yet, it is already clear

that these programs will be cost-beneficial at a time when we are struggling with problems of limited resources and inadequate care.

So it is no surprise that when the Committee for Economic Development, a group of 250 of our leading executives and educators, identified their top priority for this Nation's economic future, they recommended a major improvement in child development and education.

Their report, "The Unfinished Agenda: A New Vision for Child Development and Education", recommends beginning with good prenatal care, good nutrition and other preventive services, and emphasizes the importance of early childhood education to meet children's developmental needs.

How wonderful that they too focus on the need for family-centered and coordinated Interagency programs. My reading of the testimony suggests that, yes, there are difficulties; yes, there are challenges for State and Federal agencies to develop coordinated policies; and yes, there are new relationships which need to be established between health, social and education agencies and the families.

Change is always challenging—but far more importantly, it is working. And I think it is the most exciting thing that we have in the country today to deliver services to children and their families.

In considering this legislation for reauthorization, I'll be guided by a number of principles. First, any State which truly wants to participate in Part H should be given the opportunity to do so. We must find a way to recognize current fiscal realities while at the same time rewarding those States that have stayed on schedule.

Second, we may need to fine-tune the program, but we don't need any major changes.

Third, significant increases in funding clearly are appropriate when related to increased direct provision of services.

And fourth and most importantly, the program must remain family-centered.

A way must be found for a smooth transition for children as they move through a continuum of programs from early intervention to preschool to elementary and secondary education and beyond. It is clear to me that these goals are achievable, that it is time to get on with the job.

Having said that, I welcome my distinguished friend and colleague from Illinois who has been very active in this area for a number of years, Senator Simon.

Opening Statement of Senator Simon

Senator Simon. I thank you. I wish I could say it was an outstanding statement, but I just walked in, and I didn't hear the statement. But knowing you, I am sure it was.

Let me just add I hope we continue to move ahead in this area. The preschool assistance that we provide young people with disabilities is extremely important to them and to our society. The reality is that we ought to be providing preschool assistance to a great many people in our society, not just those with disabilities. Preschool education, particularly for the culturally disadvantaged in

our society, is something we have to move on—and I know that is not the subject of our hearing today.

The one issue that I assume we are going to be facing as we reauthorize is the question of whether we require the States to meet this deadline. And unless there is some evidence that I have yet to see, I don't see any reason for backing off of that requirement. I think the test of whether we are a civilized society is not whether we help the rich and the powerful; it is whether we help people who really have needs. That is what we are talking about here.

So I hope we can come up with practical answers, but answers that continue to move ahead with opportunity for people.

Thank you.

[The prepared statement of Senator Simon with an attachment follows:]

PREPARED STATEMENT OF SENATOR SIMON

Mr. Chairman, when this subcommittee acted in 1986 to authorize the early intervention programs we are looking at today, we were given a number of reasons by the Administration why we should not move ahead. We were told it was going to be too confusing to the States, that State agencies were not ready to pull together the services—not all education services that were needed, that it was really a job for social services and not appropriate to be added to what was then titled the Education of the Handicapped Act.

But on the other side, we had studies from the U.S. Department of Education itself showing that preschool and early intervention programs had "demonstrated beyond doubt the economic and education benefits" of programs for young children with disabilities. Their studies went on to say that "the earlier the intervention is started, the greater is the ultimate dollar savings and the higher is the educational attainment" by these children.

Today I don't think any doubt remains that we made the right decision in moving ahead in enacting the Early Intervention Services program. Although some States are apparently finding it difficult to take the final steps to full services for these children, we are certainly much farther down the road to providing these services than we would be today if we had not acted. And I think we must continue to move forward. The examples we will hear today about the success of early intervention for children with disabilities and their families—are strong evidence that this program is working and is an important addition to the array of services that children with disabilities need to reach their full potential in school and in their families and communities.

In Illinois a Special Joint Committee on Early Intervention, co-chaired by State Senator Joyce Holmberg and State Representative Terry Steczo, has recently called for a statewide system and $75 million in new State spending over a 5-year period to annually meet the needs of more than 56,000 infants and toddlers who have or will potentially have developmental problems, and their families. In the face of multiple budget pressures, the state is recognizing that funds spent on these children are going to save the state money in the future, and, as they emphasize, prevent "an unforgiv-

able loss of human potential." I would like to provide a copy of the press release on this initiative in Illinois for the record.

It is also encouraging to note the positive statement of Assistant Secretary Davila in regard to this program. I appreciate his commitment to making this program succeed, and I will join my colleagues in looking carefully at the legislative recommendations he is making for the program.

I want to thank you, Mr. Chairman, for your attention to this important program and for calling these witnesses. I look forward to hearing their testimony.

Special Joint Committee on Early (Childhood) Intervention

For Further Information: 217/782-6646

FOR IMMEDIATE RELEASE

Springfield, IL, February 12, 1991--The Special Joint Committee on Early Intervention today called for a statewide system and $75 million in new state spending over a five-year period to annually meet the needs of more than 56,000 infants and toddlers who have or will potentially have developmental problems and their families.

Committee Co-chairs State Senator Joyce Holmberg and State Representative Terry Steczo released the recommendations today in Springfield. Representing the 11-member committee, the co-chairs said a statewide system to address the developmental problems of children ages birth to three would yield valuable returns for the State.

"The evidence is clear--early intervention works. The sooner society responds to help children and families in need, the greater the positive human outcome. The longer Illinois waits, the higher the cost will be in dollars and in the unforgivable loss of human potential," the co-chairs explained in a cover letter to Governor Jim Edgar.

Early intervention means taking action early in a child's life to reduce or eliminate the adverse effects of developmental problems. This action requires a comprehensive coordination of services provided by a variety of human-service agencies. Early intervention does not mean serving infants and toddlers in

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classroom situations, but rather through a variety of community agencies and organizations which serve children and their families.

Early intervention services include developmental therapies, health services, medical services for diagnostic and evaluation purposes, nutrition services, speech-language pathology, vision services, and parental support and education.

The request for $75 million in new state spending over a five-year period to phase in a statewide Early Intervention System would support the additional services provided by the various human-service agencies. Coupled with the state dollars over the same time period would be more than $100 million in federal funds provided through a variety of programs such as Medicaid and Chapter 1 handicapped funds of the Individuals with Disabilities Education Act (IDEA) of 1990.

The State currently provides a fragmented approach towards serving children with developmental problems and their families through public and private efforts. The federal government's enactment of Public Law 99-457 (a predecessor of IDEA) has provided Illinois with federal funds over the past four years to plan and develop a statewide early intervention system.

Under Part H of Public Law 99-457, Illinois currently receives federal funds to support early intervention services for about 8,500 infants and toddlers and their families through various state agencies. The federal dollars over the past four

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years have totaled about $12 million, with an additional $5,074,652 expected for the fifth year of planning.

In order for states to continue receiving federal funds for early intervention services, Public Law 99-457 requires states to adopt a policy which establishes early intervention services as a state entitlement program. Illinois must have such a policy in place to continue receiving federal funds to implement an early intervention system.

The Part H funds have funded 27 pilot sites for early intervention programs, diagnostic centers operated by Lutheran General Children's Medical Center in Park Ridge and LaRabida Hospital in Chicago, a Birth to Three Clearinghouse which provides information on early intervention services and childhood disability issues, and a Central Directory for service linkage.

Citing the need to serve more than 56,000 infants and toddlers and their families through early intervention services, the Committee based its projections generally on statistics provided by the Illinois Department of Public Health. These figures include children with various known delays, e.g., a birthweight of less than 1,500 grams; children with a gestational age at less than 32 weeks; and infants with post-neonatal developmental disability diagnosis.

The Special Joint Committee's report also includes the following recommendations:

- Establish a legal right to early intervention services for all eligible children and their families.

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- Adopt a definition of eligibility.
- Define a State structure to provide early intervention services--geographic boundaries of the local structure as well as to create and empower local interagency councils.
- Assure that the State agency appointed as the lead agency for early childhood intervention services will have the full backing of the Governor and the full support and continued participation of all involved State agencies.
- Name the State Board of Education as the lead agency for early childhood intervention services to coordinate and assure such services, but not necessarily provide these services at the State or local level.
- Mandate agreements between and among the lead agency and the other relevant State agencies in order to assure coordination of current spending.
- Create a central billing office in order to assure that maximum federal resources are utilized and providers receive funds with minimum hassle.
- Mandate maximum use of federal resources, e.g., Medicaid, Healthy Kids funds, etc.
- Appropriate sufficient new State funds, e.g., general revenue funds, start-up and increase of current effort, with a call for further increases for each year of the five-year phase-in period.
- Create an Early Childhood Intervention Ombudsman, within the Office of the Governor, to assist families and local parties, in ensuring that all State agencies serving families do so in a comprehensive collaborative way.
- Establish procedural safeguards for families, in concert with the provisions in Illinois for special education pursuant to the Individuals with Disabilities Education Act.

Former Governor James Thompson issued an Executive Order in 1987 which established the State Board of Education as the lead agency of nine State agencies to oversee the administration of

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federal funds awarded to Illinois under Part H of Public Law 99-457 for the development of a statewide early intervention system. The Executive Order designated the State agencies as members of the Interagency Council on Early Intervention.

The mission of the State Interagency Council is to develop, promote, and ensure a comprehensive, coordinated, statewide system of high-quality prevention and early intervention services for all eligible children and their families.

The Interagency Council is comprised of the following agencies: the State Board of Education, the Department of Mental Health and Developmental Disabilities, the Department of Public Aid, the Department of Public Health, the Department of Children and Family Services, the Department of Rehabilitation Services, the Department of Alcoholism and Substance Abuse, the Planning Council on Developmental Disabilities, and the University of Illinois' Division of Services for Crippled Children.

Also serving on the Council are three parents of children with disabilities younger than age 6, three public or private providers of early intervention services, one representative of the legislature, and one person involved in the preparation of professional personnel to serve young handicapped children.

Legislators created the Special Joint Committee on Early Intervention in 1990, pursuant to House Joint Resolution 114, to study the issue of a new mandate and prepare a report on its findings and recommendations before any legislative action would

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be taken to establish a statewide early intervention system.

Members of the Special Joint Committee besides Senator Holmberg and Representative Steczo are State Representative Loleta Didrickson, Elizabeth Hoeft of Elgin, State Superintendent of Education Robert Leininger, Blanca E. Almonte of Oak Park, Betsy Voss-Lease of Flossmoor, Thomas Gott of Quincy, Erika Marshall of Oak Park, and Susan Walter of Highland.

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Senator HARKIN. Senator Simon, thank you very much for those very eloquent words.

I also want to introduce in full a letter from former Senator Lowell Weicker, now Governor of the State of Connecticut. I want to read just portions of it. I know that many in this room know Senator Weicker and know of his great work in this area when he chaired this subcommittee and later, when I chaired it and he was the ranking member.

"Dear Senator Harkin, Today you are convening a hearing on the first reauthorization of Part H of the Individuals with Disabilities Education Act. This is truly a landmark piece of legislation, and I am proud indeed to have been involved in its creation in 1986." And I will change that a little bit—Senator Weicker was not just involved in it, he was the leader of it, and he is just being a little modest in his statement that he was "involved."

He is talking about Connecticut and about the problems they are having there: "We are facing a $2.4 billion deficit. Without new revenues, fully one-third of the budget would have to be cut out if we were to balance the budget." So he has recommended a combination of revenues and cuts. He says: "The reduction were difficult, and few programs were spared the budget axe. Funding for some programs would be eliminated, funding for others reduced, and funding for still more held at this year's level. Programs proposed for increased funding were few and far between."

"When I studied the budget proposals for the early intervention program, I saw Connecticut at a crossroads We could either significantly expand our State funding in order to meet the statutory requirement to have a statewide system in place and thus continue to receive Federal funds, or we could drop out of the program and hope to re-enter when our budget picture was not so bleak."

"When it came right down to it, the choice was clear. I simply could not recommend postponement of our commitment to the thousands of disabled infants and toddlers in this State who need our special care."

"Our fiscal situation is bleak—no doubt about it—but not nearly so bleak as the prospect of seeing these precious children grow up without the help and services that can make all the differences in the quality of their lives. And what I knew in 1986 when Congress was debating the creation of the early intervention program is even more true today. What today are budgetary costs down the road will be significant budgetary savings in special education, welfare and institutional care."

"As you begin the deliberations over reauthorization of the early intervention program, I want to know that at least here in Connecticut, I intend to fight and win the battle to get the early intervention program up and running."

"Tom, I would urge you to once again provide an increase of at least the amount you did in fiscal year 1991."

"I reminded the legislature in Connecticut that the children of Connecticut did not create our budget problems and made clear my belief they should not be made to pay the consequences."

I can't think of saying it any better than Senator Weicker, and I would ask without objection permission that his full letter be made a part of the record as part of our opening statements.

[The letter from Governor Weicker follows:]

LOWELL P. WEICKER JR., GOVERNOR, STATE OF CONNECTICUT,
Executive Chambers, Hartford, CT, March 15, 1991.

The HONORABLE TOM HARKIN
Chairman, Subcommittee on Disability Policy,
Committee on Labor and Human Resources,
United States Senate,
Washington, DC.

DEAR SENATOR HARKIN. Today you are convening a hearing on the first reauthorization of Part H of the Individuals with Disabilities Education Act, the early intervention program for infants and toddlers. This is truly a landmark piece of legislation, and I am proud indeed to have been involved in its creation in 1986.

Just as its creation was no small challenge during a time of federal retrenchment in many areas of social legislation, the implementation of the early intervention program is no small challenge to states, the majority of which are experiencing budget deficits.

Connecticut is no exception. We are facing a $2.5 billion deficit. Without new revenues, fully one-third of the budget would have to be cut out if we were to balance the budget. Therefore, I have recommended a combination of sweeping changes to our system of taxation in order to enhance our revenues, along with real spending cuts, resulting in expenditures that would be almost 3 percent below the current fiscal year.

The reductions were difficult, and few programs were spared the budget axe. Funding for some programs would be eliminated, funding for others reduced, and funding for still more held at this year's level. Programs proposed for increased funding were few and far between.

When I studied the budget proposals for the early intervention program, I saw Connecticut at a crossroads: we could either significantly expand our state funding in order to meet the statutory requirement to have a statewide system in place and thus continue to receive federal funds, or we could drop out of the program and hope to re-enter when our budget picture was not so bleak.

When it came right down to it, the choice was clear. I simply could not recommend postponement of our commitment to the thousands of disabled infants and toddlers in this State who need our special care. The cost in dollars to our Treasury could not begin to match the cost in humane terms of our failure to go forward. Our fiscal situation is bleak—no doubt about it—but not nearly so bleak as the prospect of seeing these precious children grow up without the help and services that can make all the difference in the quality of their lives. And what I knew in 1986 when Congress was debating the creation of the early intervention program is even more true today: what today are budgetary costs, down the road will be significant budgetary savings in special education, welfare, and institutional care. Therefore, I have submitted to the legislature the necessary legislation, as well as a proposal for a sixfold increase in state funds to enable Connecticut to set up our statewide early intervention system.

As you begin the deliberations over reauthorization of the early intervention program, I want to know that at least here in Connecticut, I intend to fight and win the battle to get the early intervention program up and running.

I know that you are committed to maintaining a strong federal commitment to this program, and that last year, as a result of your leadership on the Labor-HHS-Education Appropriations Subcommittee, this program saw a 47-percent increase. I understand that was a difficult process, and I applaud your success. Your action sent a strong signal to States that this program will not represent another Federal program handed down to the States without the resources to do the job. But, as you know, the coming fiscal year is a year in which most States will have to make the tough decision about whether to stay in the Federal program and implement the delivery of early intervention services statewide to all eligible infants and toddlers, and it is no secret that many States are wavering. Tom, I would urge you to once again provide an increase of at least the amount you did in fiscal year 1991.

On the day I took office, I spoke to the legislature about the challenges we face if we are to turn Connecticut around. I reminded them that the children of Connecticut did not create our budget problems, and make clear my belief they should not be made to pay the consequences. And I believe that is true for all children of this nation, and none more so than infants and toddlers who happen to have a disability.

I know you will do what is right, and what is compassionate, for the infants and toddlers and their families who are counting on you across this country. I pledge to

you that here in Connecticut, we will not fail these children, who ask so little and deserve so much.

With kind regards,

LOWELL WEICKER, JR.
Governor

Senator HARKIN. We now welcome our first witness, Dr. Robert Davila, a long-time friend, assistant secretary for special education and rehabilitative services, U.S. Department of Education.

Bob, welcome back to the subcommittee. Without objection your entire Statement will be made a part of the record, and if you could please summarize your remarks, we would be most appreciative.

Thank you.

STATEMENT OF MR. ROBERT R. DAVILA, ASSISTANT SECRETARY FOR SPECIAL EDUCATION AND REHABILITATIVE SERVICES, U.S. DEPARTMENT OF EDUCATION, WASHINGTON, DC; ACCOMPANIED BY JUDY SCHRAG, DIRECTOR, SPECIAL EDUCATION PROGRAMS

Mr. DAVILA. Thank you, sir.

Mr. Chairman, members of the committee, 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.

I am here to outline and to urge you to approve our reauthorization proposal, which we will formally transmit in the very near future.

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.

During the past 4 years, we have been impressed by the spirit with which the States have accepted the challenge of the Part H program. 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.

Though States are not required to provide Part H services until the fifth year, an estimated 247,000 children are receiving those services. Thus, I am pleased to report that the challenges presented by the creation of the Infants and Toddlers with Disabilities Program have been accepted by the States and that they are working diligently and creatively to develop the comprehensive systems envisioned by the Congress.

During the time we have watched the excellent progress of States in implementing the Part H programs, we have become aware of changes in the program that would facilitate this progress. The administration's proposal will address changes that we believe would help States implement their 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 pre-

school 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 Sate Interagency Coordinating Council be composed of no more than 15 members. 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.

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. 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 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 the system under Part B.

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.

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.

Ms. Judy Schrag, director of special education programs, and myself are pleased to be here and to respond to any questions you may have.

[The prepared statement of Mr. Davila follows:]

PREPARED STATEMENT OF MR. DAVILA

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 will formally transmit in the very near future There are many Federal programs providing 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.

During the past 4 years, we have been impressed by the spirit with which the States have accepted the challenge of the Part H program. During the first 3 years, all eligible States and jurisdictions have participated in the program. During this time each State has designated a lead agency, and has identified the programs and services within the State that will be a part of a comprehensive statewide system. They have adopted policies to establish and operate a statewide system and have determined the infants and toddlers that will be 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. This is an intensive activity requiring an extraordinary level of interagency cooperation and coordination.

Though States are not required to provide Part H services until the fifth year, an estimated 247,000 children are receiving those services. Thus, I am pleased to report that the challenges presented by the creation of the Infants and Toddlers with Disabilities 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 across Federal agencies as we provide support to States. Four national conferences have been hosted by the FICC to help establish networks to disseminate information 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.

At the same time we have watched the excellent progress of States in implementing the Part H program, we have become aware of changes in the program that would facilitate this progress. 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 significantly 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 3 and to use Preschool Grant funds prior to age 3 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 to 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 children at-risk has led many States to reverse their original plans to serve these children. 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 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 8. 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.

Senator HARKIN. Thank you, Mr. Davila, and we are glad to have you with us, Judy.

Mr. Davila, it is my understanding that before Public Law 99-457 was passed, less than 20 States had mandates to serve the preschool population and that nationwide approximately 260,000 children were receiving a free appropriate public education. Because of Public Law 99-457, over 40 States now have mandates, and over 360,000 preschoolers are now served. At the same time, the funding has increased from $28 million to $292 million.

Based on conversations with States that have not yet adopted a policy of serving all 3- to 5-year-olds before the 1991-92 school year, how many of these States do you believe will adopt such a policy by the September 30th, 1991 deadline?

Mr. DAVILA. Today 49 States and Territories have mandates, and 3 of the remaining jurisdictions have reported that they are very close to enacting mandates. So we fully expect that all of the States and Territories will have mandates in the near future.

Senator HARKIN. By September 30th of this year.

Mr. DAVILA. Yes, by the end of the time line.

Senator HARKIN. So the sanctions will not have to be put into place, then.

Mr. DAVILA. We are confident that all of the States will have mandates in place.

Senator HARKIN. Currently Part H funds are allotted among States on the basis of census data. Some groups are recommending that we move to a children-served formula. What is the department's position on moving to a children-served formula at this point in time?

Mr. DAVILA. We support the continuation of a census count with the purpose of determining funding for each State. Under this arrangement, the States would have less of a burden in maintaining documentation of an actual child count. It will be less expensive in terms of administrative costs. So we support the continuation of a census count for the purpose of determining funding.

Senator HARKIN. Would you support the inclusion of a study in the reauthorization to provide the necessary data for the next reauthorization?

Mr. DAVILA. Yes, sir.

Senator HARKIN. It is my understanding that to date the department has approved Part H applications from 13 States; 9 additional applications are pending, and partial draft applications have been received from an additional 13 States.

What is your expectation on the number of States that will submit approveable fourth-year applications within the designated time period?

Mr. DAVILA. As of today, 22 States have submitted final applications, and 13 additional States have submitted draft applications; if we continue to provide technical assistance to the States in furthering development of their fourth-year applications, we are confident that the States will be able to meet the requirements of their fourth-year applications by the cut-off date of June 30.

Senator HARKIN. Thank you.

I now recognize Senator Simon for questions.

Senator SIMON. Thank you, Mr. Chairman.

I apologize for leaving after the questioning; I have another meeting I have to go to, but I hope to get back.

First, Mr. Davila, I hear good reports about your work from my staff—and I have a staff that I rely on, so I'm very pleased to hear these things. In your statement, you saw, "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," that that will save a great deal in paperwork.

Are you confident that will not diminish the services?

Mr. DAVILA. Yes, we are confident it will not. What we want to do is provide orderly transition so there will be no loss of services at any point in a child's needs from the time the child is identified as having a developmental delay to the time the child is actually in school. We don't want any interruption of program services, and I think this proposal will permit us to ensure that will not happen.

Senator SIMON. Thank you.

I have no further questions, Mr. Chairman.

Senator HARKIN. Thank you very much, Senator Simon.

Dr. Davila, we have worked together in the past very closely—when I say "we," both you personally and also the administration—in bringing forward the Americans with Disabilities Act. We

worked on both sides of the aisle, and we worked with the administration and were able to get the differences ironed out and a smooth passage of the bill. I think it is something that we can both be proud of, and if we can work together on the development of the ADA, I know without any doubt we can work together on the early education of our children.

So I am very supportive of your testimony this morning and look forward to working with you as we move ahead in reauthorizing the bill this year.

Thank you again for your leadership, and I join Senator Simon in also saying that I hear good things about your work; please keep it up.

Mr. DAVILA. Thank you very much, Senator.

Senator HARKIN. Thank you very much, Mr. Davila. Thank you, Ms. Schrag.

I want to leave the record open, before we move ahead, for any statement by my friend and distinguished ranking member of this subcommittee, Senator Durenberger from Minnesota. I know he had another commitment early this morning, and I'm glad he could make it here.

I would just yield to him for any opening statement he might want to make before we get to the panel.

OPENING STATEMENT OF SENATOR DURENBERGER

Senator DURENBERGER. I want to begin by complimenting my friend, my colleague, my neighbor and my Chairman for not only calling this hearing, but being willing to explore a subject which is much on our minds and in our hearts as well, and that is children with disabilities and how we can improve the health care system in this country to help these children and their families.

I have a formal opening statement with regard to the Part H program, and to what we are doing in Minnesota in this particular area.

I want to welcome Jeanette Behr and all of the witnesses, of all ages, who are here today including those who will not get to be witnesses but who, by being here, make everybody on this subcommittee feel like what we are doing is very, very important to a lot of people outside this room and back in our own communities.

Senator HARKIN. Thank you very much, Senator Durenberger.

[The prepared statement of Senator Durenberger follows:]

PREPARED STATEMENT OF SENATOR DURENBERGER

Mr. Chairman, I would first like to thank you for the priority you have given to moving this reauthorization quickly. I have heard from several States directly and from the Department of Education that many States have been holding back their applications to the program waiting to see what changes Congress makes to the program during the reauthorization. The concern seems to be that either they doubt the Federal Government's commitment to this program or they expect major changes or added new requirements during this reauthorization.

I believe that it is vitally important that we send an early message to the States that neither are true, that we are committed to

this program, and that any changes we make will be of the "fine tuning" nature and will not lead to significant new requirements on the States. So again, Mr. Chairman, I want to thank for your leadership in taking the initiative in moving quickly with this legislation so that our failure to act does not become an issue in a State's decision whether or not to adopt this program.

Today's hearing is the first opportunity for Congress to review the new Part H program of IDEA that Senator Weicker and yourself notably added during the 1986 reauthorization. The 1986 reauthorization provided for the first time, the framework for a comprehensive, statewide system of early intervention services for infants and toddlers with disabilities and their families.

Right now, most States are at the critical point of making the decision to go from the planning and development stage to full implementation of the program. The timing of this reauthorization gives us an opportunity to review the program, and to work out some of the early kinks so that the greatest number of States will choose to remain in the program.

I began preparing for this reauthorization by going back and analyzing the need and purpose of this program. I could site fancy statistics about what I learned about the importance of what early intervention services means to children and families with disabilities, and the potential savings in the long run, but I prefer to share with you a few stories of what these services mean to children and families in my own State of Minnesota who were not able to come out here today.

Following the passage of Public Law 99-457, Minnesota made the decision to serve children from birth beginning in 1987. So it provides us with a good example of the before and after. I was told the story about a parent, Beth Johnson, a parent of a child with an identifiable disability who lost her child just 1 year after she was born because she was unable to receive the services for her child that could have saved this child's life. That was before P.L. 99-457 and before Minnesota established a system of services for all children.

It has been different for Nicole Anderson and her mother, Maria. Nicole is a graduate of early intervention. Born 2 months early, Nicole was diagnosed with cerebral palsy at 8 months. Shortly afterward, she received her first early intervention services. Through these services she began to learn speech and language skills, first using a photo album to point, then progressing to an electronic system, and finally moving to a verbal communications system. Today at the age of 6, she goes to school full time—half day in regular education and half day in special education. She can speak in four-to-six word sentences with her peers, and has developed friendships with her classmates. Her mother Maria says "For Nicole (early intervention) skills have helped her to become as independent as she can be. And for me—I have learned about the team process and how to make it work for both of us. It has given us confidence for the future."

In addition we will also be hearing later from Jeanette Behr, from Lake Elmo, Minnesota who was one of the pioneers who fought the battle to change the system in Minnesota so that her daughter, Katy, could get early intervention services.

Mr. Chairman, the need and the benefits of early intervention are evident. Even so, we face difficult decisions ahead during this reauthorization. As you know, the real burdens of this program are on the State, not the Federal Government. A study was done analyzing the Indiana, Maryland, Texas and Washington programs. The study found that the Federal Government provided between 2.6 and 9 percent of the total funding for the early intervention program. It is important to note that this study did not include Federal funding from other related programs such as the Maternal and Child Health Block Grant or Medicaid. We simply so not have information available on the total Federal funding. However, I think it brings into perspective the tremendous financial obligations States are picking up when they choose to participate in the program.

I mention this because the decision by States whether or not to proceed with the program just happens to come at a time when many States are facing severe budget crisis—including my own State of Minnesota which expects to face a $2 billion shortfall over the next 2 years. The budget problems facing States are real and we here in Congress must be mindful of this reality as we move forward. At the same time, we cannot forget those States who have made the tough decisions and financial commitments and have already moved forward in this area and we must not do anything that will in anyway penalize them for doing what we asked.

I think we need to be mindful of the various mandates and requirements that we have asked of States under this legislation. I have heard, for example, about the difficulties my own State has had meeting all the integral components of the 14 requirements of a comprehensive statewide system under the law. This is from a State that is already serving these children. I can imagine the problems other States are having. I bring up this point because in general I do not believe the Federal Government has the right to mandate requirements on the States without providing the financial backing to uphold the requirements, and I think this is especially true for this program. There simply is not any more room for additional requirements on the States.

These are many other issues, the debate over the funding formula, coordination between Part H and the 610 program, the membership of the ICC's, and many others as well. I look forward to the testimony from the witnesses here today, and to working with you in continuing the Federal commitment to this program.

Senator HARKIN. Now we are calling our first panel, which consists basically of families. After all, this is a family-centered program. Of course, we wanted to hear the administration's position on this first, but after that I think we should look to the families, and hear what the parents have to say.

We have Michelle Marlow, a parent from Baltimore, MD; followed by Robert, Diane, Monica and Gretchen Sanny from Fairfield, IA; and Jeanette Behr from Lake Elmo, MN.

We'll hear from Michelle Marlow first, then the Sanny family, and then Jeanette Behr. We have copies of your testimony, and we'll put that in the record in its entirety. I'd appreciate it if you'd just tell us in your own words what you'd like us to know today.

Michelle.

STATEMENTS OF MICHELLE MARLOW, PARENT, BALTIMORE, MD; ROBERT AND DIANE SANNY, PARENTS, FAIRFIELD, IA; ACCOMPANIED BY DAUGHTERS MONICA AND GRETCHEN; AND JEANETTE BEHR, PARENT, LAKE ELMO, MN

Ms. MARLOW. Thank you, because that's what I'm most comfortable with.

Mr. Chairman and Senator, thank you for the opportunity to be here to share my views with you this morning. My name is Michelle Marlow, and I wear a lot of hats. The primary hat I wear is I am the mom of Tanika, who is a 12 year-old who has the following diagnoses. She has mental retardation, a seizure disorder, and cerebral palsy. Tanika is almost 13 years old, so we are dealing with becoming a teenager these days.

I am here because it is very important for me that you understand the 12-year path that we have taken to get Tanika to the point of being a pretty self-sufficient little 12-year-old given the life and circumstances that she was born into.

We were lucky because—let me go back to when she was born. For the first 2 months of life, Tanika presented perfectly in my mom's-eye view. Up to 2 months of age, she held her head up, she was a responsive, cooing baby. And then we had what most children have, which is that first DPT shot, and after that, within days, she began to change.

Just to relate that first experience with her change, she had been laid down for a nap; I heard her fussing so I went in to pick her up, and we came from out of a dark room into a light room. Her eyes were blinking, and there was some moisture around her lips. I thought that because we had come from out of the dark into the light that that was why her eyes were blinking; I thought she was focusing. I'm not a doctor; I thought she was focusing. That stopped, and then it started again; she started again with the eye-blinking and some twitching and again the moisture around the lips.

So we called the ambulance, and she had stopped and started again before the ambulance arrived. When the paramedics came, that was the first time that I had ever heard the word "seizure." She was rushed to the hospital, and that was the beginning of our jaunt into the world of disabilities.

Again, Tanika was 2 months old. For the next year she was in and out of the intensive care unit, with them trying to stabilize this seizure disorder.

Just to give you some idea of the intensity of seizure level, doctors reported at her worst point that she was having somewhere between 100 and 150 seizures a day. So when I went to see my daughter at the hospital, or when I stayed by my daughter's bedside, most of the time she was seizing, or if she was not seizing, she was so medicated she was asleep.

After about a year, medically she began to stabilize, which meant that the seizures become more under control.

Senator HARKIN. They were giving her medicine for the seizures?

Ms. MARLOW. Of course. She became more under control, and it was time to think about discharge and discharge planning. Again, medically she was becoming more stable, and we started to notice that she was not the child that she was before. She could no longer hold her head up. Her right side appeared paralyzed. Her right hand and arm were clenched and held to her body.

I had mentioned the discharge plan. The discharge plan was one of "take your daughter home and love her," to take her home and love her. But this was a child who was not the responsive child of the months previous to illness.

So I wanted more. I wanted my baby back. I wanted my responsive child back. And to "take her home and love her" was not enough. It was not enough. I was reared to expect more. I was reared to believe that a person is to be productive in life, and my charge as a parent to this child is to create that opportunity and advantage for her to be productive. So I couldn't accept what the medical community was telling me, which was to "take her home and love her."

We did get a visiting nurse who would come out—and just to give you some understanding of what discharge home meant, Tanika was on an around-the-clock medication schedule, so every 2 hours we had to wake up and give her medicines for her seizures. That is no way normalizing at all. But as time went on her seizure disorder began to get better, and I started to question doctors about, well, what else is there. She appeared to be someone who had had a stroke, so isn't there something that we can do.

We were hooked up with therapists through an infant stimulation program that we went to at the local hospital, and that was the start of being exposed to things that were going to take us forward through life and take this child forward in terms of development. That began between the 1 year and 18-month level of her age of development.

Therapy was the key, and therapy that began very early in her life was the key to her being a walking and talking, responsive pre-teen, the pre-teen that she is today—I mean, talkative too much sometimes, as most kids are. And I am not trying to say anything negative about the medical profession, but early in a child's life we need to begin to identify where we go from here—how do we help this child and family put the pieces together to move on and make the assumption that there is competency within this child, competency within this family, and we have to do our darndest to get them on the path to progression.

I believe Part H will help to answer that question. As a family, you sometimes wonder with the service system where do I get on the merry-go-round. The merry-go-round is revolving around and around, and that is the service system. But where do I put my foot on in a way and at a place that is going to benefit me and enable me to help my child to live and learn and grow.

That brings to mind the question of a single point of entry. One of the most helpful things that I came across early on was a social worker who was able to answer my questions, which I always prodded; I always wanted to know what is the justification for her not being able to use her hand; why are you saying that we won't be able—doctor, you are telling me to take her home and love here,

and this is the best that it is going to get. It can't be. I will not accept that. So I continued to ask questions about how do we address the fact that she is not talking; how do we address the fact that she is not sitting up; how do we address her development. I would not rest until I got answers that were helpful to us as a family.

I steered clear of providers that looked at us as a dysfunctional family. There are people that I have dealt with in our past who assumed because I was the black single parent of a child with a disability that I had certain expectations—which is true. The expectations I have and had are those that I Stated before. That is, that it is my job as Tanika's mother to ensure the best that she can be and give her the opportunity to be the best that she can be.

It is plain and simple. We are talking about helping families to do their job, to be parents and families to their children. It is that plain and simple.

One of the things that I do in Baltimore is I am real active in a local group that is interested in fighting to get kids with disabilities in regular schools with the support services that they need. I think I am kind of well-known to them for that. But it is important—it is important early on that we think of our kids and the system thinks of our kids as people.

Through life and through the disability field, they are fighting on the adult end. And the bottom line that they are fighting for is for people with disabilities to be recognized as people. It is so simple—at least i. is simple to me—isn't it simple to you—we are talking about people. And the same consideration I hold for myself, I should hold for you and try to make that happen for you. It is that plain and simple.

Thank you for your time.

Senator HARKIN. Michelle, thank you very much. That was very moving testimony. [Applause.]

[The prepared statement of Ms. Marlow follows:]

PREPARED STATEMENT OF MS. MARLOW

Mr. Chairman, Senators, thank you for the opportunity to speak to you this morning. My name is Michelle Marlow, and I am the parent of Tanika Marlow who is twelve years old. Tanika has a large list of labels which result in severe multiple disabilities. She is currently in a separate school in Baltimore County. I am afraid I am well known to the school system as one of those parents who is fighting for my daughter's right to be integrated into the regular school system.

My testimony will focus on the difficulties that families of infants and toddlers with disabilities face when they do not have strong supports available to them during those challenging first years of their child's life. We know that infants who receive strong and appropriate early educational and therapeutic services will have a much brighter future than those who do not. This is reason enough to create a strong system of early services. But this is only half the formula. These services cannot be provided in a vacuum. The family is the most important entity in this young child's life, and by definition "strong" must mean within the family structure.

Let me start by telling you a little about myself and my daughter. In August, 1978 I gave birth to a healthy baby girl and she progressed just as she should for the first 2 months of her life, until she was given a DPT shot. Overnight she changed. The memory of my baby as she went into the first of her endless numbers of seizures is still chilling to me. She was in the hospital for 10 months moving in and out of the intensive care unit as they stabilized her condition. During that time I was totally dependent on the medical community for my daughter's well-being. She was finally discharged when she was one year with the need for around the clock medication

and attention. The discharge plan was a message to take my baby home and love her. The plan also included a visiting nurse once per week. Otherwise, her care fell totally on me and my parents with whom I was living at the time. I was 18 years old and was a single parent. From the beginning of Tanika's life mine was totally changed.

The doctor's message was wrong. There was much more I could do for my child than love her and wait for her to die. The tone for the family and their expectations for their infant with a disability is often set by the medical community. This is their first support system and often it is less than a support. Doctors sometimes see a infant with a disability as marred individuals for whom there can be no valued future. How many times have we heard of doctors advising families to put their child away and get on with their life? Thankfully, we have moved away far from such a prognosis, but I believe we have a long way to go before we have totally sensitized the medical community on quality of life issues for individuals with disabilities. This is a very real Part H issue.

Tanika and I were lucky. There were both infant stimulation and family supports available to us in Baltimore at the time. And I am by nature not one who takes life as prescribed for me by others. I must have driven folks crazy with my questions, but I was like a dog with a bone. I would not stop with take her home and love her. I wanted to know what it meant when they said she had epilepsy, mental retardation and cerebral palsy. What could I do for my daughter to give her the best possible chance in life.

The system worked for me because I made sure that it did. This is not true for many parents. Parents who are not as tenacious as I, who have not been taught as I was to always ask questions, can be very frightened totally controlled by bureaucracies.

—Let me tell you about Joan, whose premature baby stopped breathing in the fourth month of her life, resulting in permanent brain damage, cerebral palsy and other disabling conditions. Joan was not as lucky as I. She was young, she had another baby at home who was not yet one year, and she was very frightened. The system seemed to prey on her fears. Infant stimulation could only be provided at a center and the center refused to allow siblings to accompany the parents. On a very limited income, she had to place her 10 month old in day care from two to four times per week so she could take her baby to the center. She was given no explanations about her daughter's circumstances: she did not understand the labels and needed someone to assist her in the art of questioning. When she finally did begin to question the system about services which ultimately turned out to be totally inappropriate for the young child, she was informed that they could take her child away if she refused their treatment. This young woman lived in constant fear that the State would take her baby away from her and she cried for one solid year, along with her baby who was traumatized from the inappropriate services. Perhaps the marriage was bad in the first place, who is to know. But it was not too many years after this child was born that Joan's husband her to raise her children alone.

—There must be large numbers of families, like Joan's, that have broken under the strain of an inappropriate system of services. Tom is a young man in the midwest whose parents split up after his mother had several breakdowns and the psychiatrists finally gave his father the choice of giving up Tom or his wife. Tom has multiple disabilities and it has been an uphill struggle for his father to keep him in school programs in his own county. Tom, like Joan's daughter, received early intervention services. However, even though there were real signs of that the mom was suffering unusual mental stress during this time, there were no supports available until she finally collapsed under the strain of her life. Tom's father readily admits that he was a typical workaholic, not understanding the need for him to fully participate in his infant's development until it was too late for his wife. I would hope that the family-centered services under Part H would have identified the stress points in this family and would most likely have enabled it to stay together.

Families come in all shapes and sizes and circumstances. The middle-class family has become much easier to find and, for the most part, to support. But what about families who are harder to find and for whom middle-class is unachievable. Rural poor, urban minority, ethically diverse infants and their families have fallen through the cracks for years:

—The family whose teen-age son has not been in school for four years because the mom did not understand the system. Urban poor, dependent on housing subsidies and other public welfare assists, inability to communicate with a bureaucracy that is not responsive to their particular circumstances. I wonder what might have happened for this young man and his family had there been a system of supports from his early years, supports that would have individualized to their particular circum-

stances. Would he have wasted four years of his teen-age years at home, unnecessarily bedridden by his mom who chose to work outside a system that she did not feel was responsive to them?

--The young boy in special education in rural America, severe behavior disorders and only vestiges of language, found locked in a room where he had been for most of his young life. Professionals feel that there was nothing "wrong" with this young man except that his family had locked him away from the world, raising him in isolation. A family in crisis. How much better and different would this child's life and future be, had there been an aggressive Part H system in his home county?

—The service coordinator who on her first day of work four years ago called to follow-up on 8 month old twins who were in the child find system. She was told: "I am sorry, I guess you were not told about my sister." Suicide one month earlier. "The systems didn't come in time," she was told by the sister who was left to raise the twins.

—Another poor urban family for whom services were virtually unattainable because they had no telephone. The system couldn't reach them and they couldn't reach the system in today's high tech world, because there were no funds to pay for telephone.

—The mother who was unable to keep her young child, not because she didn't want to and not because she would be unable to care for her, but because she lived on the fourth floor of subsidized housing with no elevator; her health prevented her from carrying the toddler up and down the stairs and there was no other housing available to her.

Part H is not about housing or telephones, but it is about linkages with other systems. I would hope that each State would have a system that would effectively operationalize a single point of entry for families, providing them with access to whatever supports are necessary for themselves and their infant.

These, and many others that I could share, are stories about families and their young children. The family is the natural caregiver and as we move forward with the implementation of Part H, we must move with great care to guarantee that it does not become yet another specialized system of services which has the potential of being crippled by "administrative convenience". If the IFSP is individualized on paper only, we have lost. You have before you a program that is of critical importance to the lives of thousands of infants born each year with disabilities. Please make sure it works for them.

Senator HARKIN. Next, let's turn to Bob and Diane Sanny, and Monica and Gretchen, from Fairfield, IA. Again, we have your Statement, and we'll put it in the record in its entirety.

Bob or Diane, whichever one or both, however you wish to proceed, please tell us what you want us to know today.

Mrs. SANNY. First of all, we are honored to be here. We have the product of the system as it works ideally in Gretchen, and Monica, and in our family. So we'd like to tell you a happy story, which didn't start out very happy, actually.

When we took Gretchen home from the hospital for the first time, she was 10 weeks old. She had been through major surgery, several near-death episodes, and endless, endless painful medical procedures. But she had a lot going in her favor in that we were all very thankful that we could be together again, and we immediately were hooked up with the area education agency in our area, even though they told us that they had no idea what we could expect the outcome to be with Gretchen. She was being fed through a tube in her nose; her arms and her hands were completely paralyzed, they just hung lifelessly at her side. And you can see how she is today. Her legs were casted up to her hips. We didn't really know what the outcome of that would be. She had severe club feet. And I guess her whole general body tone was very, very weak. "Low muscle tone" is what they call it.

We didn't know if she would be able to speak because she could not eat, and those two functions are very intimately connected.

So we were pretty scared. Actually, we were very scared and very overwhelmed by the whole experience. And I think that had we been alone, I don't know what we would have done, and I don't know what the outcome would have been. But we weren't. We had a lot going in our favor. I think it helped that we were older, more mature parents. Maybe some people think we are too old to start a family—like our parents thought we were—and we came from a very, very close and supportive community, which was a huge help, too.

But the biggest thing was that we lived in Iowa, and Iowa is a birth-mandate State and has been for a long time. And because of that, the area education agency provided us immediately when we came home from the hospital with a preschool teacher who came to our home, a physical therapist that came to our home, and an occupational therapist.

All three of these professionals would come and do their services there. We didn't have to abandon Monica to daycare centers. She was only 4 years old at the time. So the integrity of the family was maintained throughout that.

The women who came guided us every step of the way. They were completely supportive and knowledgeable. As I said before, I have no idea what I would have done without their input because we didn't know what to do with a child whose arms and hands did not move. We had to bring the whole world to her. She couldn't sit up when normal kids sat up, and she couldn't reach out for something that she wanted to play with and stick in her mouth. We had to do all of that for her. And they told us what was normal and how to have her have those normal experiences at the right time. So she was getting that stimulus that was necessary to her nervous system—that's the way I thought, anyway—for it to develop in a very normal progression.

They also emphasized that we were the ones who should be doing this; that we were the natural caregivers; that it wasn't for someone in a center somewhere, some therapist on a daily basis to be working with her, but that we were the natural therapists. So what they did was teach us how to incorporate it into our normal routine so that on a day-to-day basis she was getting what she needed.

So here she is, 3 years later. She is still fed through a tube; she still doesn't know how to eat correctly. We don't know what the outcome of that will be. But she is very happy, she is very bright—almost precocious—she is very social, as she said "Hi" to you in the microphone when she came up, and she is a complete delight; we just adore her.

And Monica has come through it very well, too. She is very strong, very secure, and happy—and shy. [Laughter.]

So I can't really begin to think of what Gretchen's life would have been like without the input that we got from the area education agency. They still to this day come to our home and monitor her. And we are led to believe that—I don't know how long this is going to go on—but until she is completely at her maximum development, we'll have that input.

So the girls are thriving, but what about us through all of that, what about mom and dad? We had a lot of responsibility. We were the therapists. And also, Gretchen wasn't able to eat. Her digestion

couldn't tolerate any prepared formulas, and they had to be tubed in. So I was spending two hours a day cooking, pureeing, straining, blending, and then I'd have to tube feed her five times a day, which altogether was almost four hours of my day just keeping her fed, on top of all the other responsibilities of being a mom with a regular family and normal functions in life.

So what it came down to was that there was a point when 1 day the physical therapist asked me, "How are you doing?" and I looked at her with fatigued eyes and depressed demeanor, and I said, "I'm drowning. I am drowning in my life." Up until that point I really didn't know—I thought I should be able to do all this. I'm the mom. I should be able to do all of it. And it wasn't until she sort of reflected that back to me that I realized that I wasn't doing it, that something was wrong.

So she suggested that fortunately at this very time, Part H was being implemented in the State of Iowa—this was last year. So she suggested that we be a part of this, that we have an IFSP, an individualized family service plan, done. So we were the first family in our area; we were the pilot family.

The assessment itself actually was the most beneficial thing to us. There were seven professionals who came to our home. This was the first time they had done it, and they really didn't know who was necessary for one of those things, so we had the department of human services, we had public nurses, we had a couple of education people, and we had social workers. Seven ladies trooped into our living room. Just talking to them—first I was so overshadowed by their sheer numbers—but I felt their support, and that was to me the most beneficial thing was for them to say, "It's okay. There are ways we can help you. You don't have to do this all alone. You don't have to drown."

Immediately what came of it was that I told my husband what happened that day, and he started helping. That was the immediate result. He had been working day and night, trying to start a business. He cut back on his hours and started to share the load with me in the kitchen. He is very good in the kitchen.

Mr. SANNY. Better than she is. [Laughter.]

Mrs. SANNY. He is more efficient. He is the efficiency expert.

Anyway, with this IFSP it was also very educational. They explained to me the complete system. There is a huge system out there, already in place, and I had no idea it was there. They gave me the telephone numbers and the contacts, people to actually talk to; actually, some of them were sitting right there in my living room. And that was extremely beneficial. So at any time in the future, if things should change, I know how to—I think the word is "access the system." So this is extremely beneficial to me.

Unfortunately, the two programs they recommended were child care, and at that time the funds in our area in Iowa had run out. They had used it all up for the previous year. I don't understand the whole thing, but I just heard that recently there are monies available. The other thing was in-home health care. This would have been someone to come in and give me a hand, maybe three hours a week or so. I applied for this, but we had a very difficult time accessing the system.

My major impression was that the department of human services in Iowa is overworked, understaffed, too many cases, their case load is too heavy, and they are underfunded. So we finally just gave up. It was too frustrating, already at a time when we didn't have much time to be trying to continually deal with getting help from these people. But in the future I think I will not hesitate because our life has gotten a little bit better.

In closing, I want to say that we feel, we have every reason to believe, that Gretchen is going to be a productive, fulfilled, happy individual when she grows up. And I know in my heart that it is because she was reached at such a tender age, and I feel that there are miracles out there. They call her "the miracle baby," and there are miracles out there waiting to be worked. It is just that the kids need to be reached immediately; that's when it is the most important.

And also, our family is happy. We were saved, too.

So I thank you, and it was all due to the laws that have been passed. So thank you.

Senator HARKIN. Thank you. That's a great story. [Applause.]

[The prepared statement of Mrs. Sanny follows:]

PREPARED STATEMENT OF MS. SANNY

In April of 1988, we took Gretchen home for the first time after 10 stress-filled weeks of hospitalization during which time Gretchen had stomach surgery and several near-death episodes. Needless to say, we were scared and overwhelmed. But we were also thankful that our family could be together again. Gretchen was being fed through a feeding tube inserted into her nose; her arms and hands hung lifelessly at her sides; and her legs were casted up to her hips. No one could tell us if or when she would be able to eat, speak, walk, or move her arms and hands.

Two questions stayed with me. What is the quality of her life going to be? And what can I do to make it better? Also I was very concerned about Monica, her older sister. I had read that often the siblings of children who are disabled can feel so neglected that they wished they were the disabled ones. But fortunately we had a lot of things in our favor. We were older, more mature parents. We had a solid marriage. We had great health insurance and came from a very close, supportive community. And we lived in Iowa, a birth-mandate State—we were not alone. Through the Area Education Agency the State of Iowa provided a home intervention preschool teacher, physical therapist and occupational therapist from the time Gretchen was 3 months old. All three of these professionals came to our home which meant that Monica, who was then 4, was not abandoned while Gretchen was receiving services. These women were a wealth of ideas and fountains of support, and guided Gretchen's development every step of the way. The emphasized that we were the Gretchen's natural care-givers and therapists and, as such, they taught us how to include therapeutic exercises into our daily routine.

Three years later Gretchen is still fed through a tube, but she is a bright, lively, walking, talking, charming little girl. And thankfully her arms and hands have limited function which continues to improve. Monica has come through the ordeal remaining strong and secure.

I cannot begin to image what the quality of Gretchen's life would have been without the knowledge, direction and support we received. And thankfully, it all happened in our home where Gretchen still continues to be monitored by both occupational and physical therapists.

So the girls are thriving, but what about the parents? A host of therapies were basically our responsibility. And since Gretchen's digestion could not tolerate any prepared formulas, I spent two hours of each day cooking, juicing, blending and straining her special diet. And to top it off, she had to be fed five times a day. This, of course, was all in addition to my "normal" responsibilities—I was drowning.

However, as our good fortune would have it, at this time, Part H was begin implemented in Iowa; and we became the first pilot family in our area to have an Individualized Family Service Plan done. The process itself, the evaluation, was extremely beneficial because having to explain to these various professionals what I was feel-

ing for the first time clarified why I was overwhelmed and exhausted by life. The results were immediate. After hearing the outcome of the IFSP, my husband, who had been working day and night starting a new business, immediate cut back on work and began sharing the load in the kitchen. My life was saved.

The IFSP was also educational. I learned what programs were available and I was provided with contacts and phone numbers. The two programs that were recommended to me were childcare and in-home health care. Unfortunately, all childcare funds had been exhausted, and we eventually gave up on in-home health care as a result of difficulty in accessing the system. Throughout this process, it was my impression that the Department of Human Services was understaffed and underfunded. It goes without saying that this needs to be addressed.

In closing, I cannot emphasize enough the impact that these services have had on our lives. For Gretchen, it means a brighter future than we ever imagined. There's little doubt that she'll be a self-sufficient, productive member of society due largely to very early and excellent care she received. As for Bob and myself, having a child with disabilities has been the greatest challenge of our lives and we have coped well with much thanks for support we were given.

Senator HARKIN. Jeanette Behr, from Lake Elmo, MN. We are privileged to have you here today, as well as our distinguished Senator from Minnesota. Your statement will be made a part of the record, and please tell us what you want us to know.

Ms. BEHR. Thank you very much, Mr. Chairman and Senator Durenberger.

I am Jeanette Behr, a parent of three children, so if Diane is old, I'm a dinosaur. [Laughter.]

My daughter Katherine is now 8 years old and has autism, which means that she has great difficulty communicating and interacting with other people, and also interprets her world quite differently. If I could get inside of her head for 1 day, I could explain it more how she interprets the world.

I would like to introduce to you today the interagency puzzle—and I'm not sure if you were given one of these, but you will be.

Senator HARKIN. I have one of these; what is it?

Ms. BEHR. That's it. If you can imagine this interagency puzzle and put a picture of a child on one side, parents and siblings on another, professionals, community health care, and there could be others, medical, on each side of this cube, this is my visualization of Public Law 99-457. And as you can see, when you move one piece of the puzzle, it changes how the other pieces fit together as well.

I don't mean to say that this puzzle is a negative connotation. I think that the flexibility and creativity and individual solutions that can be reached in solving this puzzle can produce growth and development and a sense of accomplishment.

I feel in looking back, searching for early intervention when my daughter was born, before Public Law 99-457 was passed, and seeing how things have changed now as she is 8 years old, I have seen great progress. I do feel that one of the overriding issues is health care access. This is a bigger issue than just Public Law 99-457, and yet it affects everything that we are trying to do here.

Health care can be doubly difficult to access for children with disabilities, and it definitely affects their families as well. And I would urge you, Senator Harkin and Senator Durenberger, to continue your efforts to address those needs.

I think case management is another puzzle; a term we use when we talk about how do you pull everything together, how do you get

this puzzle to fit, which is a challenge, I can tell you; I did it all the way on the airplane.

Senator DURENBERGER. I've got it down to the last piece. [Laughter.]

Ms. BEHR. Well, I didn't want to make it too easy, because as families can tell you, it's not.

My daughter right now has at least four case managers, including me, and sometimes after 8 years, I am rather unwilling to play that role.

I would not say that one person could manage effectively all of her educational, health care, safety, growth and developmental needs. But I would say that we can do a lot more right now with what we currently have to coordinate how case management is delivered and how people who have some part of case management communicate with each other, how they communicate with families, and how they coordinate what they do.

For example, I have seen in the 8 years that my daughter has been alive that schools and counties did not speak to each other in the beginning. When we originally got services, it was an infant stimulation program through the county; then people kept thinking that Katy was blind, which is very typical for children with autism—they act like they don't see. Eventually, because of that, we got into an educational system for visually impaired children, and the county closed the file on our family. That was it. Goodbye. You're in education. We're done with you.

Today it is very different. If I go to an IEP meeting, an individual educational plan meeting, my county case manager will come along, the service provider, the people who work with Katy and our family in our home, will come along, and we can together build a much more effective plan that carries out strategies not only the six hours that she is in school, not only the 4 hours on a Saturday when we have a break from supervising Katy.

So I would encourage you to continue your efforts to build coordination among and between systems before we get overly concerned about how to continue the issue of funding.

I did submit an interagency process analysis that will shed more light on this in my written testimony.

Also under the IFSP, which I think Diane explained so well, we have tried to get away from evaluating a family, and I don't think a system has a right to come in and evaluate a family, and I think most of the professionals in this room would agree that that would be extremely intimidating.

However, we have come up with trying to elicit a family's concerns, priorities and resources in regard to enhancing the growth and development of their child's future.

I would like to submit that we could use the term "preference" instead of "resources" because that would more clearly lead to how services are delivered in a way that fits the family's routine. I think as Diane alluded to, you get into a situation where you have all these responsibilities for your child, and you attempt to do it without questioning—is this the way that it works for me. If we could use the word "preferences" in section 303.344 of the Federal Register, it may be more clear to service providers that we need to

ask how is it that you live your daily life, and where is it in your daily life that you have time to do this or to do that.

Underlining that issue, the outcome of that is a more effective service. If I have a therapy that I can fit into Katy's daily routine and do it every day when it fits my schedule, it is far more effective than if I have to drive 60 miles away, two times a week, as I originally did when Katy was born. So those, I think we need to continue, and I would like to see the word "preference" included.

The last idea that I had when thinking all of this over was the idea of power. Before my daughter was born, I was going to run a marathon, and I didn't do that, but I got Katy instead. Actually, when Katy was two, I did train and run that marathon in Duluth, MN. And as I was running that marathon from Two Harbors to Duluth, I thought this was probably really not worth it—but what was worth it was the training and developing my stamina and feeling in such a State of health that I could continue to face the days that came, whatever the stresses were.

I really think that early intervention is like the beginning of a marathon. I think we have a potential here to give parents the power to choose, the power to cope, and the power to develop each member of their family in spite of what they are faced with. I really believe that, as Michelle alluded to, another overriding issue for parents of children with disabilities is that we realize at some point that there is some basic discrimination against children with disabilities. They are people first. And in early intervention, we have that chance, we have that opportunity to provide parents with some training to be able to face that marathon.

Thank you very much.

Senator HARKIN. Thank you, Jeanette. [Applause.]

[The prepared statement of Ms. Behr follows:]

PREPARED STATEMENT OF MS. BEHR

Mr. Chairman, members of the committee, I, Jeanette Behr, parent of three children, sincerely appreciate this opportunity to introduce the interagency puzzle. I would like to stress that this puzzle does not necessarily carry a negative connotation. The individual creativity and flexibility allowed in searching for a solution to a puzzle is indeed, an important step in growth and discovery. Envision a cube with pictures on each side, one of a child, one of parents or parent, one of community and one of professionals. As one picture on one side of this puzzle cube is adjusted, it affects each of the other sides as well. This is a visualization of Public Law 99-457 which attempts to demonstrate the unique attributes of interagency coordination to support families and communities. As the reauthorization of Public Law 99-457 proceeds the importance of family centered and community based implementation cannot be overstated.

To illustrate, we live in a small community not far from the twin cities of St. Paul and Minneapolis. When our oldest daughter Katy, was eventually diagnosed as having autism, she was 9 months old. (before passage of Public Law 99-457). I drive her from 20 to 50 miles, two to four times a week to the most appropriate early intervention program. When Katy graduated from early intervention at age 4, we worked with professionals in two school systems to enroll Katy in a community based non-profit preschool. It was at this time that Katy made the most substantial gains in her ability to communicate. It also provided us the opportunity to meet other families in the community with young children and begin to build an informal support system of shared child care, car pools and friendships. As you listen to testimony today, Mr. Chairman, members of the committee, please keep in mind the three dimensional aspect of this remarkable law, and a key concept of viewing issues through a family centered approach. (See enclosures #1, #2 from Project

Dakota Outreach for further discussion of family focused and community based strategies and philosophies.)

While our family had choices about the type of early intervention services, and three systems, a private medical provider, county social services and an educational system cooperated on our behalf this was more of an exception to the rule and took quite a bit of time. However, seen in terms of long term outcomes, each success that Katy attained in early childhood settings has enabled us to seek more inclusive and typical settings. Today Katy attends a regular second grade classroom with special education support. She is learning to say more words each day, and is also interacting more with other children. This is not to say Katy is cured of autism. She has some very difficult times and needs a great deal of supervision. However, she enjoys eating in restaurants, has learned to swim at a community pool, and will be taking a community based gymnastics class next month. We attribute many of these opportunities to the early intervention Katy has received. The interagency puzzle worked for us before Public Law 99-457 was passed.

However, this puzzle will be unresolvable for many States, children and families unless the overriding issue of health care access is addressed. Health care goes beyond this legislation, but lack of basic health care inhibits problem solving and ability to cooperate between agencies. Access to health care can be extremely difficult for children with disabilities. Our daughter is not able to use words to describe how she feels. With a dedicated and talented pediatrician who really listens to us as her parents, Katy has been able to reach a relatively stable health status. Involving the medical profession and private insurance as option is part of this interagency puzzle. Many parents of young children seek information and support first in a medical setting; it is a natural point of access and referrals.

Developing timetables for ensuring that appropriate early intervention services will be available to all infants and toddlers with disabilities is problematic for States. However, it is the most difficult issue for families. Many parents in rural areas do not have the choice to drive to reach appropriate services, as we did. (As a point of progress, if Katy were born today, we would not have to go so far out of our own community to receive services.) Allowing States a differential funding system and some flexibility to continue participation in Part H is warranted as long as the goal is clearly geographically accessible services by a Stated time.

There are two issues which follow closely on this one. The barriers to service are often cultural as well as geographical. As we strive to build this comprehensive system we must use the existing networks and people in communities. This means the puzzle must allow for personnel development that reaches out to people in rural communities as well as into communities within cities. Also, rather than trying to entice professionals to move to an unfamiliar setting, it is my opinion that personnel development should pull in people who have already chosen to live in a particular setting and/or culture, provide them the added training and then allow them to build the community connections on a long term basis. In our personal experience, our daughter's first 'infant stimulation' teacher, who worked in a county based system, has sought further educational licenser and now work sin a more consultative role in community based preschools. Her understanding of both county and educational systems is extensive. And to illustrate family-centered practices, this teacher stood in line on a cold winter day in Minnesota to reserve a preschool slot for a child because the mother was at was home with newborn twins!

As the interagency puzzle demonstrates, a change in the picture for the child affects the family too. As the systems are directed to change for more coordination and collaboration, parents must be provided a range of roles to choose from. A cue should be taken from Head Start, to involve parents at every level. Also, the issue of evaluations of families continues to be a concern. As part recommendations have been to avoid the terms strengths and needs in order to avoid judging a family, the terms concerns, priorities and preferences (rather than resources) are now being suggested. For families who have to live the interagency puzzle, the way a service is delivered is as critical as the service itself. In order to make the service most efficient and effective for the child, it must fit the preference of the family. Our daughter Katy receives speech therapy in our home, a tour request, which has been the most effective learning for her as well as for us, in terms of expanding on strategies used by her speech therapist.

In addition, the role of parents as partners at a policymaking level should be addressed. Historically, parents have been in the forefront as advocates for progress and more effective services. Public Law 99-457 reflects this by the appointment of parents to Interagency Coordinating Councils. It is recommended that review boards such as OSEP, MCH, SPRANS etc. include parents as grant applications are devel-

oped and rewarded. (See enclosure #3 Recommendations Concerning ICC Parent Development and Support, March 1991.)

As the reauthorization of Public Law 99-457 is considered, the concept of a lead agency is also a puzzle. With permission from the family involved I would like to illustrate the importance of this concept. A child who clearly qualified for early intervention moved into a county in Minnesota. The parents were interested in providing their child some time in a typical setting with other children his age (twenty months) as he had no siblings. The county defined this setting as educational, the school district defined it as respite, and both agencies refused to provide the service. For some time the parents felt they were caught in the middle. A lead agency concept is difficult for systems, but clearly needed by families, to prevent being caught in the middle, or being passed from one agency to another. In this case, the professionals from both agencies and the parents agreed to hold a joint meeting on the issue and did resolve it in a relatively timely manner. It is my belief that agreements and resolution of disputes must start at the local level. There is much that could be done to facilitate the communication by professionals between systems in order to coordinate intervention. (Please see enclosure #4 Interagency Process Analysis Survey Summary). One set process, to be "mandated" across agencies is trying to flatten out the three dimensional puzzle. it is simplistic and limits the flexibility, creativity and individualization that is possible with the different systems. What is necessary are processes that can work in collaboration if necessary. Setting up another State agency or policy council on the State level, would complicate the issues rather than solve them.

In regard to dispute resolution, which the previous example alludes to, the puzzle is quite complex. Rather than form another council or agency to resolve disputed, it would follow the inference of the law that the Interagency Coordinating Council play a role in the assignment of financial responsibility to the appropriate agency. While this can be interpreted as advising and assisting the lead agency it could also ensure that the Council would play a more central role in assessing the nature of early intervention in each particular State.

The interagency puzzle is a complex and sometimes confusing array of issues. However, it is a recognition that children, and the families that love and nurture them, have needs that cannot be easily compartmentalized. Especially in early childhood a families' priorities may be rapidly changing and may cross over numerous "systems" boundaries. As I recall the hours of early intervention our daughter received, the most valuable lessons were based on recognizing her worth as an individual, taking into account our abilities, as her parents, to seek out ways to encourage her growth and development and finally, reaching out to other families with children, with or without disabilities, to participate in a mutually supportive relationships that meet the needs of each individual in the family as well as the community.

Figure 4

Project Dakota Outreach

MISSION STATEMENT

The agency mission for early intervention is to assist the family and community to promote optimal development of the child and reduce the negative effects of delay or disability.

PROJECT DAKOTA GOALS

- Focus on the child and family needs considered essential by parents.
- Insure direct and meaningful collaboration among parents and staff throughout the intervention process.
- Promote the acquisition of knowledge, skill and confidence by parents to describe their child's strengths and needs and to identify and carry out goals and strategies for their child.
- Encourage the transmission of these strategies by parents and staff to other caregivers and settings.
- Increase the child's ability to function in less restrictive environments. Draw upon natural settings and resources for intervention.

OPERATING PRINCIPLES

Family Resources

- Families govern their investment of time and energy; there is no "hidden agenda" to increase or alter it. The goal is to have their current commitment fit their current energy, schedules, and priorities.
- Intervention strategies can be a natural part of the daily routine and fit comfortably into the interactions and styles of family members.

Community Resources

- Families should be offered on-going information and assistance in using community resources so they may make informed decisions about what is available and whether it may play a role in their efforts.
- Settings used by non-delayed peers should be used in preference to specialized or segregated settings.

Staff Resources

- Staff resources should supplement not supplant family and community resources.
- Consultation and assistance should be available in the settings where the skills will be used or practiced.

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Handicapped Early Intervention
Training and Consultation Services

Project Dakota Outreach

EARLY INTERVENTION AND
COMMUNITY-BASED INTEGRATION

1. We can focus our energies on integrating our programs	or	We can focus on integrating children's childhood.
2. We can portray early intervention as that which specialists do in special places	or	We can deliver direct and consultative assistance and thoughtful problem-solving in a variety of settings among staff, family, friends.
3. We can consider early intervention as what happens only in the early years	or	We can see early intervention as the family's introduction to how they and professionals can work together in the decades to come. It can be an introduction to the possiblities of lifelong contributing and learning in typical settings.
4. We can continue to promote the assumption that children with disabilities learn only from adults working from IEP's	or	We can promote the reality that children with disabilities are influenced, challenged, motivated, and matured by time with children.

Linda Kierland

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A Division of Pacer Incorporated
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Tailor Made Early Intervention
Training and Consultation Services

Enclosure #2

Project Dakota Outreach

A Different Perspective for Staff

Traditional Staff Role	Collaborator Staff Role
* "Sage on the Stage"	"Guide at the Side"
Needs to give directions.	Asks questions
Has the ideas.	Problem-solves with parents and staff for creative ideas.
Assesses child and reports the child's developmental to parents.	Asks parent about child and collaborates in assessment.
Recommends goals and objectives and then asks parent for theirs.	Asks parents for goals and objectives and then supplements when necessary.
Feels they should know all the answers.	Feels it is appropriate to search for resources and refer parents to others.
Assigns activities for parents to do at home.	Brainstorms ideas with parents to find functional activities that work for them at home in their daily routine.
Uses technical jargon extensively.	Speaks in layman's terms and explains technical terms that will be used with the child.
Expects the parent to look at the professional as the expert.	Helps the parents to recognize their own strengths and expertise.

* Paraphrased from letter by Nancy Bell, former Dakota BESE teacher for twenty years.

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Enclosure #3

ICC PARENT REPRESENTATIVES OF THE GREAT LAKES STATES
(Illinois, Indiana, Michigan, Minnesota, Ohio, Pennsylvania, Wisconsin)

Recommendations Concerning ICC Parent Development and Support
March 1991

Background

One of the many challenges presented by PL 99-457, Part H, is the development of new kinds of relationships between parents and professionals. New ways of relating are needed not only in planning and providing services to individual infants and toddlers, but also at the policy level, as parents and professionals serve together on Interagency Coordinating Councils.

Parents serving on state-level Interagency Coordinating Councils for early intervention in the Great Lakes states (IL, IN, MI, MN, OH, PA, WI) have participated in a regional networking activity since the fall of 1989. The activity has been facilitated by the Great Lakes Area Regional Resource Center in response to needs identified by parent representatives to its Advisory Committee. The activity has focused on addressing the needs of ICC parents for information, support, and training through their linkage with each other, existing parent training and information center, and other resources. Two meetings were held which included the majority of ICC parents in the region, many representatives from parent training and information centers, and representatives from other interested groups. The second of these meetings was conducted in the format of a conference entitled "The Art of Storytelling", which was planned and organized by a smaller work group of parents selected from the larger group. This work group met two additional times, once to organize the conference and a second time to develop materials and resources which reflect the collective experience of the group.

Members of the group felt that they had learned much from this experience about ways to support parents in their role as ICC members, at both local and state levels. They were eager to share that learning with ICC parents, with the professionals who serve on ICCs, and with others who want to support parents in this new role. The following recommendations were developed by the work group and have been reviewed in draft by all participants. They represent the best thinking of the group regarding the effective support of parent representatives to state and local ICCs.

It is important that parents be valued and respected in their role as ICC representatives.

1. Parents value relationships with professionals who provide them with information and listen and appreciate their expertise. Actions such as the following empower parents:

   - spending ICC meeting time on issues identified by parents;
   - attending conferences concerning parent identified needs;
   - explaining rules and procedures, both written and unwritten, official and unofficial;
   - providing opportunities for reciprocity.

2. The relationship between parents and professionals on ICCs should be viewed as reciprocal; parents contribute and learn as do professionals.

3. The ICC needs to spend time developing an understanding of the parent representative's role and the benefits and value of parent participation.

4. ICC parents' time and expenses (e.g., travel & per diem, postage, copying, phone calls, child care, etc.) should be reimbursed. (See relevant OSEP Memo)

5. The age limit for children of ICC parents should be reexamined and made more flexible to increase continuity and to reap the benefits of the perspective of parents looking back at their child's early years.

6. The national early childhood TA provider (i.e., NECTAS) should have an ICC parent on its Advisory Committee if they are to include ICC parents as a constituency.

7. All these recommendations need to be implemented in a manner sensitive to the cultural and socioeconomic diversity of families.

ICC Parents need accurate and appropriate information in order to function effectively.

1. ICC parents identified these key needs:

   •Shared experiences
   •Listening friends
   •Time for rest
   •Timely and clear information

   The above could be a starting point for exploring the needs of individual ICC parents and implemented in a manner sensitive to the cultural and socioeconomic diversity of families.

2. Orientation materials should be developed to meet a broad range of learning styles and preferences (e.g., written information, video, personal contact, mentoring, audio tapes, etc.) Note: See orientation materials to be developed through Great Lakes area regional activity.

3. Parents should be given clear information about their role, including being a spokesperson for other parents, at the time they are asked to join an ICC.

4. ICC Parents should be supported in connecting with a constituency of parents of young children and in receiving support and input from parents of older children. PTIs, advocacy groups, parent support groups, etc. may be helpful in establishing such connections. Parent training and information centers (PTI), in particular, need to examine their role in providing information and support to ICC parents.

5. Professionals and representatives of parent groups, advocacy agencies, PTIs, etc. should help ICC parents establish efficient ways to exchange information and gather input.

6. ICC parents should have access to a clearly identified staff-parent liaison to assist with reimbursement and other logistical issues.

7. ICC parents should have opportunities to be put on various mailing lists in order to receive pertinent information.

8. ICC parents should be supported in gaining free access to relevant electronic communication such as SpecialNet. An ICC Parent bulletin board should be established on SpecialNet. The current dissemination to ICC parents of information from the SpecialNet bulletin board "Programs Involving Parents" (PIP) by NECTAS is a good start in this direction.

ICC parents experience support when they are connected to a variety of parents and professionals interested in the implementation of Part H.

1. In order to avoid isolation, ICC parents need meaningful relationships with a variety of professionals. Options and opportunities for the development of such relationships need to be provided.

2. State and local ICC parents in a given state should have regular contact.

3. ICC parents need opportunities to network with their peers in other states or locales (e.g., conferences, conference calls, planning committees, etc.).

4. Regional activities are an ideal size for facilitating networking among state ICC parents.

5. Parents leaving ICCs should be considered as possible mentors to new parents and compensated for time and expenses.

Suggested dissemination list:

Part H Coordinators
NECTAS
PTIs/TAPP
DEC
RRC
OSEP
Senator Harkins Office
Various disability groups
MCH
Mental Health Law Project
FICC
OSEP
State ICC Chairs
Special ED. Directors
NASDSE
National Parent Network on Disabilities
TASH

Senator HARKIN. My personal congratulations to all of you for all of your stamina and for running the marathon and finishing the marathon. It is a tough race; I know it is. It is time-consuming, emotion-draining, and frustrating at times. But I know that each of you have also experienced the joy and the happiness of seeing your children develop and grow as full human beings. And that is really what this legislation is all about; Michelle, just as you have said, it is getting to these kids early, recognizing them as human beings and as people, understanding that with early intervention and with the kind of coordinated approach that Part H envisions, that we can build a system out there that supports families, that keeps the children in their families, with their parents, and gives them every reason to hope and to work for a better future for their kids. That's what it's all about. All of your stories touch me very deeply.

Michelle, Tanika is now how old—did you say 12?

Ms. MARLOW. Yes, she's 12.

Senator HARKIN. How is she getting along now?

Ms. MARLOW. Just fine. Medically, she does fine. She is doing very well. She is real involved; she has best friends in the neighborhood, right nextdoor, that she spends time with, and they spend time over at our house. She is a part of our community. We are a part of our community. And we continue to look for services and try to do things that will help to meet our needs over time. But she does very well; we're doing very well.

Senator HARKIN. Michelle, you now are vice chair of the Maryland Planning Council on Developmental Disabilities and also a planning coordinator at the Kennedy Institute at Johns Hopkins Hospital. As we reauthorize this legislation, and as you look back at your experiences, and obviously you are working with other parents now, what would you like us to really focus on? What is the one thing—is it coordinated services, perhaps? When you think of all the problems that are out there, is there something missing? Is there something that we've got to do better?

Ms. MARLOW. We are talking about early intervention, and part of that early intervention responsibility is helping to instill in the family that they are an active participant, and they have expertise in that child, and that is a very important part of any planning to be done around services for that child and that family.

I believe it is the responsibility of service providers in part to elicit that from families, to ask people what it is—that was something that Jeanette said earlier. I find over the 13 years that I have been in the disability field that to this day there are people who are floored by the fact that I ask them, "What is it that you want, and what services do you think will be helpful to you to continue to maintain your child and your family?" People are floored by being asked, "What do you want, and what do you think you need to be able to exist?" And a part of that is what they see their role is in making those things happen. The system needs to be that responsive. This system needs to be that responsive to families.

Senator HARKIN. One of the things I hear about a lot from parents with young children who are disabled—one of the most common refrains I hear is, "I need some time off. I don't have any time. I love my child, and I want to take care of him, but I just need a break. I need to go to a movie. I need to go shopping. I need

to take a vacation." And there isn't that structure. Now, this was folded in, and this is a part of the early intervention program.

I see you nodding your head. Is that something you hear from parents, too?

Ms. MARLOW. Yes. That's something I hear from me, in the mirror. [Laughter.] I think we were somewhat lucky because my family was available to me for daycare so I was able to go to school and take that break and do some things for me. But as Tanika is getting older and her needs are changing, and it is just her and me, it is becoming real clear that the need for respite and a break is something that we really have to plan so that we have a life, but she has a life, and I have a life as well. And there are resources to address this.

Senator HARKIN. Bob, let me turn to you. Diane had a very moving story to tell. Tell us just in your own words how, as a male, as a father, how did this affect you.

Mr. SANNY. It is a little embarrassing, actually, considering Michelle is a single parent and doing all this. But if you take the normal exasperation of being a parent—and people who aren't parents don't understand that getting married is a big step in your life, but having a child completely changes everything—and basically, having a child with disabilities is an exaggerated situation. In my case, I was the principal breadwinner, and the demands, just the time and energy demands, were just too much for Diane.

So the situation is that normally a father who goes off to work has to balance a little something for himself, something for the boss, and something for the family, and it winds up that there is just not enough of me to go around.

So what you do is you make priorities. In our case, I made the priority that the family was more important, so the finances have suffered. But that was a decision I made, and it was a decision that had to be made.

I could sit and whine about all the things that you have already said, and that's why this legislation came about, the difficulties that parents have. I think one thing that I should admit is that I have had as much as anyone probably a leaning toward not seeing handicapped or disabled people as people because they stand out—they walk a little different, they talk a little different, whatever.

I remember when Gretchen was in the hospital, and she was just lying there, and her arms barely moved, and I think to relieve myself more than anything, I used to joke with the nurses. I said, well, she'll never be a piano mover, but that's fine. And it really hit me—about a year ago when she started walking, I was sitting in the living room, and she walked in, and she was carrying Monica's Casio keyboard, and I realized that this girl had turned into a "piano mover." [Laughter.]

I think a lot of times—maybe it is just human nature that anything different stands out and we think it is inferior—but we write potential off too early. And if we write it off too early, it will be a self-fulfilling prophecy.

That's about all I have to say. Thank you.

Senator HARKIN. Monica, you haven't said a thing yet.

Mrs. SANNY. She's a little shy.

Senator HARKIN. Hi, Monica. I'll bet you've been a big help to your parents, haven't you, and to your sister?

Miss Sanny. Yes.

Senator HARKIN. What are some of the good things about having a special sister like Gretchen? Are there some special things you think maybe I ought to know about? [Pause.]

Senator HARKIN. Well, she carries your Casio keyboard around; I know that. [Laughter.]

Mrs. SANNY. She wants Bob to answer for her. She knew you were going to ask her this question.

Mr. SANNY. It is interesting that two children out of the same union could be so different, but they are. Actually, Monica has been very strong throughout this. She went without mom basically for two and a half months in the beginning, and I turned into the "mom" and I think I'm second-best at best.

But when we talked about this question last night, she said that having Gretchen as a sister basically seems like having any other—you know, a sister—and that the only advantage that she saw was the fact that Gretchen couldn't run so fast, so she wasn't quite such a pain to endure. [Laughter.] Other than that, the two of them get along very well and are mutually supportive—and Gretchen has even started beating up on her a little bit.

Senator HARKIN. She'll catch up to you, Monica. Be careful. I know. My older daughter used to always beat up on my younger one, but the younger one finally caught up to her after a while. So it all evens out in the end.

Thank you very much for being here, Monica.

I have a couple more questions, but I'll defer to Senator Durenberger if you have any questions. The Senator from Minnesota.

Senator DURENBERGER. Thank you, Tom. First let me compliment you on your questions and for bringing Iowa's first pilot family here today.

As I was trying to figure this puzzle out and listen at the same time, I got the point. I have been struggling, as many of us have, for a long time with the issue that each of you have raised in an implied sense, and that is—why is it in a country as rich as ours is it so complicated to have access to all these wonderful health, medical and social service professional who have dedicated their lives to helping us in one way or another. There are a lot of them, and they are in our communities—why then is it so hard to put together this system?

I have a young man, Christen Fink, sitting behind me who is from a city near Dusseldorf, Germany. He finished law school a couple years ago and then came over to this country because in Germany they have to wait 2½ years before they can take the bar exam. He is going to leave in 4 weeks and go back and take the bar exam, and become a lawyer. But he listened to me make a speech earlier this morning and told me afterwards about the differences in his country and ours. He mentioned that one of the things that goes on in this country is that we beat up on Japan and Germany because they are so powerful economically. And he said, "But I have really noticed in this country, that you are just as powerful powerful, but you don't seem to get it together the way we seem to. We're a little bit better organized. And while it is of expensive, we

use the social insurance system to get a lot of things done. And it is there for people when they need it."

One of the constant struggles that we have in the United States, because we have a health insurance system set up for medical emergencies; for example, something like breaking your leg or getting a disease. You go to the doctor, then you go to the hospital, then you come home. You send the bill to the health insurance company, and that's it. But that's not where most of the health and medical problems in our country are brewing. They are generated somewhere else. They are either genetically predictable, or they are in the prenatal phase, or they are the results of birthing—they develop during the course of life; they develop in the course of less than adequate relationships between parents, they develop because of ignorance, or they develop because of bad advice.

Senator Moynihan and I in the Finance committee have been holding hearings on behavioral and social sciences—on what actually comes from a lack of concentrating on behavior and lack of concentrating on the tie between the social sciences and the biomedical sciences in this country.

So I have just been sitting here, making notes to myself about Tanika, Gretchen and Katy, because there is no way in a national health insurance system that we could say everybody is going to have health insurance in America—it simply wouldn't cover your situations. It just wouldn't do it in the current system because the current system is set up to let the social insurance system, or the welfare system, or some program in special education do it. Over here, the local government and the State government and the Federal Government are providing these services, but over here you are your own.

What I hear—and Jeanette said it specifically in her statement—all of you saying is that what we really need to be getting at in this country is somehow integrating all of these things that we define as health. And if you set this program up just because you have a Tom Harkin, and you have a committed Senator, and you have a commitment to people with disabilities, and you've got all of these wonderful things that I have come to admire of Tom, you get a program, and you get it going, then has to get turned over to somebody else to implement.

So it never really becomes a part of the culture in our communities or in our governments or anywhere else. I must say I read Assistant Secretary Davila's Statement, and he deals with all these words like "coordination" and "cooperation" and interagency this and interagency that, and then we're going to have these 14 components that everybody has to meet—none of that spoke to what I'm seeing here. That is somewhere up here in what you call the bureaucracy. I don't say that in a demeaning way at all.

But it is a frustration that I am expressing, which adds to the value of all of you being here today to express yourselves on the need in America. I guess we'll never be a Germany and we'll never be a Japan, but there are some things to learn from other cultures about how they have learned to put a high value on education, health and family, and how they have found a way to put that all together.

I particularly enjoyed going through your statements and then listening to your comments about the stress on family. In America, of course, that gets defined in a variety of ways, and it can be extended to some degree. But certainly the people I have met on this committee long ago came to the conclusion that whatever we do in public policy to strengthen the role of the family in this whole system by making available education, information and then professional assistance as appropriate, we ought to be doing.

The other thing that is a great frustration to me is how we set up a policy direction, and the requirements to implement it, and then we say to others, "You go and implement it." Then to make sure somebody doesn't misuse the system, we have to set up all these interagencies, coordinations, cooperations, guidelines, plans and all the rest to make sure it comes out right. The fact is that we never know whether it comes out right or not. We don't have a system to measure what "come out right" or outcomes means. I see the satisfaction or frustration or somewhere in between in your eyes—but if we could ever measure that, I think there will be a lot more resources that could go into the families and into the professional support systems for families—resources that would not have to go into the interagency meetings and the plans and all the rest by way of requirements just to make sure that there is somebody there when you need them. But it is costly. It is costly to add all of that dimension to the system.

So I wish out loud that we would put our efforts into measuring what is now being called outcomes instead of all of these little inputs and big inputs and important inputs. To you, the seven people who showed up in your home are a pretty important influence in your life. And yet if Iowa learns that it didn't take seven people, but maybe just one, or two, darn it, let the folks in Iowa do it that way. If that is the level of satisfaction experienced by the citizens of Iowa and the pilot families and the other families in Iowa, and if there is a consensus among the professionals that meets an ideal standard, then I'm frustrated by the fact that we say you've got to have two of this and six of that and seven of that, and you've got to come to the house rather than going here, and you've got to do this, that or the other thing.

So I suppose what we will all do is strive for the time when we can let you, as the growing experts—I mean, as you get from mile one to 12 to 20 to 26 in the marathon—and to the degree that we can allow you a larger role in the assessment and therefore the it.. t, I really think that is where we ought to be headed as we look at reauthorization.

So I'm grateful to all of you, and Jeanette, I hope that we will have a working relationship in the future that will help me be a better participant in this process as well.

Thank you.

Senator HARKIN. Thank you very much, Senator Durenberger.

I haven't read this yet, but I was just given this booklet, "Alice in ICCLAND," a play in one act by Jeanette Behr, with a little help from her friends, at the Great Lakes Regional ICC Parent Conference in 1990. I get the thrust of it just by kind of looking at it. It is sort of a little bit about what you are saying as to dealing with all these different agencies and so on.

But I thought in letting this panel go, because we have got to move on to the next one, I thought I would end this panel by reading the last sentence here. Alice is waking up, and Alice's sister says: "Wake up, Alice, dear. What were you dreaming?"

Alice says: "What a curious and wonderful dream. Children with disabilities will achieve things no one thought possible. If we hang onto the dream and work with families, children with disabilities will grow up to have dreams of their own."

Thank you all for being here. [Applause.]

Senator HARKIN. Our next panel includes Tom Gillung, Connecticut Department of Education, on behalf of the National Association of State Directors of Special Education; Dr. Richard Nelson, from the University of Iowa, Iowa City, on behalf of the Association of Maternal and Child Health Programs; Jonathan Wilson, member of the school board, Des Moines, IA, on behalf of the National School Boards Association; Ruth Rucker, Mazique Parent/Child Center, Washington, DC, on behalf of Low-Income and Minority Parent Empowerment Task Force.

Mr. Gillung, who is accompanying you, please?

Mr. GILLUNG. Dr. Brian McNulty, from the Colorado State Department of Education, a member of the National Association of State Directors of Special Education, has joined me today with your permission.

Senator HARKIN. Thank you for being here.

We are running a little late, but you can understand why with such a great panel we had before. We'll just go down the line as I read your names off. All of your statements will be made a part of the record in their entirety, and if you could again, as I asked the other panelists, just summarize and on behalf of the different organizations you are representing tell us what you would like us to understand and know in reauthorizing this legislation.

We'll start first with Tom Gillung, from the Connecticut Department of Education.

STATEMENTS OF TOM GILLUNG, CONNECTICUT DEPARTMENT OF EDUCATION, MIDDLETOWN, CT, ON BEHALF OF NATIONAL ASSOCIATION OF State DIRECTORS OF SPECIAL EDUCATION, ACCOMPANIED BY BRIAN MCNULTY, DIRECTOR OF SPECIAL EDUCATION, DENVER, CO; DR. RICHARD P. NELSON, UNIVERSITY OF IOWA, IOWA CITY, IA, ON BEHALF OF ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS; JONATHAN WILSON, MEMBER, SCHOOL BOARD, DES MOINES, IA, ON BEHALF OF NATIONAL SCHOOL BOARDS ASSOCIATION, AND THE AMERICAN ASSOCIATION OF SCHOOL ADMINISTRATORS, AND RUTH E. RUCKER, MAZIQUE PARENT/CHILD CENTER, WASHINGTON, DC, ON BEHALF OF LOW-INCOME AND MINORITY PARENT EMPOWERMENT TASK FORCE

Mr. GILLUNG. Mr. Chairman and members of the subcommittee, my name is Dr. Tom Gillung, and I am the director of education support services with the Connecticut Department of Education. I am also the president of the National Association of State Directors of Special Education, who I represent today. With me is Dr.

Brian McNulty, director of special education in Colorado, who will respond to any questions that you might have.

In both our States, the State education agency serves as the designated lead agency to the Part H program. We appreciate the opportunity to share with you our perspectives on Part H, particularly on the critical impact that it is having on the delivery of services in the States.

Our written statements describe in more detail several of the selected recommendations we would offer for your consideration. I would like to highlight a few of them and offer to provide at a future date any additional information and assistance that may help in your deliberations. But before I do, I would like to share with you some of the accomplishments of the program to date.

The Carolina Policy Studies Program, which is a federally-funded project to examine and document the implementation of Part H, has found that on balance, States are by and large on schedule in meeting the 14 program components. But most importantly, there have been two additional accomplishments. Interagency coordination in beginning to work for families at the local level. In addition, there has been a shift in values from a clinical intervention model of service delivery to a family support/empowerment model. This has changed the way the systems operate, moving toward a more family-oriented approach. Services are now being driven by the needs of family rather than by the needs of the system. Families are now being linked to natural support and community resources through the Part H program.

One of the parts of the Part H program's strength has been its emphasis on building upon States' existing services and programs and on their unique organizational and governance structures. Thus a comprehensive system of early intervention looks different from one State to another. For example, the definition of the eligible population may differ to some extent across States, as would services and finance configurations.

The experience over the last 4 years confirms the critical importance of maintaining flexibility in order to capitalize on the creativity and resources of the States. We urge Congress to maintain this critical focus on flexibility during this reauthorization.

It will also be important to minimize change in the statute that may impede States' progress in reaching full implementation at the earliest possible date.

Some adjustments in the law are clearly essential. However, whenever possible, we would encourage you to provide clarification without changing the nature or intent of the program.

As you are aware, not all States have been able to keep to the original timetable for certain components of the Part H planning and development process. Currently, nearly a third of all States are on schedule, but even in those States which have delayed entry into the fourth year of the program, substantial progress is evident, as mentioned earlier by Dr. Davila.

It is increasingly clear that the work of implementing Part H has been more complex and challenging than originally envisioned. For example, the interagency nature of the Part H system requirements and insufficient resources, exacerbated by fiscal crises in over 30 States, have hampered States' progress.

Despite these challenges, however, the goals Congress set out in 1986 are still very important and appropriate. We believe Congress should continue to encourage the participation of all States by giving serious consideration to allowing differential participation for up to 2 years. This proposal would reward States who have reached the programmatic milestones set out in the original legislation, with increased allocations, while continuing to provide a smaller amount of planning money to those States that have demonstrated that they are making serious progress toward these goals.

We would also support the continued use of a census-based formula to allocate funds until all States are in full implementation.

Thus we recommend that the issue of how to allocate Part H funds in the long-term, for example on the basis of child count, be addressed preferably in the next reauthorization of Part H, at which time all States will have reached full implementation.

Finally, NASDSE believes continued Congressional support of increased appropriations for the programs as States would move into full implementation is vital to the continued success of this program. We look forward to opportunities to work with you and your staff in examining over time whether the current approach or others will be needed to secure the long-term financing of a State's systems.

Thank you for permitting us to share NASDSE's views with the committee. We look forward to other opportunities to work together to enhance the Part H program.

In concluding, I am reminded of the puzzle analogy mentioned earlier by Ms. Behr, and I would submit to you that the National Association of State Directors of Special Education want to be a part of the solution to solving that puzzle.

Thank you.

Senator HARKIN. Thank you very much.

[The prepared statement of Mr. Gillung follows:]

Prepared Statement of Mr. Gillung

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 necessar 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 for up to two additional years. 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) 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.

(3) 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.

(4) 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 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 at which time all States have reached full implementation.

(4) 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 Senate 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 suggest to us that some States may 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) The 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 useful 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. There is concern in States over how they will finance full services to all infants and toddlers with disabilities. Further, 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.

(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.

(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.

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. 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. 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 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 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 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. 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.

In its recommendations for amendments to the Part B program, DEC/CEC has requested that consideration be given to adding the term "developmental delays" to the categories of disabilities included in Part B in order to facilitate the most appropriate diagnostic procedures for young children. NASDSE does not favor adding a new category of disability to the Part B definition of children with disabilities. Because a large number of States have already implemented regulations that permit the use of a non-categorical approach for the identification of preschool children, NASDSE believes that sufficient latitude already 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 are hesitant to do so out of concern they may be found out of compliance or be subject to later audit exceptions because their approach for 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. NASDSE recommends that the Subcommittee consider including language in its report supporting States' use of non-categorical approaches to the identification of preschool age children, and further clarifying that such approaches, when implemented, must be designed to assure that they are effective in identifying as eligible the intended population of children.

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.

(2) On the recommendation to include family services within the definition of related services NASDSE cannot offer support at this time. This position in no way revises NASDSE's long history of support for parents' participation in the development and implementation of their child's educational program. 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. 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

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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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Senator HARKIN. Mr. McNulty, did you have anything that you'd like to add?

Mr. MCNULTY. The only point I would like to add is maybe a clarification, that when Colorado entered into participating in Part H and put together our interagency coordinating council, very clearly, parents were in the forefront of that council and came to the State and said that if Part H meant doing more of the same that we had done in the past, that they didn't want to participate; what they wanted was a different system of service delivery that focused on families' abilities and found ways to support families in making choices that were best for them.

That meant doing business differently than we had done in the past. The example of having seven people enter the home was unfortunately not unusual, and often what resulted was our making families feel like they were disabled and unable to care for their own kids. Instead, the model has to move much more toward that naturalistic support model that empowers families, that links them with the natural community resources that are out there.

Again, as we met around the State with different families, I had a mom come to me and say, "It is amazing to me, but all I really need is babysitting, and all I can get is respite care, for $27 an hour."

Now, that's linking families with natural resources. If you need a respite care worker, somebody who is specialized, fine, but if you only need a babysitter, you only need a babysitter.

That is the difference in shift in the system that we're seeing is how do we link that. And as we use Part H as that model, that visionary model, for other systems, the challenge for us is how do we do that across agencies when we don't have the authority necessarily to mandate those agencies, but we're trying to lead them through a new vision to bring those services together. And that is a very different challenge, and something that is difficult for States to do.

The last piece of that is, as we look at the sequence of how we do that, we have the same challenge that faces you, which is oftentimes pieces of legislation within the States only come up for reauthorization once every 3 to 5 years. So as we right now are trying to look at our developmental disabilities legislation that comes up for reauthorization next year, we see a major change being recommended by our interagency council on infants and toddlers of writing a whole new section for that statute. We had to wait 5 years for that to come up for reauthorization.

The States are facing those same kinds of challenges in doing the policy development piece that I think is envisioned by Part H. So that is the challenge I think we will continue to bring to the table, is how do we do that in a systemic way that really does empower parents and families.

Thank you.

Senator HARKIN. Thank you.

Dr. Richard Nelson on behalf of Association of Maternal and Child Health Programs, University of Iowa.

Dr. NELSON. Good morning, Senator Harkin.

I am the director of Iowa's Title V program for children with special health care needs and the current president of the Associa-

tion of Maternal and Child Health Programs, which represents all of the State Title V programs administering maternal and child health services throughout the country.

I am also the current chair of our Part H interagency coordinating council in Iowa.

I believe Part H represents a critical national initiative for our Nation's youngest citizens. I also support the notion that the legislation has the potential to be a template for future health and human services legislation that requires the concerted efforts of multiple programs to address the special needs of populations, in contrast to parallel categorical programs that cannot accomplish comprehensive services.

State Title V maternal and child health and programs for children with special needs are responsible for promoting the health of all mothers and children consistent with national health objectives. We plan, develop and coordinate and support family-centered, coordinated systems of care and support throughout the Nation.

We support reauthorization of Part H. Part H provides for a system of services consistent with family-centered coordinated care espoused by the former United States Surgeon General C. Everett Koop, which has been very much part of our mandate during the past several years.

The role of State Title V programs in implementation of Part H is vital Title V involvement may include program administration as the Part H lead agency, participation in State interagency coordinating councils, providing staff support to ICC's and local coordinating committees of early intervention programs, and providing early identification, assessment and health and developmental services through existing Title V programs, such as perinatal centers, child health clinics and service programs for children with special needs.

Title V programs maintain a special focus on prevention and health care provision for families with low income or with multiple needs. This, we believe, places our programs in a unique position to identify, to reach out, and to serve those children and families eligible for Part H.

State health or health and human services agencies in 20 jurisdictions, including 17 States, are the designated lead agencies for Part H early intervention programs. But in other States, including our own State of Iowa, we have had a major role in the design and implementation of the law.

While all States have made progress in planning for this comprehensive system, progress has been somewhat slower than originally anticipated. This is because of the significant complexity of policy decisions required, and to some extent the lack of authority for lead agencies to require other agencies to participate in a specified plan of action.

But a great deal has happened since 1986. There have been significant Medicaid eligibility expansions through OBRA's (Omnibus Budget Reconciliation Act) 1989 and 1990, including expansion of EPSDT (Early and Periodic Screening, and Diagnosis Treatment), and during this past year significant changes in the SSI program for disabled children, both as a result of OBRA 1989 and the Zebley

U.S. Supreme Court decision, which should establish many more young and very young children as eligible for SSI and Medicaid.

Without the ongoing leadership provided by Part H, however, we have concern that the broadest population of children, those infants not only meeting the definitions of developmental delay, but also those at risk, will not be included if we don't continue to progress in our service system development.

The association of MCH programs therefore requests Congress to reauthorize Part H, with the following provisions: That the authorization level be increased to $250 million to provide additional resources; that there be incorporation into the law the funding mechanism that allows State completion of the required planning process within an extended time period not to exceed 2 years; that there be establishment of allocation methodologies that provide financial incentives for States to serve greater proportions of their infant and toddler population. Eventually these allocations could be based on annual State reporting of children served. And finally, that there be a requirement for States to maintain or establish an eligibility category to be certain that at-risk infants and toddlers at least have adequate assessment and monitoring as a minimum level of service since so many of these children will eventually become eligible for special education services.

We again express our appreciation for this opportunity to comment and for your personal commitment, Senator Harkin, to achieve a national comprehensive system of early intervention services for infants, toddlers and their families.

Thank you.

Senator HARKIN. Thank you very much for your Statement, Dr. Nelson, and for coming a long distance today.

[The prepared statement of Dr. Nelson follows:]

PREPARED STATEMENT OF DR. NELSON

The Association of Maternal and Child Health Programs (AMCHP) appreciates this opportunity to provide our perspectives to the Subcommittee on Disability Policy today on reauthorization of Part H of the Individuals with Disabilities Education Act. This Federal program supports interagency development and implementation of State systems of early intervention services for infants and toddlers with developmental or other health impairments and their families. Part H represents a critical national initiative for our Nation's youngest citizens. The legislation has the potential to be a template for all future health and human services legislation requiring the concerted efforts of multiple Federal programs to address the needs of a population. We commend the subcommittee's commitment to these most vulnerable children and families.

Our association represents State programs funded by Title V of the Social Security Act, the Maternal and Child Health Services Block Grant, as most recently amended by the 1989 Omnibus Budget Reconciliation Act (OBRA). State Title V Maternal and Child Health (MCH) and Children with Special Health Care Needs (CSHCN) Programs are responsible for promoting the health of all mothers and children, consistent with national health objectives. State Title V programs plan, develop, coordinate, and support family-centered, coordinated systems of health care and support services. Title V Amendments included in OBRA 1989 strengthened requirements for State needs assessment and planning; for collecting and reporting data on MCH health status and services; for developing systems of pediatric preventive primary and specialty health care; and for coordination with Medicaid to assure access to comprehensive, quality care.

The complementarity of the Part H and Title V mandates has become increasingly clear over the several years of implementation of this landmark early intervention legislation. The purpose of this Statement is to support reauthorization of Part

H (Public Law 101-476) and to describe our experience in participating in State Part H program implementation to achieve comprehensive and coordinated service system design and care delivery. Based on that experience, we would further suggest some modifications that we believe are needed to ensure that all States remain fully engaged with, and can fulfill the promise of, Part H.

The Need for and Impact of Part H

Prior to the mid-1980's, many young children with disabling conditions or at risk for developmental delay received few or no services during the critical developmental period from birth to 3 years of age. Many States lacked the means to provide such children with coordinated care, forcing their families to contend with multiple agencies in order to obtain services. Categorical and inconsistent service eligibility criteria often constituted formidable barriers to families seeking developmental, health and social services for their children.

The statutory requirements for interagency system development contained in Part H have assisted States in developing statewide comprehensive systems of early intervention services for infants, toddlers and their families. These systems of services are consistent with the principles of family-centered, community-based, coordinated care advocated by the former United States Surgeon General, C. Everett Koop, M.D. and incorporated in the Title V statute.

Additionally, with the financial support and technical assistance available under this Act, all States have made progress in coordinating planning and services for children from birth to 3 years of age. As of December 1990, ten (10) States had an approved plan for fourth year funding. In its Twelfth Annual Report to Congress on the Implementation of the Education of the Handicapped Act, the Department of Education reported services being provided to nearly 56,000 infants and toddlers in the 39 reporting States in 1988 (1). By the following year, with all 50 States and the District of Columbia reporting data for 1989, 210,160 young children received Part H early intervention services (2).

The Role of Title V Programs in the Part H Program

While differences in State needs, agency structures and resources contribute to significant variation in activities across the States, the role of State Title V MCH and CSHCN programs in implementation of Part H is vital in every State. Title V involvement may include program administration as the Part H lead agency; participation in State Interagency Coordinating Councils; providing staff support to ICC's, local coordinating committees or early intervention program offices; and providing early identification, assessment and health and developmental services through existing Title V supported programs such as perinatal centers, child health clinics and services for children with special health care needs. Title V programs maintain a special focus on prevention and health care provision for families with low income or multiple needs. This focus places State Title V programs in a unique position to identify, reach and effectively serve the children and families eligible for Part H.

State health or health and human service agencies in 20 jurisdictions (including 17 States) are designated lead agencies for the Part H early intervention program (see Table 1). In most of these health agencies, program administration is overseen by the maternal and child health program. These arrangements facilitate strong planning and service delivery linkages beginning with high risk maternity and infant services, assuring prompt identification, assessment and follow-up of medically or developmentally compromised infants. In these and additional other States (such as Iowa, Washington, and Florida), Title V-sponsored high risk infant tracking systems assure direct referral for provision of developmental services for the infant, and counseling, parenting education and other support services for their families. Pediatric preventive and primary health care services are supported by Title V in all States as are specialty health and family support services for children with complex special health care needs.

Considerations in Reauthorization of Part H

While all States have made progress in planning for the statewide comprehensive system of early intervention services, progress has been somewhat slower than originally anticipated. This appears due in part to the significant complexity of policy decisions required and the lack of authority for the lead agencies to require other agencies to participate in a specified manner (3). With over one-half experiencing significant budget deficits caused by the recession, the current financial situation

faced today by States threatens to undermine State capacity to meet congressional timeliness for implementing early intervention service entitlements.

In the Committee Report accompanying the initial Part H legislation, Congress emphasized the interrelationships between Part H and the Medicaid EPSDT program. Significant Medicaid eligibility expansions and EPSDT enhancements enacted in OBRA 1989 and 1990 offer potential for alleviating State fiscal constraints in regard to Part H by paying for an expanded scope of health and health-related services for low income Part H program participants. However, while of substantial promise in making Federal fiscal resources available to support implementation of this program, the complexity of the mandated changes in the EPSDT program have proven difficult for States to promptly implement. In addition, despite these eligibility expansions, only very low income families remain eligible for Medicaid program participation, leaving substantial proportions of the birth to 3-year-old population ineligible.

Recent changes in the 551 Program for Disabled Children subsequent to legislation enacted in OBRA 1989 and to the Zeblev Supreme Court decision are expected to establish many more young and very young children as 551 and Medicaid beneficiaries. A permanent outreach program for disabled children is now implemented by the Social Security Administration. New 551 disability determination rules and procedures include consideration of functional as well as medical disability and facilitate evaluation by establishing differential criteria for separate age categories of children. However, with the final new rules published only within the last few months, expanded 551 caseloads have not yet been realized. Optimal expansion may not occur without collaboration at the Federal and State levels between the Social Security Administration's 551 program, Title V and Part H.

Without sufficient State and Federal fiscal support, concern exists that service to the "optimal" Part H population—infants and toddlers "at-risk" for disability or developmental delay will not be included by States as an entitlement in their early intervention programs. Intervention for this group of infants has been documented as both effective and cost-efficient by reducing the eventual need for special education services (4, 5).

Recommendations to Build on the Success of the Part H Program and Assure Ongoing Systems of Early Intervention Services

The Association of Maternal and Child Health Programs therefore requests that Congress re-authorize Part R of the Individuals with Disabilities Education Act in 1991. State executive and legislative branches, program administrators, parents, academic centers and professional groups have demonstrated their commitment to meet the spirit and intent of this legislation. Nearly 40 States have policies supporting their Part H program in place (6) and many are engaged in fourth year activities as specified in the law. However, Part H presents a complex charge for interagency system design, policy development and program implementation. Particularly given the current economic climate of the country, some modification in that charge is needed to assure that all States can build a sound and enduring system that will assure ongoing service availability and access to young children and families in need of early intervention and support services.

The Association therefore requests that Congress enact legislation re-authorizing and amending Part H that includes the following:

1. Establishment of an authorization level of $250 million for the Part H program;
2. Incorporation of a funding mechanism that allows State completion of the required planning process within an extended time period not to exceed 2 years;
3. Establishment of allocation methodologies that provide financial incentives for States to serve greater proportions of their infant and toddler population. These allocations should be based on annual State reporting of the numbers of all children having an established Individualized Family Services Plan (IFSP);
4. Requirements for States to establish an eligibility category for "at-risk" infants and toddlers with assurance of assessment, tracking and monitoring as the minimal level of service to be provided. In establishment of these requirements, States should be ceded the authority to determine the definition of "at risk"; and
5. Inclusion of the Social Security Administration and the U.S. Department of Agriculture, Food and Nutrition Services, on the Federal Interagency Coordinating Council.

In conclusion, the Association would again express its appreciation for this opportunity to comment and for the Committee's commitment to achieve nationally State comprehensive systems of early intervention services for infants, toddlers and their families.

ADDITIONAL COMMENTARY ON THE ROLE OF TITLE V IN IMPLEMENTING PART H

With a major focus on reducing infant mortality, prenatal care is supported by Title V to significant proportions of women giving birth in the States (exceeding 500,000 women each year) (7). State MCH programs have established relationships for primary referral and service arrangements with a range of providers including local heath departments (74 percent); community/rural health centers (36 percent), community hospitals (58 percent) and private physicians (56 percent). Pediatric preventive and primary care service arrangements similarly facilitate access to child and family assessment, health care and education/developmental and social services (8). Nursing, social work and nutrition disciplines figure significantly in both prenatal and pediatric service delivery.

Demonstrating a slightly different focus in provider arrangements and relationships, State Title V service arrangements for CSHCN are established with tertiary centers, specialty and subspecialty physicians, related health professionals (including occupational therapists, physical therapists, speech/language pathologists, audiologists, etc.) as well as with local health departments (9). These linkages broaden the base of important planning, service and personnel preparation resources for State implementation of the Part H program by providing many avenues for primary referral of infants and toddlers to program services, facilitating local service provider arrangements, and by increasing opportunities to educate health care professionals regarding the value of early intervention.

Beyond these resources and services which the State MCH programs bring to the early intervention program, the organization of State Title V programs themselves provide important ties to nutrition services through administration of the Special Supplemental Food Program for Women, Infants and Children (WIC) in one-half of the States (10). As importantly, in fiscal year 1987 14 State Title V programs were administering some aspect of the Title XIX Early Periodic Screening Diagnostic and Treatment Program (EPSDT) and were EPSDT providers in over one-third of the States (11). Additional potential linkages between Medicaid and the Part H program through Title V are found in CSHCN involvement in home and community-based or case management waiver programs for children with chronic health or developmental impairments (11). Established Title V relationships with WIC and with the Medicaid program offer those education and other non-health agencies administering Part H expertise and experience in designing and implementing collaborative service and financing arrangements for a broad range of early intervention services as specified in statute and regulations.

State Title V programs bring substantive experience in multidisciplinary health services planning, case management and home visiting services that are key to implementation of Part H. Case management is an integral component of State Title in services provided to CSCHN in over 80 percent of the States (FY 1987 data) (13). In 1989, 43 State Title V programs provided home visiting to CSHCN, and 46 States provided these services to infants (14).

Title V also mandates broad program responsibility for health promotion and disease prevention for the entire population of women, children and families in each State. Efforts to carry out these mandates in most States include statewide outreach and public education programs. Our 1988 survey of the States revealed that even in the first year of implementation of the Part H program, over 60 percent of the Title V programs were engaged in special health promotion and/or outreach initiatives related to early identification of children with or at-risk for disabling conditions (15).

Further, OBRA 1989 Amendments to Title V now require that States operate a toll-free phone line providing information on Title V and Title XIX providers and for Title V identification of and assistance to infants and pregnant women eligible for Medicaid (16). Prior to the effective date of these legislative provisions, fifty-seven percent of the Title V programs were already implementing toll-free lines, and 22 remaining jurisdictions were planning for start-up in fiscal year 1991 (17). States' fiscal year 1991 MCHS Block Grant applications evidenced a high level of interagency planning in designing information services including specific focus around incorporation of information on early intervention services. Analysis of these same State documents revealed that in mid-1990, 96 percent of the States were actively engaged in targeted initiatives to identify and provide assistance to Medicaid eligible pregnant women and their infants (18).

These public awareness, case finding and referral activities, including preconceptional, pregnancy and infant primary care concerns, are important contributions to implementation of Part H public awareness, central information directory and child find components. Children and families in need of support, especially those with low-income who often require more highly sustained intervention than well-educat-

ed, middle class families, can be located early through Title V supported services and assured prompt access to health care, early intervention services, financing and related community services and supports. Participation of education, social services, developmental disabilities and other focal State agencies engaged in the Part H program further assures that Title V-supported care is extended beyond medical concerns to comprehensively address child and family needs. The participation of Title V MCH and CSCHN programs in early intervention systems development and service delivery recognizes the importance of health assessment and care in child development, education and social functioning.

For over 55 years, Title V has been an important, effective, and enduring mechanism in the distribution of resources and support, planning, leadership, program development, and establishment of standards for health services for women and children. It integrates information, programs, and care for families. It adds State, local, and in-kind resources to very modest Federal investments. Most important, in most jurisdictions Title V has effectively engaged all levels of public and private sector leadership in maternal and child health activities. These longstanding Title V traditions have contributed to the documented achievements in development of comprehensive statewide systems of early intervention services. Likewise, inclusion of State MCH programs as integral partners in development of the Part H program has enhanced public awareness and political support for MCH, and created new incentives for collaborative State and local action to improve the health and well-being of young children and families.

Table 1

State Health/Health and Human Service Departments Designated as Part H Lead Agencies

Alabama*	South Carolina*
Alaska*	Texas
Hawaii*	Utah*
Kansas*	West Virginia*
Maine	Wisconsin*
Mississippi	Wyoming
Massachusetts*	Washington
New Mexico	Samoa
New York	Puerto Rico*
Ohio*	Virgin Islands*

*Denotes States where Part H administration is located in the Title V program

FOOTNOTES

1. U.S. Department of Education. *Twelfth Annual Report to Congress on the Implementation of the Education of the Handicapped Act.* 1990, page 52.
2. U.S. Department of Education. Unpublished. 1991.
3. Harbin, G.L. et. al. *Status of States' Progress in Implementing Part H of Public Law 99-457: Report #2.* Chapel Hill: Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill. 1990.
4. Shonkoff, J.P. "Early Intervention for Disabled Infants and Their Families: A Quantitative Analysis." *Pediatrics.* Vol. 80. No. 5. November 5, 1987.
5. Smith, B.J. and Strain, P.S. "Does Early Intervention Help?" ERIC Digest #455. 1988.
6. NEC-TAS. "Update: Public Law 99-457." *Workshop Proceedings: Health and Education Collaboration for Children with Handicaps.* University of North Carolina, Chapel Hill. February 1991.
7. Association of Maternal and Child Health Programs. *Caring for Mothers and Children: A Report of a Survey of fiscal year 1987 State MCH Program Activities.* March 1989, pages 10-12.
8. Ibid., pp. 8 and 16.
9. Ibid., p. 31.
10. Ibid., pp. 78-80.
11. Ibid., pp. 70-72.
12. Ibid., pp. 74-76.
13. Ibid., pp. 39-41.
14. Association of Maternal and Child Health Programs. *Building on the Basics: Four Approaches to Enhancing MCH Service Delivery.* December 1990, p.3.
15. Op. cit., pp. 51-53.

16. *Social Security Act. Title in:* Section 505. (a) (F) (iv).
17. Association of Maternal and Child Health Programs: *Meeting the Challenge: A Report on the First State Program Applications for Title V as Amended by OBRA 1989.* February 1991, p. 18.
18. Ibid.

Senator HARKIN. Next, we have a long-time friend of mine, Jonathan Wilson, a member of the school board in Des Moines, IA, who is here on behalf of the National School Boards Association and the American Association of School Administrators.

Jonathan, welcome to the subcommittee.

Mr. WILSON. Thank you, Tom.

I am a lawyer and a member of the Des Moines board of education and the immediate past chairman of the National School Boards Association Council of Urban Boards of Education.

I am very much pleased to have this opportunity to present joint testimony on behalf of the American Association of School Administrators, the AASA, and the National School Boards Association, the NSBA.

The Nation's 97,000 local school board members and 16,000 local school superintendents are proud that under Public Law 94-142 the public schools serve over 4.5 million children with disabilities annually. With the creation in 1986 of the preschool program, public schools also now serve, as the Senator pointed out earlier, 360,000 children aged 3 to 5 with disabilities.

The Federal Government has played a significant role in producing these results. Unfortunately, it is very much a junior partner in the financing of this massive educational effort. This is of increasing concern to school leaders, as growing numbers of children come to the schoolhouse door each year with severe barriers to learning. Our resources are being stretched ever thinner by new demands for specialized services.

That is why Part H is of special value to the public schools. Part H stresses early intervention and prevention as an alternative to expensive crisis intervention and long-term remediation. Its emphasis on interagency collaboration is a major part of our vision for the future of American public education.

I would like to highlight several recommendations to enhance Part H and to facilitate transition to the preschool 3- to 5-year-old program under Part B. Our complete set of recommendations is in the written Statement.

First, we support differential participation and funding by States in early intervention and preschool programs. A significant number of States have not been able to meet the full requirements for continued participation in Federal funding of the early intervention services program. Similarly, several States may not be able to meet the deadline to provide under State law a free appropriate public education for all handicapped children aged 3 to 5 years. They too are targeted to lose Federal funding. Neither one of these outcomes is favorable for children with disabilities or the local school systems that provide them with much-needed services.

Solomon in his wisdom recognized that the child should not be made to suffer when the grown-ups can't get their act together.

Congress should consider extending the time frame for full participation of such States in these programs if the Secretary of Edu-

cation determines that there is a reasonable basis for the delay and evidence of a good faith effort to provide services under the circumstances. The effect of the current recession on State budgets, for example, particularly education funding, is one example of an unforeseen problem that could legitimately delay full implementation.

During the interim, the affected States should receive funding at the level received for fiscal year 1990 under Part H or section 619 as the case may be.

Given its inability to even approach full funding of its 40 percent share of the cost of education of the handicapped, the Federal Government should appreciate the need for some flexibility for States charged with gathering the fiscal and organizational resources necessary to put these ambitious new programs in place, particularly in light of the fact that most States are prohibited, like the State of Iowa, from deficit spending, unlike the Federal Government.

Second, we recommend strengthening the role of the Federal interagency coordinating council. Both NSBA and AASA have made coordination of Federal services a high priority. NSBA is strongly supporting the Link-up for Learning Act, sponsored by Senators Bradley and Kennedy, and AASA has endorsed the children's trust bill to be introduced by Senators Dodd and Chafee. Both bills encourage integration and coordination of funding and services for children and youth.

Under Part H, we recommend that the role of the Federal interagency coordinating council (FICC) include specific charges to identify and eliminate Federal program regulations or practices that impede coordination and collaboration, to develop and implement plans for joint funding streams and resource banks, unified eligibility and application procedures, and regulations that facilitate information sharing; also, to make reports and recommendations to Congress annually concerning progress and legislative action needed to facilitate coordination of early intervention services for infants and toddlers.

In addition, Congress should authorize the FICC to conduct a study of State early intervention programs to identify the common obstacles encountered by State lead agencies in developing interagency programs and the means developed to overcome these obstacles. The study should also make recommendations for further actions to facilitate coordination at the Federal level.

We also support the recommendations of the Council for Exceptional Children to name in the statute the specific Federal agencies with programmatic and fiscal responsibilities for children with special needs.

The FICC should also investigate whether local education agencies, given the reality of limited resources, can effectively function as lead agencies without harmful results for preschool and kindergarten through 12th grade programs and recommend remedies.

While we recommend the trend toward greater interagency collaboration, we are also mindful that school districts historically have not always been equitably treated in the distribution of financial responsibility for special education and related services. We strongly recommend that the current protections provided in the law such as payor of last resort be maintained and strengthened if necessary.

Third, we have several recommendations for effective coordination of the Part H and Part B programs. It is critical that local school district representatives have a direct opportunity to provide advice and express concerns as plans are developed for coordination of services birth to age 5. We strongly recommend that State interagency coordinating councils have a statutory function that will provide for conducting public hearings to get that input. At a minimum the hearings should address financial responsibilities of agencies, definitions of handicapping conditions, and determination of appropriate ages for transition to Part B services.

In addition, to ensure a smooth transition for children from the infants and toddlers program to the preschool handicapped program, we recommend that lead agencies contact the local education agency at least 90 days prior to the 3rd birthday of every child in service so that the local education agency will have at least that 90 days during which it can complete its assessment of the child before preschool services will begin, and during that time the agency providing services under the infant and toddler program should continue to do so.

We also strongly recommend that the provision of family services for 3- to 5-year-olds must be the primary responsibility for noneducational agencies.

In conclusion, we believe that the efforts of the Subcommittee on Disability Policy to enhance early intervention services for infants and toddlers, minimize the later costs of special education for school-age children, and encourage interagency collaboration, are highly commendable.

We applaud the successful efforts of the chairman, Senator Harkin, to increase Federal funding for Part H and the preschool program. But we must also note that the Federal Government continues to be very much a junior partner with the States and local school districts. In the bait-and-switch process of Federal funding, we would urge you to support budget and appropriations legislation for fiscal year 1992 that will make the significant increase in Federal investment in education, including the disabled, a top priority.

Thank you very much.

Senator HARKIN. Thank you very much, Jonathan.

[The prepared statement of Mr. Wilson follows:]

PREPARED STATEMENT OF MR. WILSON

I. INTRODUCTION

I am Jonathan Wilson, a member of the Des Moines, Iowa Board of Education and the immediate past president of the National School Boards Association's Council of Urban Boards of Education. I am pleased to have this opportunity to present joint testimony before the Senate Subcommittee on Disability Policy on behalf of the American Association of School Administrators (AASA) and the National School Boards Association (NSBA).

NSBA and AASA appreciate the opportunity to testify in support of the reauthorization of Part H of the Individuals with Disabilities Education Act. The Nation's 97,000 local school board members and 16,000 school superintendents are proud of the fact that since the enactment of Public Law 94-142 in 1975, the public schools have been able to put in place high quality programs that annually provide special education services for over 4.5 million children with disabilities. With the assistance authorized in 1986 under section 619 of Part B, local school districts have been able to develop preschool programs serving 360,000 children aged 3 to 5, about 25 percent more than originally estimated.

The Federal Government has played a significant role in producing these results. But unfortunately it has functioned as very much of a junior partner in the financing of this massive effort to educate individuals with disabilities. This is of increasing concern to school leaders as growing numbers of children come to the schoolhouse door each year with severe barriers to learning. Our resources are being stretched ever thinner by new demands for specialized services. For example, we are just beginning to deal with the tragic epidemic of drug-exposed infants and children.

In this environment, programs that stress early intervention and prevention as an alternative to expensive crisis intervention and long term remediation are of special value to the public schools. Part H, the Early Intervention Services to Infants and Toddlers program, is exactly the sort of innovative Federal program that we need. Its aim is both to enhance the development of handicapped infants and toddlers and to minimize educational costs to society by minimizing the need for special education after handicapped infants and toddlers reach school age. Also significant is its emphasis on creating a program design that is comprehensive, coordinated, multidisciplinary, and based on interagency collaboration.

NSBA and AASA would like to make a number of specific recommendations to enhance Part H particularly in the area of coordinating the Infants and Toddlers program under Part H with the Preschool 3- to 5-year-old program under Part B, Sec. 619.

II. SUPPORT FOR DIFFERENTIAL PARTICIPATION AND FUNDING BY STATES IN EARLY INTERVENTION AND PRESCHOOL PROGRAMS

A significant number of States have not been able to meet the fourth or fifth year application requirements that would qualify them for continued participation in Federal funding of the early intervention services program. Similarly, seven States may not meet the deadline to have in place under State law and practice a plan assuring the availability of a free appropriate public education for all handicapped children aged 3 to 5 years. They are subject to sanctions including the loss of Sec. 619 funds and the use of Part B funds for 3- to 5-year-olds.

Neither one of these outcomes is favorable from the point of view of providing new services to handicapped children and preventing greater and more costly needs for special education when children in these States reach school age. Rather than punish the children and the local school systems by withholding Federal funds, Congress should consider extending the time frame for full participation of such States in these programs if the Secretary of Education determines there are: (a) reasonable basis for the delay; and (b) evidence of a good faith effort to provide services under the circumstances. The effect of the current recession on State budgets, particularly education funding, is one example of an unforeseen problem that could legitimately delay fill implementation. During the interim, the affected States would receive funding at the level received for fiscal year 1990 (school year 1990-91) under Part H or Sec. 619.

Given that the Federal Government has promised to fund 40 percent of the excess costs of educating individuals with disabilities and after 15 years is currently providing only nine percent, it should appreciate the call for some flexibility on the part of States charged with gathering the fiscal and organizational resources necessary to put these ambitious new programs in place.

III. STRENGTHEN THE ROLE OF THE FEDERAL INTERAGENCY COORDINATING COUNCIL UNDER PART H TO FACILITATE INTERAGENCY COORDINATION

The great wave of school reform initiatives over the last decade has in many ways not directly affected special education in our schools. But in one significant arena—coordinated early intervention services under Part H—Public Law 94-142 is on the cutting edge. The importance of approaching the needs of children and families holistically through comprehensive, coordinated, multi-disciplinary interagency programs is becoming more widely recognized in the education and social service community as essential for the educational success of at-risk students.

For the last 5 years, Part H has underwritten the development of such programs for infants and toddlers in States across the country. But the barriers to interagency collaboration remain formidable. They include conflicting agency missions and target populations, separate funding streams, arbitrary jurisdictional boundaries, confidentiality requirements that prevent information sharing, separate eligibility requirements, service providers unfamiliar with services and procedures outside their agency, and a dearth of incentives to overcome barriers and pursue collaboration.

Both NSBA and AASA have made these concerns a high priority in their legislative initiatives for this session of Congress. NSBA is strongly supporting S. 619, the Link-up for Learning Act sponsored by Senators Bradley and Kennedy, which funds projects to link up families with the resources of schools and social service agencies to improve the educational performance of at-risk youth. AASA has endorsed legislation to be introduced by Senators Dodd and Chafee that establishes a Children's Trust fund to finance from one source the major Federal programs providing services to children and youth including special education. We have no doubt that further integration of services and interagency collaboration are essential if schools are to cope with the worsening social and economic conditions of incoming students.

A. *FICC Responsibilities*

We recommend that the role of the Federal Interagency Coordinating Council (FICC) be strengthened to include specific charges to:

—identify, and to the extent possible, eliminate Federal program regulations or practices that impede coordination and collaboration;

—develop and implement whenever possible plans for joint funding streams and resource banks, unified eligibility and application procedures, and confidentiality regulations that facilitate information-sharing;

—make reports and recommendations to Congress annually concerning progress and legislative action needed to facilitate coordination of early intervention services for infants and toddlers.

B. *FICC Study*

In addition, Congress should authorize the FICC to conduct a study of State early intervention programs to identify the common organizational, regulatory, and legislative obstacles encountered by State lead agencies in developing and implementing comprehensive, coordinated, multidisciplinary, interagency programs and the innovative procedures and program designs developed to overcome them. The study should also make recommendations to the participating agencies and Congress for further actions to facilitate coordination at the Federal level.

C. *Statutory Listing of Collaborators*

We also support the recommendations of the Council for Exceptional Children's Division for Early Childhood to name in the statute the specific Federal agencies with programmatic and fiscal responsibility to develop and implement a comprehensive community based system of services for children with special needs and their families. This includes the Department of Education; the Office of Human Development; the National Institute of Mental Health; the Office of Maternal and Child Health; the Administration of Developmental Disabilities; the Administration on Children, Youth, and Families; and the Health Care Financing Administration.

D. *Investigation of Lead Agency Effectiveness*

In addition, the FICC should investigate whether the designation of local education agencies as lead agencies under Part H is effective and without harmful results for school programs. We are concerned that local school district resources may not be able to meet the needs of infants and toddlers and also effectively provide required services to 3- to 5-year-olds and school-age handicapped children. There is no recourse for the LEA if they are designated the lead agency by the State.

The FICC should report on this situation and determine whether Federal remedies are required, such as limiting the designation of lead agency to social service and health providers within the State.

E. *Maintain School District Protections*

While we welcome the trend to greater interagency collaboration, we also are mindful that school districts historically have not always been equitably treated in the distribution of financial responsibility for special education and related services. We strongly recommend that the current protections provided in the law, such as payor of last resort, be maintained and strengthened if necessary.

IV. SUPPORT FOR EFFECTIVE COORDINATION OF PART H AND PART B PROGRAMS AGES THREE TO FIVE

A. *ICC Hearings*

It is critical that local school district representatives have a direct opportunity to provide advice and express concerns as plans are developed for coordination of services between Part H State programs for birth to 2-year-olds and Part B local school district programs for 3- to 5-year-olds. We strongly recommend that State Interagency Coordinating Councils have as a statutory function conducting periodic hearings concerning plans for the coordination of services between Part H and Part B programs. The hearings should be public, address proposed plans as well as provide oversight of plans as they are implemented, and invite testimony from representa-

tives of local school districts, parents, service providers, and others with an interest in developing and implementing effective plans for coordination.

At a minimum the State ICC should be required to conduct a hearing prior to implementation or issuance of a plan or directive by the State lead agency concerning financial responsibilities of agencies, definitions of handicapping conditions, and determination of appropriate ages for transition to Part B services.

B. *Notifications to LEA*

In addition, to ensure a smooth transition for children from the infants and toddlers program to the Preschool Handicapped program, we recommend that:

—the lead agency responsible for coordinating services to infants and toddlers (ages 0-2) contact the Local Educational Agency (LBA) at least 90 days prior to the third birthday of every child in service.

—the LEA will have 90 days—or the State-mandated period for placement and evaluation, if it is longer—during which it will complete its assessment of the child before preschool services will begin.

—the agencies providing services under the Infant and Toddlers program will continue to provide those services to the child, during the 90-day period in which the LEA is completing its assessment for evaluation and placement.

—if a child is a ward of the State, there will be a clear designation of a representative to act as the parent for educational purposes in the preschool program in the I.E.P. and placement process.

—furthermore, where Educational Service Agencies exist, those agencies should be considered for delivering Infant and Toddler services or coordinating those services between other agencies and schools.

C. *Developmental Delay*

We recommend against carrying over the term developmental delay from Part H into the definition of handicapping conditions for 3- to 5-year-olds without further study. While the use of the same term birth to 5 has advantages, at age three the designation would carry with it much greater consequences for the child, its family, and the school system. Of particular concern is the fact that there is no uniform standard of severity to determine when a child with a developmental delay requires special education services rather than services that might be more readily provided through, for example, a Chapter 1 preschool program, a school-based Head Start program, or a community-based child care program.

D. *Family Services*

We would also recommend against authorizing services to families of 3- to 5-year-olds under Part B. The range of potential social, psychological, health, nutritional, and other services that could potentially be of value to parents in supporting proper development of their handicapped child is limitless. Provision of family services must be the primary responsibility of non-educational agencies. Finally, case management services should be an allowable use of Federal funds rather than a mandated related service for 3- to 5-year-olds.

E. *No Extension of Federal Mandate*

We strongly urge that Congress maintain the current preschool program separate from the Public Law 94-142 mandate for school-age children. Given the continuing and chronic funding shortfall under both basic State grants and section 619, a consolidation of the 3- to 5-year-old program with the school-age program would inevitably dilute resources to all children with disabilities.

V. CONCLUSION

In conclusion, we believe that the efforts of the Committee on Disability Policy to enhance early intervention services for infants and toddlers, minimize the later costs of special education for school-age children, and encourage interagency collaboration are highly commendable. We applaud the successful efforts of the Chairman, Senator Harkin, to increase Federal funding for Part H and the preschool program. But we must also note that the Federal Government continues to be very much of a junior partner with States and local schools in providing funding for the education of individuals with disabilities. In the bait-and-switch process we urge you to support budget and appropriations legislation for fiscal year 1992 that makes a significant increased Federal investment in education including the disabled.

Thank you for this opportunity to testify.

Senator HARKIN. Ruth Rucker, director of the Edward C. Mazique Parent Child Center, District of Columbia, on behalf of Low-Income and Minority Parent Empowerment Task Force.

Ruth, welcome to the subcommittee.

Ms. RUCKER. Thank you so much for having me here today and permitting me an opportunity to speak on behalf of the Parent and Child Center and certainly the Low-Income and Minority Parent Empowerment Task Force.

We are one of 36 parent and child centers nationally. We were born in 1968 as a part of that whole effort to improve the quality of life for low-income children under the Head Start concept for children birth to 3 years of age.

The Low-Income and Minority Empowerment Task Force is a group of 26 members, and we are parents, service providers and advocates for young children. The main purpose of the task force is to work toward full participation for low-income and minority families, or families of color—we are interchangeable—in the Part H program.

We are very supportive of Part H, and we feel that it is one of the best avenues that we can find that has come about in a long time to benefit families with very young children where there is delay or where the children are disabled.

The Part H early intervention program signals new directions in Federal policy. It is the first indication on a broad scale of the Federal commitment to infants and toddlers who are disabled and who have disabilities, and it also breaks new ground in moving toward the family-centered rather than the child-centered services, and we think that that is really the way to go. It also represents a significant departure from the way most States view early intervention programs.

We are very supportive of Part H, but we do have some concerns. We do have a concern about how States will assure that low-income families and minority families have access to the appropriate early intervention services.

We are concerned that little effort is being made by State Part H policymakers to include low-income families and minorities in the Part H planning process. It is troubling that sensitivity in the issue of cultural competence is lacking on such a broad scale throughout the country.

We are equally concerned about personnel. There is a shortage of early intervention therapists in general throughout the country, not to speak only of therapists who are of color. There has to be a broader move to recruit and to train ethnic therapists in order that they may be more sufficient in dealing with the families they are serving.

In our country, we are multicultural, multiethnic throughout our Nation, and in some way we are going to have to find a way to compare or to have equal service delivery systems compared with the kind of ethnic families that we have in our country today.

We do not believe that enough outreach is put forth to recruit low-income families and families of color, as I said before, neither to recruit personnel.

Now, I realize that financing is a major situation. It is a major situation with the States, and we respect that. We realize that the finances will have to be increased. States are citing finances as the cost factor and a reason for not recruiting at a maximum basis for the personnel and for the families. We feel that this has to change. There has to be a stronger investment in these two areas. And I

am pleading that you will consider this remark that I am making today and this testimony because we feel that this is a fantastic program, and we feel that it can become even better if we find ways of reaching the underserved and the unserved families, which certainly includes minorities, families of color and the low-income.

Our written statement contains recommendations that we certainly would like for you to consider, but there is one recommendation in particular that I would like to read for the record. That recommendation is that 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 have also included in our statement for your consideration some policies and practices that we feel would result from the implementation of this assurance anyhow.

Thank you very much for giving me this opportunity. That is my main reason for being here, to let you know that this is an area that needs to be strengthened.

Thank you.

Senator HARKIN. Thank you very much.

[The prepared statement of Ms. Rucker follows:]

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EXECUTIVE DIRECTOR
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SENATE COMMITTEE ON LABOR
AND HUMAN RESOURCES

SUBCOMMITTEE ON DISABILITY POLICY

HEARING ON REAUTHORIZATION OF PART H
(PL 99-457)

March 15, 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 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 levels 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 policy-makers 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 compatent 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(a), 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 we believe would result from the implementation of this assurance:

* 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 con ·ct 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

Marva Benjamin, Assistant Director
Initiative on Cultural Diversity
Child & Adolescent Service System Program
Washington, DC

Deborah Booth, Special Projects Manager
East Coast Migrant Head Start Project
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Alan K. Chambers, Director
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Lauran Davin
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Paula F. Goldberg, Co-director
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Angela Herring
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Edward C. Mazique Parent Child Center
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Beverly Jackson, Senior Policy Analyst
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AVANCE Family Support and Education Programs
San Antonio, TX

Ruth Rucker, Executive Director
Edward C. Mazique Parent Child Center
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Justine Strickland
East River Child Development Center
New York, NY

Debi Tisdale
Parent Participant (FICC)
Tacoma, WA

Virginia View
Coordinator, Project 0-3
National Center for Clinical Infant Programs
Arlington, VA

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 public increase 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.

Senator HARKIN. Tom Gillung, currently Part H authorizes States to adopt a sliding fee scale under which States may charge parents for certain services based on ability to pay. The discretion is left solely with the State. Would you support an amendment which either mandates all States adopt a sliding fee scale, or an amendment which prohibits the use of a sliding fee scale?

Mr. GILLUNG. It would be our position that this provision be optional. We recognize that in many States there currently are service providers that already do provide a sliding fee scale for the provision of service.

Senator HARKIN. Dr. Nelson, do you have any view on this?

Dr. NELSON. I would agree that the States should have flexibility in making that determination.

Senator HARKIN. Mr. Gillung, in your testimony you expressed opposition at this point in time to replacing the current formula that relies on census data with a formula based on children served. You also described the experience of the Department of Education under which section 619 bonus funds were distributed on the basis of estimates of children served in the upcoming year as an administrative nightmare.

I'll ask you the same question I asked Mr. Davila. Would you support a study to be included in our bill, looking at this issue and revisiting the formula change question in the next reauthorization?

Mr. GILLUNG. Yes, we would. We believe that that would be the most equitable way to address that issue.

Senator HARKIN. Mr. McNulty, do you feel the same way?

Mr. MCNULTY. Yes, definitely. I think that again, to switch formulas in the middle of the program would not be the most effective way to get services to kids, but I think certainly we would feel comfortable studying that.

Senator HARKIN. Jonathan, you talked in your testimony about concerns about several changes in the preschool program. Specifically I'm referring to including the Part H term "developmental delay" under Part B; permitting school districts to use the individualized family service plan instead of the IEP; including the terms "family services" and "case management" under Part B.

In reviewing the testimony of both the DEC and the CCD, I don't really believe that your organizations are too far apart in trying to get these definitions worked out. I am asking if both the National Association of School Boards and School Administrators would meet with my staff and representatives from those organizations to see if we can work out a consensus on these issues.

Mr. WILSON. In a word, yes.

Senator HARKIN. Good. We're going to invite you and your organization, and we'll sit down and see if we can't work out a consensus on this.

Dr. Nelson, you are an advocate for serving as many children who are at risk of experiencing developmental delay as is possible because you believe in prevention. Given limited resources, what is the best policy we could adopt to encourage more States to serve the at-risk population?

First, would you authorize Part H to be used to serve some but not all of the population; second, would you authorize the use of Part H funds to provide some but not all early intervention serv-

ices; or would you require that if a State provided a certain service that it must make that service available to the entire population of at-risk children?

Mr. Nelson. I don't know if those are all mutually exclusive options. But I think in general the legislation should provide incentives to States to serve the at-risk population.

We know that it is very difficult to differentiate children who are at risk at times from children who might meet a definition of developmental delay, and we certainly do not want to create the artificial sense that there are groups of children who are "at risk" whose needs and the needs of their families are substantially different from children who may have mild but recognizable developmental delay.

Senator HARKIN. Thank you very much, Dr. Nelson.

Ms. Rucker, thank you for being here and for your testimony. I don't really have a question so much as I'll say that your suggestions are all right on target. We are going to seriously consider them, and again I'd like to work with you in the upcoming weeks to incorporate those suggestions in our reauthorization bill. I think they are right on point.

Ms. RUCKER. Thank you very much, Senator.

Senator HARKIN. Senator Durenberger.

Senator DURENBERGER. Thank you, Mr. Chairman.

Dick, let me start with you. I thank you for being here. We usually see each other over on the Finance Committee, so it is nice to see you here.

Dr. NELSON. Thank you.

Senator DURENBERGER. I am relatively new to this, and I am glad to be here. But in my previous statement I think I indicated one of my frustrations is explained by what Lawton Chiles told us here a month or so ago, which was: "There are 160 programs out here in my State of Florida for kids, which I helped to create when I was a Senator. Why don't you just total them up, see what they come out to in dollars, send me a check, and I'll solve these problems."

I have been in the Senate for 13 years now, and I know what he is talking about. I would like to know what the problems that we heard about from these young people here had to do with education as opposed to health. Why in my State is this program in the Department of Education, and in 17 other States in the Department of Health and Human Services.

I am really anxious, and what I am expressing here is an anxiety, to take advantage of what we have learned because there are many programs, and especially this one, that we need to get more of the dollars to the people who need it, in the form that they can use it.

So when I see MCH, which I work on over in the Finance Committee—and I have been through the blocking process, and I've been through the whole struggle about block grants. Every organization that is involved says, "Please don't do that because we are going to lose here, and we're going to lose there," and so on. Then sure enough, they start losing because we start cutting money out, because you put this one in competition with that one in competition with that one in competition with that one, and it becomes a self-fulfilling prophecy.

So I can understand why people hang onto these categorical programs with their relatively narrow target and their claim to be coordinating—when I'm not really sure they are.

You have a perspective because you have been working in MCH for a long time, and it has a focus on children and everything else. What do you see to be the special value of continuing the relationship, but the separateness, in the way we approach accessing children with disabilities to what looks to me to be—I know there are educational functions here, particularly inside the family and so forth—but mainly we are talking about access to health services.

Dr. NELSON. One of the reasons I think Part H was written the way it was written, namely, to allow a great deal of flexibility in States as to who would be lead and what system of providers would actually have responsibility to families, was that is the way early intervention had evolved throughout the country. In other words, in the 17 States or so where health or human services became lead, that was because in those States those were the providers who were offering early intervention services, and that was the case in Minnesota, for example. Whereas in other States the public school system or the special education system within the State had that primary responsibility.

I think we are always struggling with how to reduce the arbitrary categorical nature of Federal/State programs so that families aren't faced with bewildering and totally incomprehensible sets of eligibility and so forth, which even those of us in the States have a hard time understanding, and yet I guess to preserve focus so that we don't end up having a lack of resources eventually because there aren't requirements.

I think what Part H does is to lay out a framework for services, these 14 components, most of which are fairly straightforward in terms of understanding what children and families need, and yet recognizes that in various communities those components are going to be implemented quite differently.

Health inevitably has a major role to play in Part H because most parents who have infants that are recognized as having a special need are going to turn to their primary physician or to another health professional for initial advice and evaluation. And we have a tremendous job I think to educate those health professionals that they need to work with this whole array of other community services to see that children are referred promptly, and that families receive what they need.

I think the comment you made earlier that we do have a wonderful array of services around the United States—they are simply often very inequitably distributed, and——

Senator DURENBERGER. And the ethnic provider point that Ruth made is essential, too.

Dr. NELSON. Yes. That is a major problem. And the problem of growing childhood poverty is even more daunting. We have counties in Iowa where one in four children in the preschool period are living in a family with an income below the Federal poverty level. The needs in those counties are tremendous, and the resources do not match the needs.

So there is really quite a challenge out there. Part H in some ways maybe is a traditional piece of legislation. It is to help that

system improve without necessarily implying it is the ultimate framework for services.

Senator DURENBERGER. What is—and maybe the rest of you can answer this question for me—from the standpoint of these families that we had up here before, what is the principal function of a State definition of developmental delay, a central directory of information, timetables for serving all eligible children, public awareness program, comprehensive child-find system, evaluation and assessment system, individualized family service plans, comprehensive system personnel development, personnel standards, procedural safeguards, lead agency designation—the big 14. Why have we formalized this whole access thing this particular way and expressed it in these terms?

Mr. MCNULTY. Let me express it from what we have heard from families—and those are all fancy words for trying to make the system work for families.

We have a question of access because depending upon the age of the child, the disability, the severity of the disability, the income level, families get shuttled from agency to agency. Many of our parents tell us that they way they found their way into the human service delivery system is through the yellow pages. Literally they search, trying to find ways, because they find out what they don't qualify for rather than what they do.

So the approach of Part H is very much on that it must be the States' and the local agencies' responsibilities to coordinate their systems in a way that no matter what door parents come in, that they will get taken into the system and get the customized services that they need for their families.

But those are all fancy ways of saying that the system needs to find ways to coordinate itself in a way that works for families, that does the work for them rather than having them jump through all the hoops.

Senator DURENBERGER. The Assistant Secretary was here before I got here, and in his first paragraph he says, "There are many Federal programs providing services and benefits for infants and toddlers"—has that got a generic meaning——

Senator HARKIN. I guess it does; I don't know the difference.

Senator DURENBERGER. —"There are many Federal programs providing services and benefits for infants and toddlers with disabilities and their families, but Part H has this population as its sole focus."

Would it be fair to say that Part H is sort of the "Lawton Chiles" of Federal programs, providing services and benefits for infants and toddlers—in other words, it is trying to say knock down all this stuff—is that the direction of Part H?

Mr. MCNULTY. I think that is very much at the heart of Part H is that interagency coordination. The stumbling block of it again is that you now have a lead agency that has the responsibility to coordinate those programs, but not the authority to make them work together.

Senator DURENBERGER. Of course, all these other people are still sitting back there; they've got their Federal guidelines and their State plan, and you can only serve this population if it qualifies

like this, and then you can only do this for them if they do that, and so on—right?

Mr. McNulty. That's certainly part of the difficulty

Senator Durenberger. It sure must be frustrating.

Dr. Nelson. It is frustrating, but we have been seeing in our pilot areas in Iowa some real improvement over the last couple of years where human services, education, and health professionals at a community level finally have realized that the so-called Federal restrictions that they faced over time perhaps are not as absolute and restrictive as they perhaps had thought in the past; that Part H has created a different sense that we really need to use and employ all the resources at hand. I think it has created a different view of a lot of the Federal/State programs than in the past. It has been positive.

Senator Durenberger. Ruth.

Ms. Rucker. Senator, I think Part H does something else as well. I think it encourages States to look at themselves, to see what their programs are like internally—because if you don't have it on the inside, you can't deliver it to the outside. I think that is one of the things that Part H is doing, and that is what I commend it for.

We must also understand that there are language barriers with families that regardless of how well-coordinated you are internally, if you are not able to speak the language and understand the personal values and the cultures of people, then you are still not going to be successful to any sufficient degree, and I think that needs to be understood.

Senator Durenberger. Yes, Mr. Wilson.

Mr. Wilson. It has been said, Senator, that the road to hell is paved with good intentions. And I would have to suggest that the disjointed collection of educational and social services that we find across this country represents the asphalt and the cement for that paving job.

I think Part H provides an avenue for coordination. It would be nice to be able to say let's just send money, and go thou States and do good with it—under present circumstances maybe not a check, but actual cash. [Laughter.] At any rate, the fact of the matter is that we have to rely on language to share our common objectives and then finally rely on the testimony that we heard from Michelle and others who are here as families to find out whether it is actually getting through and doing what we want it to do.

Senator Durenberger. Let me ask one other question which deals with the way in which we—and I come to this question because I have done this sort of thing before over in the Finance Committee—the way in which we describe services. And there are two ways of describing services. One is the way the medical professions want us to describe them, which is by their licensure standards, so they can keep certain people out of a business they think they are good at and can charge a lot for.

I was looking at a description here of services—audiology, family training, counseling, nursing, occupational therapy, psychological services, special instruction, transportation, case management, health services, nutrition services, physical therapy, social work services. Some of those border on talking about a profession or a licensed skill, and others seem to be sort of generic. I have here a

set of recommendations from the education task force of the Consortium of Citizens with Disabilities. They are recommending that we add to the definition of "qualified personnel marriage and family therapists, pediatricians, and other physicians."

Maybe I could get some of your thoughts on whether or not we should be restricting anybody from providing services, or if we should have another way to determine what it is we expect from these professionals. What are your thoughts?

Mr. McNULTY. I would caution us to a large degree because one of the points that we have heard over and over again is keeping families linked to their communities and to their networks and to their neighborhoods. The more we specialize the disability system, the more we remove families from those natural support systems.

So I would caution that while we want to have well-trained staff that we not focus on again such a system that is so specialized that focuses first again on the disability and second on the child. That is what we heard from parents, and that is what we continually hear is that what the system has done in the past is to push families with kids with disabilities into a disability-oriented system that they never get out of because of that specialization. We convince people through our language and through our disciplines, sometimes, that these children are so different that they cannot be part of regular neighborhoods or regular schools or regular community systems. So I would caution us to be very careful about overspecializing our system.

The second point of that is this already happened in the initial part of Part H when we talked about case managers. Parents came to us and said the first contact we want is from other parents; they were saying parent-to-parent contact is what we want after the family comes home from the hospital. Initially we were told no, this is a profession of case management; we can't have a parent talking to another parent and having that called case management.

So again I caution us on the overspecialization at a time when what we are trying to do is assure that people with disabilities are a part of regular schools and neighborhoods.

Senator DURENBERGER. Ruth?

Ms. RUCKER. I tend to agree with him, but I'd just like to add one little point to that; that training of the case managers or case coordinators is one of the important elements. They have to know where the supportive services are. They should know their communities, and that should be a part of their training.

Senator DURENBERGER. Thank you all very much.

Thank you, Mr. Chairman.

Senator HARKIN. Thank you, Senator Durenberger.

Thank you all very much.

Senator HARKIN. We'll call our last panel now.

George Jesien, University of Wisconsin, Madison, WI, on behalf of the Division for Early Childhood, Council for Exceptional Children; Phillipa Campbell and Aric Murray, Akron Children's Hospital, Akron, OH, on behalf of the Consortium for Citizens with Disabilities; and Ann Taylor from Nichols Hills, OK, on behalf of the Council of Interagency Coordinating Council Chairs.

Mr. Jesien is Director of the Personnel Development Project at the Waisman Center, a University-Affiliated Program (UAP) at the

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University of Wisconsin. I understand that you are the president of the Division for Early Childhood of the Council for Exceptional Children. And would you introduce the two people you have with you?

Mr. JESIEN. I'd be happy to. To my right is Joseph Ballard, director of governmental relations for the International Council for Exceptional Children, and to my left is Barbara Smith, executive director of the Division for Early Childhood.

Senator HARKIN. Your complete statement will be made a part of the record. If you could please summarize it, I'd be most appreciative.

STATEMENTS OF GEORGE JESIEN, UNIVERSITY OF WISCONSIN, MADISON, WI, ON BEHALF OF DIVISION FOR EARLY CHILDHOOD, COUNCIL FOR EXCEPTIONAL CHILDREN; ACCOMPANIED BY JOSEPH BALLARD, DIRECTOR OF GOVERNMENT RELATIONS, AND BARBARA SMITH, EXECUTIVE DIRECTOR, DIVISION FOR EARLY CHILDHOOD

Mr. JESIEN. Thank you very much, Senator.

I would also like to point out the full endorsement of the International Council for Exceptional Children and ask that the recent letter from Joseph Ballard, stipulating to the support that CEC has for the DEC recommendations, be put into the official record.

Senator HARKIN. Without objection, it will be included.

Mr. JESIEN. Thank you.

I'd like to thank the Senator and this committee for the opportunity to join with service providers and parents from all across the country in thanking this committee and the staff who work with it for the leadership and attention that they have paid to the infants and toddlers with special needs in this country and their families.

I'd like to do three things this morning: My opening comments will answer the question "What have you done?;" second, highlight some of the recommendations that we have gathered from around the country; and third, closing remarks and some humble advice on future deliberations.

To answer the question "What have you done?," DEC believes that Part H and Public Law 99-457 will be looked back upon years from now as a hallmark piece of legislation that has set us on a new path. DEC and its 7,000 members have marvelled at what has happened in States across the country. In a real sense, you have harnessed some of the basic energies of our country—the energy of families, of local communities and the service providers that work within them.

Let me give you two examples. In the State of Ohio, 88 counties have local interagency coordinating councils that meet on a regular basis to address the needs of the families they serve. Let me paraphrase Winston Churchill in saying that never have so many done so much with so little in those counties. A recent meeting had 144 participants discussing the needs of families.

In my own State of Wisconsin, we recently gathered professors and faculty members from every, single campus in the State and all 10 disciplines mentioned in Public Law 99-457 with a group of parents from every region in the State, to discuss the future of

training of future professionals and how we can more adequately address the needs of families.

In our State, it is the first time that parents, higher education faculty and State personnel have met to discuss how we can best work with families and meet the needs of infants with special needs.

With this law, I believe that we have set a foundation for services to all families in this country that may have a challenge that they have to meet in raising their children, we would like to support, encourage and applaud these efforts.

Our recommendations, that you have before you in our formal testimony are not offered in the spirit of wanting to change the law, but rather to fine-tune it. We have now gained 4 years of experience. DEC has been around the country and held hearings where over 120 people (representing 29 States) participated. These people included, parents, State bureaucrats, professionals, professors, and direct service providers. Let me highlight some of these recommendations.

First, the need for differential participation: States began in different places, they are in different places right now and will write their own history on how they will attend to the challenges of meeting the needs of families.

Second, incentives and encouragement for States to plan their systems across the age range of birth through 5: the division into birth to 3 and 3 to 5 is more a result of historical accident and political expediency than it is of clinical best practice.

Third, incentives and encouragement to serve children and families at risk: We have before us a major opportunity to address some of the most vulnerable infants and families in our country. Initially the States exhibited a great deal of interest in serving at risk children and their families, but as we see the formal applications for year 4 come in, States have shied away from serving at risk children and their families, and unless we do something, I am afraid that only a handful of States will address themselves to this opportunity.

Last, we ask that States be given the opportunity to define for themselves the technical age of 3 and be able to use preschool funds to fund services for children below 3 and Part H funds to fund services for children over 3, so that there is a smooth transition and there is no cessation of services for children as they approach that age.

Let me move on to a topic that has not been talked about thus far this morning, the 619 provisions. We see P.L. 99-457 as leading-edge and truly beginning to address the needs of young children and their families.

Part 619 is more related to previous legislation (P.L. 94-142), and I think what we have to do in spirit is push the provisions of Part H so that it would at least allow States the flexibility to incorporate those concepts in their planning for children 3 through 5. At the very least we should remove obstacles from States doing so. In order to do that, DEC proposes that the definition of developmental delay by statute be allowed to be used for children 3 through 5. We do not see this increasing the overall number of children who

would be served, but would at least provide an opportunity to serve children who may not have a specific diagnosis in their early years.

We would encourage the provision of family services in 3 to 5; allow States to use IFSP's with children 3 to 5, and provide sufficient resources for States to do so.

We see the child at 4 and his or her needs much more akin to the needs of a 2 year-old child than to that of a middle or high school special education student and would ask that legislation reflect this.

The last set of recommendations in our testimony have to do with providing the necessary training and technical assistance to States, the coordination of training by the FICC and the necessary support system for the work of P.L. 99-457 to continue.

Due to the lack of time let me move to my closing comment, which is that I also come to you as the father of a 6 year-old and a 4 year-old. My 6 year-old daughter came into this world weighing 2 pounds, 12 ounces, and spent her first 8 weeks in an intensive care unit. That experience provided me at least a glimpse of the challenges that face many parents in this country.

One of the things I have learned as a father is: showing your children is much more effective than just telling them what to do. That is my guidance for this committee in your future deliberations. We are asking providers to work collaboratively and in partnership with parents; to have parents and families identify their concerns, their priorities and their resources, and enable and empower parents to make decisions for their children regarding the kind of services they want. I ask that this committee work with States in the same way that States are asked to work with families—in a partnership, collaborating with them, asking States to identify their resources, their preferences and their priorities, and enabling and empowering personnel in those States to address the needs of their families.

Terry Smith in Wisconsin recently said as he was talking about the IFSP—he was lecturing a group of 115 professionals—as he said, "To you this (the IESP) is a piece of paper, to you it reflects requirements and regulations, bureaucracies and procedures. For me, it is the goals for my child, and a challenge that we have to face to meet them."

Thank you very much for this opportunity. We have heard of different epochs and periods in this country. I would hope that this legislation may truly begin this next decade as the decade of the family in this country.

Thank you very much.

Senator HARKIN. Mr. Jesien, thank you very much for a very good statement.

[The prepared statement of Mr. Jesien follows:]

Prepared Statement of Mr. Jesien

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 terminolog; "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) (b)). 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

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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

Senator HARKIN. Now we welcome Phillipa Campbell and Aric Murray. "Pip" Campbell is an early childhood specialist in the Family/Child Learning Center at Children's Hospital Medical Center in Akron, OH. She works there with children like her young friend Aric Murray. Aric, I understand you are 9 years old. Aric has severe visual problems and cerebral palsy. In spite of this, Aric uses a computer and he is very mobile in his motorized wheelchair.

Pip is here to testify in behalf of the Consortium for Citizens with Disabilities. Pip, welcome to the subcommittee, and Aric, welcome.

Ms. CAMPBELL. Thank you.

Mr. Chairman, members of the subcommittee, the education task force of CCD has identified a number of issues that they request be considered by you. In the interest of time and I think in the interest of keeping Aric, my friend, for longer than today, I will highlight some of these recommended changes.

As you all have heard, Aric is 9 years old. He attends a regular education second grade classroom in Akron city schools. He, like so many children, was born prematurely at 30 weeks gestational age; he weighed about 3 pounds. At 11 months of age he was referred to and enrolled in an early intervention program where he received both early intervention and preschool services until he began to attend kindergarten.

Aric is here to talk with you about some of the opportunities that he has had and to discuss with you some of his ideas concerning his life and his thoughts.

Children like Aric exemplify the significance of early intervention and family support, and also highlight the importance of enabling States to be able to deliver services for infants, toddlers, and their families all across the country.

Many States are facing significant hardship in delivering these services. Out of recognition for these difficulties, the task force recommends the addition of a provision permitting the secretary to grant up to two one-year waivers of specific requirements.

In addition, a second recommendation concerns the formula for funding Part H services. This formula will have a significant impact on the States' incentive to find and serve children. While the task force supports the distribution of administrative planning monies as they currently are, the task force requests your consideration of a funding formula based on the numbers of children served once the States are fully implementing Part H and are able to provide the necessary data for such a distribution.

CCD has numerous recommendations relating to parents and families of infants and toddlers. Supports to families, as we have heard this morning, are integral to the success of services for infants and toddlers. CCD holds the family provisions in this bill up as very important and as a beacon for other service delivery systems. However, there are a number of refinements that would support the underlying value expressed in the bill, and these refinements are discussed in greater detail in the testimony.

Finally, it is important that services and supports should be provided in settings for infants and toddlers that are the same settings that would be used for infants and toddlers without disabilities.

One very clear example of this would be integrated daycare, although there are many other ones.

As Aric probably exemplifies to you, assistive technology is of critical importance in liberating infants and toddlers with disabilities and allowing them to participate in all aspects of daily living. We have been made aware of many instances in which the provision of assistive technology has dramatically altered prospects for a child's future. The task force recommends that these services and devices be included as defined early intervention services.

I think it is important to recognize that the result of quality early intervention services that support families and their infants and toddlers with disabilities are children who grow up to be full members of their communities despite lifelong disabilities.

Aric has helped me in many, many different instances and has often done what we call "co-teaching" so he has agreed today to talk with you today about himself and some of the things that have been important to him.

OK, Aric, your turn.

Senator HARKIN. You're up, Aric.

Mr. MURRAY. Hi. [Pause.]

Ms. CAMPBELL. How is school?

Mr. MURRAY. School has been a lot of fun.

Ms. CAMPBELL. What do you like best about school?

Mr. MURRAY. My friends.

Ms. CAMPBELL. You like your friends best.

Mr. MURRAY. Yes.

Ms. CAMPBELL. Who is your best friend?

Mr. MURRAY. All of them.

Ms. CAMPBELL. All of them are your best friends. I wish I could say the same.

What did you tell me last night that you liked the very best?

Mr. MURRAY. My teacher.

Ms. CAMPBELL. And what else?

Mr. MURRAY. I forget.

Ms. CAMPBELL. You forget. OK. Are there any other things that you'd like to say? [Pause.] Not now.

Thank you.

Senator HARKIN. Well, Aric, thanks for being here. [Applause.]

Senator HARKIN. Have you got a reverse on your wheelchair? Does it go backward and forward?

Mr. MURRAY. Yes.

Senator HARKIN. I understand your mother is here; is that right, Aric?

Mr. MURRAY. Yes.

Senator HARKIN. Let's have your mother stand up so we can meet her. Where is your mother? There she is. Very good.

Mr. MURRAY. Rachel's here.

Senator HARKIN. Where is Rachel? Stand up, Rachel. Good. [Applause.]

Senator HARKIN. Well, I'll bet your mother and Rachel are very proud of you.

Mr. MURRAY. Yes, they are.

Senator HARKIN. Well, Aric, welcome to Washington, DC.

Mr. MURRAY. I am very glad to be here

Senator HARKIN. Good for you. We're happy to have you here, too, I'll tell you that. Thanks, Aric.

Mr. MURRAY. Thank you

[The prepared statement of Ms. Campbell follows:]

TESTIMONY OF THE EDUCATION TASK FORCE
CONSORTIUM OF CITIZENS WITH DISABILITIES
DR. PHILLIPA CAMPBELL AND ARIC MURRAY
Senate Subcommittee on Disability Policy Hearings
Part H, Individuals with Disabilities Education Act

Mr. Chairman, members of the Subcommittee, I am Dr. Phillipa Campbell, Director of Family Child Learning Center, a program that is operated jointly by Children's Hospital of Akron and Kent State University in Ohio. I am happy to be before you today on behalf of the Education Task Force of the Consortium for Citizens with Disabilities, to testify on the reauthorization of part H of the Individuals Education Act.

The Education Task Force of CCD has identified a number of issues that they request be included in your reauthorization legislation. In the interest of time, I highlight some of these recommended changes. I believe you have before you the written CCD testimony which discusses all the recommendations in more depth. I request that the document be included in the record.

As you can see, I am accompanied today by Aric Murray. Aric is nine years old and attends a regular education second grade classroom in Akron City Schools. Aric was born prematurely at 30 weeks GA, weighing about 3 pounds. At eleven months of age, he was evaluated for delayed development and was enrolled in a community based early intervention program where he received services until he began attending kindergarten. Aric is here today to talk with you about the many opportunities he has had to be successful despite his severe disbility from cerebral palsy secondary to premature birth. Children like Aric exemplify the significance of early intervention and family support as well as illustrate the necessity of enabling states to implement family-centered services to all infants and toddlers across our country.

In terms of specific recommendations, CCD feels that although the five years given states to fully operationalize their early intervention services was adequate time, a number of states are facing significant hardships in implementation and it appears that without additional time will be unable to best serve the infants and toddlers in their states. Out of recognition of these difficulties the task force recommends the addition of a provision permitting the Secretary to grant up to two one year waivers of specific requirements. States operating under one of these waivers would be funded at a lower level than those who are fully operational. This limited waiver would allow states time to overcome any administrative and planning barriers that have been encountered.

A second recommendation concerns the formula for funding Part H services. This formula will have a significant impact on the state's incentive to find and serve children. While the task force supports the distribution of administrative planning and

development funds based on a census count, as is now the practice, the task force requests your consideration of a funding formula based on numbers of children served once the states are fully implementing Part H and are able to provide the data necessary for such a distribution.

CCD has numerous recommendations relating to parents and families of infants and toddlers who will benefit from the Part H program. Supports to families are integral to the success of services for infants and toddlers. CCD holds the family provisions in this bill up as a beacon for other service delivery systems. However, there are a number of refinements which would support the underlying value expressed in bill that family support is an attitude, not a program. Primary care giving for infants and toddlers belongs to families, not to systems, agencies and paraprofessionals. CCD proposes the following recommendations, recognizing that the family is the one most able to care for their child:

o Replace the concept of families as "cases to be managed"; by changing case management to service coordination;

o Allow families to be their own service coordinators.

o Increase Part D funding for the Parent Information and Training Centers to allow for more equitable outreach to families of children of all ages by the Centers;

o Very carefully examine the whole issue of the sliding fee schedule and its potential negative impact on the family. In this regard, CCD is strongly opposed to the addition of any provisions that would mandate or in any other way bias a state's decision regarding the establishment of a schedule of sliding fees.

Finally, family protections in the law must more strongly be reflected in the procedural safeguards section of the law. Records must be kept confidential. Public and private agencies should not be permitted to exchange information freely without parental consent. The IFSP should be fully explained to and signed by parents as evidence of their informed consent to the provisions of the services in the plan. The parents must have the right to refuse services recommended by the interdisciplinary team without jeopardizing their right to the remainder of the services. The law should be changed to protect these rights.

Services and supports should be provided in settings for infants and toddlers that are in settings that would be natural for similar services and supports for infants and toddlers without disabilities. One very clear example of this would be integrated daycare services.

Assistive technology is of critical importance in liberating 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 . The task force recommends that these services and devices be included as a defined early intervention service.

CCD has a number of other recommendations, which time does not allow me to highlight but which are clearly spelled out in the written testimony. These recommendations must be considered in terms of individual families and their infants and toddlers who will participate in services in communities and states across our country. The result of quality early intervention services that support families and their infants and toddlers with disabilities is children who can grow up to participate as full members of their communities despite life-long disability. Aric has helped me by being a teacher for early intervention professionals and has agreed, today, to talk with you about himself and the things that have been important to him.

Consortium for Citizens with Disabilities

March 5, 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 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 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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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, 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. 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.

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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

RECOMMENDATIONS OF THE EDUCATION TASK FORCE OF THE CONSORTIUM OF CITIZENS WITH DISABILITIES ON THE REAUTHORIZATION OF PART H OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

- 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).

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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

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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

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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

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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, we believe that authorization for fiscal year 1992 should be a minimum of $250 million. 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.

Senator HARKIN. Now, I am going to turn to Ann Taylor, of Nichols Hills, OK, on behalf of the Council of Interagency Coordinating Council Chairs.

I am going to have to excuse myself. I have already read your testimony and I wanted to discuss with you some other things, but I have a plane to catch at 1:00, and I am really going to have to move fast to make it right now. So I am sorry, and I really apologize for having to leave.

Senator Durenberger will continue to chair the hearing and take testimony and has some questions to ask of all of you.

Thank you all for being here, and all of you in the audience who have been here today. I can just say that Senator Durenberger and I will work very closely together and get the reauthorization done, but we will be working with all the different groups to make sure we are all together on this one just as we were on ADA.

So again, thank you very much, and I'll turn over the chair to Senator Durenberger.

Senator DURENBERGER. [Presiding.] Please proceed, Ann.

Ms. TAYLOR. Thank you. I want to thank Senator Harkin personally for all he does.

I am here representing the ICC's, not only the State ICC's, but the Council of the State ICC Chairs. Several of them have written a statement, and it is in with the testimony we have submitted.

I want to say that the reason I am on the Oklahoma ICC is because I am the parent of a child with handicaps. As you might guess, she is quite a bit older than birth to 3; she is 29 years old. She was born without any arms and with only two leg stumps. Right now, she is a graduate of law school, graduated college Phi Beta Kappa, and is the clerk to a Federal judge in downtown Oklahoma City.

Although there were none of these wonderful things that Part H has available to her at that time or to the family, we find in looking back at them that they were the very components that made her life go forward in this way.

So because when I was trying to let her do all of the things that I wanted her to do, I didn't try to help anyone else along—now I have the time that I can come back and help the parents and the children who are younger and need those things for themselves. So I am happy to dedicate a great part of my life to doing this.

I think Public Law 99-457 is great. It provides for parents and children with disabilities do go through one door to receive early intervention services. It means that these services are coordinated in a way that crosses the lines of disciplines and agencies and incorporates the best practices of services to families who are full partners in choosing goals for their child.

In my opinion, the States who have progressed the most with the planning and service delivery are those whose lead agency accepts the advice and assistance of the ICC and its coordinated comprehensive planning when it occurs.

Following the law, these ICC's have worked through the agency turf issues, investigated and studied where services are needed, planned for the education of therapists with EI components, trained parents and coordinators to properly write IFSP's, figured out where the moneys can come from for all of these services,

where it should be delivered, whether it should be at home or in a daycare setting, and planned an active child-find and awareness plan.

ICCs have been the catalyst, the spirit, the conscience to cause agency cooperation where none existed before.

In Oklahoma there is now a new bill to study implementing all the best features of early intervention into a program for children 3 to 21. Hopefully, multidisciplinary and interagency will permeate other programs.

Reauthorization offers an opportunity for these ICC roles to be strengthened as the individual States require. Let States decide the maximum number of ICC members. Require them to have a 20-25 percent membership be parents. Let States decide if their current service delivery works better for them to expand these services birth to 6. Let States elect their own chair. Putting the FICC into statute so it can serve as a model for these States would be wonderful.

In most States like mine, the process is new. It is almost controversial, so it will take time to work efficiently. But it is working. It will happen.

Services cost more right now. I believe the cost will come down when everything is properly in place. And we have given children with disabilities a big boost. We are holding the door open longer for them to get through.

Thank you.

[The prepared statement of Ms. Taylor follows:]

Prepared Statement of Ms. Taylor

This testimony represents that portion of P.L. 99-457 delegated to the particular role of the Interagency Coordinating Council. The views expressed here are officially a recommendation of the Steering Committee of the Council of Interagency Coordinating Council Chairs (CICCC) and certain other State Interagency Coordinating Councils (ICC's).

We mean it to be a plain statement concerning this role and so it will be as brief as possible.

P.L. 99-457 is a wonderful piece of legislation aimed at delivering comprehensive, quality services to infants and toddlers and their parents. This to replace a system in most States that is fragmented, duplicated and referral-burdened. Parents have long wished for one door to enter for all services, their pleas have been answered.

The ICC role is a primary component. We are to "advise and assist", the Lead Agency in the development of this plan. We are an independent group, representing all agencies that deliver services to this population, but are not the property of any one agency.

Legislators wisely chose the ICC to be multi-disciplinary and multi-constitutional so we represent consumers, political, clinical and administrative communities. We have the authority to advise and assist the Lead Agency in certain areas such as: identification of the sources of fiscal support; assignment of financial responsibility to the appropriate agency; monitoring interagency agreements and preparing pertinent applications and amendments.

Also, the ICC is to prepare an annual report to the Governor and Secretary of Education on current status. Further, the ICC is to assist in policy development; help achieve full coordination, cooperation and participation of all public and private agencies; assist in the statewide implementation by establishing a process that includes timely service delivery, resolution of policy problems, and, assist the Lead Agency in dispute resolution, where appropriate.

There are gray areas in the proper roles and functions of most governmental advisory groups that could be better delineated including the ICC role. When the service planning is completed, ICC's can help to study their own roles so they may function in a production and coordinated manner for Early Intervention Service Delivery

Obviously, the role of the ICC plays different roles of authority from State to State. If the legislators want this to be more clearly defined—and strengthened—new authorization would be a good place for resolution of this important part of P.L. 99-457.

COUNCIL OF INTERAGENCY COORDINATING COUNCIL CHAIRS

Statement of Sort for the Reauthorization of Public Law 99-457. Part H.

We, the Interagency Coordinating Council for Early Childhood Intervention, believe that the Reauthorization of Part H and amendments to Part 8 (P.L. 99-457) regarding early intervention and other services to children from birth to 6 years is mandatory.

We thank Congress for the family-oriented perspective that drives Public Law 99-457. The emphasis on interagency cooperation is appreciated and must be maintained and strengthened in the reauthorization.

The importance of the role of the ICC to advise and assist the lead Agency can be strengthened in several ways. First, we support the selection of the ICC chair by the ICC membership. Further, at least one parent of a child with disabilities, age birth to 6, should serve as well as other parents of children with disabilities who have knowledge and experience of these programs for their children.

We support the following Statements:

1. The ICC membership cap should be lifted from a minimum, of 15 members and each State should be allowed to decide the maximum number of members.
2. 20 to 25 percent of the ICC membership should be parents.
3. We agree with the current statute regarding the composition of ICC membership.
4. Expanding the focus of the ICC to include 0-6 should be a decision of the individual State.
5. The FICC should be stipulated in statute as a model for the State ICC's.
6. The FICC should have specific responsibilities as outlined in Part H which include: coordination of early intervention policies and activities including interagency agreements across Federal programs; coordination of all Federal technical assistance activities across all participating agencies and programs; advisement of the lead agency (Department of Education); dissemination of information; facilitation and support of States' efforts; receipt of all State ICC annual reports and the requirement to address any concerns and issues raised in those reports that specifically relate to developing collaborative and effective systems across Federal programs and the elimination of Federal interagency barriers.
7. The FICC meetings should be publicly announced and when appropriate, open and accessible to the general public.
8. The law should stipulate a budget be provided to the ICC for such activities as parent reimbursement, staff, office expenses, training, and special projects.
9. We applaud the 47-percent increase in funding for service provisions and believe it should be further increased appropriately over the next several years. Funding a basic amount for each State plus a figure based on the census count seems a fair distribution of monies.

Senator DURENBERGER. Thank you all, and thanks for expressing as he left what I think everybody here feels about the Chairman of this Subcommittee and expressing gratitude for all he has done—and the staff, too, who make all of this possible.

The first question deals with the sliding fee scale—I think you have heard it asked of previous witnesses. The recommendation from the administration was to move in the direction of mandating a sliding fee scale according to the family income or parent income. The response of the previous panel as I recall, the professional panel, was at best to keep it optional, State by State.

I wonder if each of you who is here in a representative capacity would indicate how you feel about imposing sliding fee scales either at the Federal level or at the State level.

George?

Mr. JESIEN. DEC, and CEC I believe, would concur with the previous recommendation that it is already in statutes; those States that are interested in doing so may do so right now.

It would be particularly troublesome for the seven birth-mandate States who by law need to provide services that are free and would therefore create difficulty for them.

Another concern would be that the system that we would have to develop in order to monitor and collect those dollars may in fact cost considerably more than the actual dollars that may be collected based on a sliding fee schedule.

Then I think last, parents are in a State of dealing with such an array of concerns that for us to move in and start discussing how much of this they are going to pay and getting income Statements from them at that particular moment in time, I think, would be quite counterproductive.

Ms. TAYLOR. I would agree.

Senator DURENBERGER. The second question, the previous professional panel was asked to sit down with the organizations on this panel and talk about your recommendations regarding the preschool program. The Chairman indicated that he thought the positions were fairly compatible and wanted me to ask you the question would you be willing to sit down and meet with these people—sponsored by the staff of this subcommittee. Are you willing to sit down and meet with these folks?

Ms. TAYLOR. Absolutely.

Mr. JESIEN. We feel we have been communicating and would certainly continue as long as we had to to iron out the details.

Senator DURENBERGER. The third question relates to the professional skills and professional personnel that are available in America with proper training to make Part H a reality. I asked part of this question previously, and I think one of the responses I heard was that there are a lot of professionals available but they are not necessarily available in the right places or in certain professions. Do you have observations as you view it either from your communities or your representative capacity about whether or not we need to provide additional incentives for additional professional training in order to have available the professional skills that we need to make Part H a reality, and if so which are the skills that are currently deficient?

Mr. JESIEN. Looking at the whole question of personnel, I think we have a three-pronged problem. One is a real shortage and growing shortage of the necessary personnel. Unfortunately, I think the Statement that the services a family receives in this country may be much more dependent on where they live rather than the needs that they may have for their child, is certainly very true in my State of Wisconsin and I know true across the country. So we do have a real need for additional personnel, especially additional students going into the various disciplines.

The second concern or challenge is that of retraining the professionals that are already in the field providing services so that those services are family-focused rather than program or system focused; in other words, a reorientation of professionals to looking at families as true partners, collaborators, and those who have the expertise in their own right to be worked with on a partnership basis.

Additional retraining, as we all know, the field of early intervention is moving very, very quickly based on research, best practice,

and the need for personnel in the field to have access to that information.

Third, we are almost going in opposite ways right now in this country. The clients that we are working with are increasingly coming from culturally diverse backgrounds. If you look at our universities and graduate schools, we are seeing fewer and fewer students and professionals from those various backgrounds coming into the system. I think we are going to have to provide incentives, encouragement, and really look for innovative and creative ways to bring in people from culturally diverse backgrounds into the professional system.

Then just a last point that I would make on personal preparation. If there is one place where interdisciplinary orientations make sense, it is when working with that very young infant, toddler, and the family. I would encourage us to look at ways of fostering and expanding the opportunities for people from different disciplines to work together on a team basis.

Senator DURENBERGER. Thanks. Does anyone else have an observation?

Ms. CAMPBELL. I would basically concur that there are definitive shortages in certain areas of the country, but potentially more important is the fact that we need to focus on training personnel to work with families and not just to work in a deficit model with infants and toddlers.

Ms. TAYLOR. I agree as well. I also think if parents and teachers can learn to be transdisciplinary, then I think professionals ought to be able to do that as well.

Senator DURENBERGER. On behalf of the members and the staff of the subcommittee, I want to express my appreciation to all of you first for what you do and for your own life commitments; second, for coming to Washington, DC, taking the time to share your experiences and your expertise with us and for your patience, this panel particularly, with us in getting to you in the last couple of hours. We certainly appreciate that more than we can express it to each of you and to those that you represent across this country.

And to Aric, thank you for bringing your personal photographer, Rachel, with you and your mom and your very special friend, Ms. Campbell.

Mr. MURRAY. You're welcome.

Senator DURENBERGER. I am reminded that either the Chairman or the Ranking Republican on this committee, that by the time we get to markup, will have figured out this puzzle. [Laughter.] And I don't want to delay the markup any longer than I have to. So I have a little secret here that I haven't shared yet with the Chairman, that these colors reflect a differing degree of difficulty in solving it. So I'm going to make sure he gets the easy one so we can get to markup quickly.

Thank you very much. The hearing is adjourned.

[Whereupon, at 12:22 p.m., the subcommittee was adjourned.]

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