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ABSTRACT

This report to the governor and legislature of Illinois concludes that the state currently has no comprehensive coordinated system of early intervention services for children and families needing such services. The report is in question and answer format and covers federal and state activities in early intervention, a definition of early intervention, current Illinois services being provided, eligibility, and recommendations. An executive summary lists the 21 recommendations. These include: establish a legal right to early intervention services for all eligible children and their families; adopt a definition of eligibility; define a state structure to provide early intervention services; name the State Board of Education as the lead agency for early childhood intervention services; create an Early Childhood Intervention Ombudsman; establish procedural safeguards for families; assure the use of the current program of home visiting and followup services for newborn infants; build linkages between at risk programs and local literacy programs; and appropriate sufficient new state funds. Appendices include the executive order mandating the interagency council and report; members of the Council, committee meetings dates and sites, and a synopsis of testimony at public hearings. (DB)

REPORT OF THE

SPECIAL JOINT COMMITTEE ON EARLY (CHILDHOOD) INTERVENTION

January 1991

January, 1991

Dear Governor Edgar and Members of the General Assembly:

We, as co-chairs of the Special Joint Committee on Early Intervention, present the enclosed report to you pursuant to House Joint Resolution 114 concerning early intervention services.

We were charged with the task of reporting on the adoption and implementation of a statewide system of early intervention. We have studied the issue at length, and report to you that Illinois currently has no statewide, comprehensive, coordinated system of early services for children and families in need of same. While we sensed that was the situation last Spring, and the impetus for HJR 114, we now know how critical the provision of early intervention services is to the current and future well-being of Illinois citizens statewide.

The following report outlines what the current situation is within Illinois and what we believe should be done.

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.

We urge you to read this report, now, and take action on it this Spring in the regular course of business of the General Assembly. We feel it is critical that Illinois enact an entitlement for eligible children and their families. Now is the time to do so, without letting another session pass us and Illinois' babies by.

Should there be a need for special hearings or committee meetings on this issue, we know that our colleagues on the Committee, and families statewide, would be pleased to be of assistance.

Sincerely,

Joyce Holmberg

Sen. Joyce Holmberg, co-chair
(D-34th)

Rep. Terry Steczo, co-chair
(D-78th)

Enclosure

Executive Summary

Report of the Special Joint Committee on Early Intervention

The members of the Special Joint Committee have reviewed all policies adopted, plans developed and problems identified by the State Interagency Council on Early Intervention with respect to the adoption and implementation of a statewide early intervention system. The Special Joint Committee members have conducted two statewide public hearings to gather information personally and add these comments to what they had already reviewed from work done by the Interagency Council and staff of affected State agencies. Additionally, Committee members have benefitted from the experience of the last three years by the current service providers who have been involved with planning and implementing Illinois' initial efforts.

Through the public hearing process and the assimilation of much background information, members have become more attuned to the needs in Illinois of young children with disabilities, and their families. They have a better understanding now of the need for immediate and comprehensive services to be available across Illinois.

The stories told by families at the public hearings served to "bring home" to members what Illinois must do to ensure greater self-sufficiency and services for eligible infants and toddlers, and their families.

As a result of this understanding, we feel that we must move Illinois from the pilot or exploratory stage to the full implementation of a statewide coordinated system to serve these children and their families. The devastation of having a child with a disability can be to some extent ameliorated by early and comprehensive services. To take that step, a small one for Illinois, will be a major stride for families currently receiving minimal or no services, and will be cost-effective for the future of Illinois. It will show that State government recognizes the value of all children and is supportive of a goal in which society recognizes that all citizens can become productive and independent as a result of early and comprehensive attention.

Among the recommendations the Committee offers to colleagues in the General Assembly is a call for legislation in 1991 which will:

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

- Adopt a definition of eligibility.

- Define a State structure to provide early intervention services--geographic boundaries of the local structure as well as creating and empowering local interagency councils.

- Assure collaborative local child find and public awareness efforts, in conjunction with the local councils.

- Create in state statute an Illinois Interagency Council on Early Childhood Intervention.

- Mandate agreements between and among the lead agency and the other relevant state agencies, in order to assure coordination of current spending.

- Define the local structure in accord with the provisions of the State Interagency Council on Early Childhood Intervention's proposed service delivery system.

  ** a core provider responsible for assessment of eligibility and services;

  ** a local interagency council responsible for coordination and design of child find and public awareness; and

  ** a coordinating/advocacy provider responsible for staffing the local council, carrying out child find and public awareness activities and providing advocacy for eligible families within the given area.

- 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.

- 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 (IDEA).

- Examine the existing system and expand it into a comprehensive statewide system of opportunities for parent information on early development and advocacy, in order to empower families.

- Assure the use of the current statewide program of home visiting and follow-up services currently available for newborn infants through the Adverse Pregnancy Outcome Reporting System (APORS), through local public health departments and/or community-based organizations.

- Assure linkage of prenatal initiatives to high risk pregnant women.

- Build linkages between at risk programs and local literacy programs.

- Mandate maximum use of federal resources, e.g., Medicaid, Healthy Kids funds, etc.

- Create a central billing office in order to assure that maximum federal resources are utilized and providers receive funds with minimum hassle.

- Create a resource review committee on use of public and private sector resources.

- 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.

- Require all early childhood intervention staff to hold the highest entry requirement necessary for that position.

- Assure that rules will be developed by the lead agency which will ensure quality personnel and program standards statewide.

As noted, such legislation must be accompanied by a specific annual appropriation, phased in to the maximum over five years. It is the intent to use all other financial resources, e.g., Medicaid, Part H federal funds from the Individuals with Disabilities Education Act and so on. We acknowledge that Illinois will be responsible for the remaining resources needed. Although it will cost more to provide what is not being provided, the Committee feels it will be a cost savings to the State in the long run.

Report of the Special Joint
Committee on Early Intervention

Why Another Report?

What do we know about early intervention? What does that term mean to the average Illinois citizen? Let's look at it from a public perception or point of view.

> Spending on children, any economist can prove, is a bargain. A nation can spend money either for better schools or for larger jails. It can feed babies or pay forever for the consequences of starving a child's brain when it is trying to grow. One dollar spent on prenatal care for pregnant women can save more than $3 on medical care during an infant's first year, and $10 down the line. A year of preschool costs an average $3,000 per child; a year in prison amounts to $16,500.
>
> But somehow, neither wisdom nor decency, nor even economics, has prevailed with those who make policy in the state houses, the Congress or the White House. "We are hypocrites," charges Senator John D. ("Jay") Rockefeller IV, chairman of the National Commission on Children. "We say we love our children, yet they have become the poorest group in America." Nearly a quarter of all children under six live in households that are struggling below the official poverty line -- $12,675 a year for a family of four.
>
> In some cases, the abandonment of children begins before they are even born. America's infant mortality rate has leveled off at 9.7 deaths per 1,000 births, worse than 17 other developed countries. In the District of Columbia, the rate tops 23 per 1,000, worse than Jamaica or Costa Rica.
>
> Fully 250,000 babies are born seriously underweight each year. To keep these infants in intensive care costs about $3,000 a day, and they are two to three times more likely to be blind, deaf or mentally retarded. On the other hand, regular checkups and monitoring of a pregnant woman can cost as little as $500 and greatly increase the chances that she will give birth to a healthy baby.
>
> > **Time**, October 8, 1990 "Shameful Bequest to the Next Generation"

From an individual parent's point of view, as heard by the Committee at the public hearings, we saw the need for *another* report. A parent from Palatine brought it to our attention very clearly when she related to the Committee:

> ...I would say that one of the key themes for my family since the arrival of our children has been that of continual transition. Sometimes the changes come fast and furious and

demand immediate action; sometime it is a more gradual process that gives us time to reevaluate and adjust. Our expectations and hopes and plans, and the very direction and priorities of our lives have had to be revised over and over again. Maintaining a status quo is just about the impossible dream.

In our early optimistic parenting, we expected that our children's problems would be corrected or eliminated by the best medical care we could provide...Doctors and therapies continue to multiply and consume more time every year.

My husband expected to be as free as anyone else to climb the corporate ladder and pursue another job, when he desired; but we found ourselves locked into one employer and one insurance company, because our sons' pre-existing conditions are uninsurable...

Hand-in-hand with this constant stressful revising of our expectations and our lives is the second hallmark of challenged parenting--isolation. Parenting a special needs child is an isolating lifestyle....every meal at our house is prepared three different ways...A good night's sleep? If I get up only two or three times, it's been a quiet night... Self-help from your preschoolers?...Sending the kids off to school?...Grocery shopping?...Family outings and recreation?...Child care and play groups?...Nothing is the same.

With this glimpse into my life, I'd like to say: to better support my family as the unit we are, look beyond the diagnosis and the typically-expected medical or therapy pictures and even beyond the child who is presented to you...Realize that my family is already an isolated entity, and that your classifications and placements, referrals and therapies separate us even more from the world we live in--and the world my children must adapt to and function in. Consider our need for normalcy...Give us the education, empowerment, encouragement and self-confidence that will enable us to persevere and triumph in helping our children become the best people they can be.

A November 15, 1990 column in the Chicago Sun Times stated:

What are we going to do to help the thousands of cocaine babies? Ignoring their special needs isn't going to make them go away. Some low birth weight babies face similar special needs, as do infants poisoned by lead-based paint. Thousands of children in Illinois are developmentally delayed and need help. They are all human beings, they are all terribly vulnerable, and the longer we wait, the more expensive their problems become.

> The good news is that these children can be helped. What they need is the special combination of medical, educational and family services known as early intervention...The bad news is that fewer than a third of the babies who need early intervention are getting it. That means that some babies needlessly face lifelong disabilities.
>
> A waiting list won't do when you're talking about services for infants and toddlers. The window of opportunity closes quickly. So, too, will the opportunity to plan for a comprehensive early intervention program in Illinois.

This report is critical because Illinois has not addressed the issue of infant services. While there was the major effort as part of the school improvement package of 1985 to institute preschool services (ages 3-5) for those at risk of school failure, this is the first statewide report to discuss the need for and recommendations regarding early intervention for infants and toddlers.

We seek to raise awareness through this report, and offer information for Illinois decision-making **and** action in 1991.

What Has The Nation or State Been Doing In This Regard?

Federal Picture

In October, 1986, President Reagan signed Public Law 99-457. This new statute, known as the Baby Bill, is an intricate set of amendments to the Education of the Handicapped Act. The latter act guarantees a free appropriate public education to all schoolage children.

The 1986 law, P.L. 99-457, went beyond the earlier statute's concern for education to portray a wide vision of immediate effective societal response to the risk or presence of mental, communicative, physical, or emotional delay in the first three years of life. Specifically, P.L. 99-457 offered planning funds to the individual states in return for each state's promise to create, over five years, a comprehensive system to address the full range of developmental needs of all eligible children during their first three years of life. All fifty states have accepted the federal challenge.

The impetus driving Congress was a combination of the consensus around the incredible rate of human development during the first years of life, and the therapeutic evidence that prompt, skilled intervention (sometimes starting while an infant is still in the hospital) will make an enormous difference in the outcome for a child with a real or potential developmental delay. For children and families this difference translates to increased opportunity for lifetime independence and achievement. For public policy, it translates to the saving of dollars which would have to be spent later for care, services, and education. For society as a whole

it translates to the benefits of productive and independent citizens. The same impetus should drive Illinois forward.

State Picture

Today Illinois children have no legal right to early intervention services during their first three years of life. The lead agency for P.L. 99-457 planning, the Illinois State Board of Education, estimates that *about 8,500 children are currently receiving early intervention services through some 120 different local providers* who are guided and funded to some extent by eight different State agencies and various community funding efforts.

To put it bluntly, the present system is a labyrinth which families are forced to grope through in the dark, searching for services for their child. Also, there is no sustained effort to find families who may not know that their child needs early intervention.

Nevertheless, Illinois has accepted the challenge of creating a comprehensive system, a system where children will have a right to early intervention; and the State has made some real progress in its planning for that system. Task forces of the State Interagency Council on Early Intervention have completed work on the problems of personnel, program standards, finance, and a suggested structure for a comprehensive system of service delivery. The possible structure, which is being tested now and which may be revised, is a partial basis for the description of the future for Illinois presented in this report.

In 1987, Governor Thompson issued a challenge to the people of Illinois to demonstrate their commitment to Illinois children by adopting the Class of 1999. The goal of his challenge was to provide a better society for the children of Illinois. A commitment to the Class of 1999 required us to see beyond the rush of daily events, to anticipate the future, to plan, and to shape an image to guide us. The problems of poverty, teenagers bearing children, individuals lacking the skills necessary to work in the 21st Century, high school dropouts, youth and adults with disabilities unable to find significant employment, drug abuse, and crime are interrelated. The problems these children face are not predestined nor are they insurmountable. Just as the problems facing our children cannot be considered in isolation, so our strategy to combat these problems must not be circumscribed. Governor Thompson said:

> Without preventive action, some members of the class of 1999 will become victims of poverty, inadequate education, and substance abuse. Without intervention, ill health, poor nutrition and substandard living conditions may blight the lives of too many of our children. (*Adopting The Class of 1999: A Challenge for the State of Illinois*, The Governor's Office, Office of Planning, August, 1989)

Through private and public efforts, Illinois has served infants and toddlers with developmental delays, and their families, since the 1970s. P.L. 99-457, the Education of the Handicapped Act Amendments of 1986, provided the opportunity to plan coordination and expansion of these services.

In June, 1987 Governor Thompson through Executive Order Number 4 and its amendment (see Appendix A) established the Illinois State Board of Education as lead agency to oversee the relevant federal financial assistance given to the state for the purposes of:

* developing and implementing a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services;

* facilitating the coordination of early intervention resources from federal, state, local, and private sources; and

* enhancing Illinois' capacity to provide high-quality early intervention services.

The Executive Order also established an Interagency Council on Early Intervention to assist and advise the State Board of Education in implementing its lead agency responsibilities (see Appendix B). There are nine state agencies represented on the Council. Each of these agencies provide services to handicapped infants/toddlers and their families. The following state agencies are represented on the Council:

* Illinois State Board of Education;
* Illinois Department of Mental Health and Developmental Disabilities;
* Illinois Department of Public Aid
* Illinois Department of Public Health;
* Illinois Department of Children and Family Services;
* Illinois Department of Rehabilitation Services;
* Illinois Department of Alcoholism and Substance Abuse;
* University of Illinois' Division of Services for Crippled Children; and
* Illinois Planning Council on Developmental Disabilities.

In addition to agency representation, the Council is composed of: three parents of children younger than age 6 with disabilities; 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 children with disabilities.

The mission of the State Interagency Council on Early Intervention is and remains 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.

What Is The Special Joint Committee on Early Intervention?

The State Interagency Council on Early Intervention was critically aware that in order to have fourth and subsequent year federal funding, a policy must be in place that provides for early intervention services as an entitlement. In Illinois terms, that would need to be a mandate afforded through the legislative process rather than a decree at the State level by an agency director or the State Superintendent of Education. Rather than pursuing that process in the Spring of 1990 without having done the prerequisite homework, members called upon the legislative member of the Council, Rep. Lee Daniels, to pursue the concept of a special legislative committee. The result of the pursuit was House Joint Resolution 114. This resolution was subsequently sponsored by Representatives Daniels, Steczo, Didrickson and Leflore (see Appendix C).

The intent of the resolution was to consider all of the work done to date, hold public hearings as deemed necessary to gather information regarding adoption and implementation of a statewide early intervention system, and then report to the General Assembly and Governor. That report, embodied herein, cites the findings, conclusions and recommendations of the members, including any recommended legislation and specific necessary funding regarding the creation and implementation of a statewide mandatory early intervention system.

Members of the Special Joint Committee were appointed in the fall of 1990 (see Appendix D). Members scheduled a series of meetings for basic information, public input and then discussion purposes (see Appendix E).

Committee members were particularly interested in finding out the public perception of the need for early intervention services, and how those services should be provided and paid for. Comments by the many families and public and private organizations throughout Illinois who attended the two public hearings afforded the members the opportunity to hear about the issue in detail. Some of that information is specifically cited later in this report (see Appendices F and G).

What Is Early Intervention?

Early intervention is a term of art in the education, health and social services field which means the provision of appropriate services which address the cognitive, physical, language and speech and social-emotional developmental needs of children, available to families from pregnancy through their children's developing years.

Services are "appropriate" if they are:

* tailored to the unique needs of the eligible infant or toddler and his or her family;

* designed to enhance both the development of the child and the family's resources to meet the child's special needs;

* selected in collaboration with the family;

* provided under public supervision;

* provided by qualified personnel in conformity with an individualized family service plan; and

* to the extent appropriate, provided in the types of settings in which infants and toddlers without disabilities would participate.

Early intervention **is not** serving eligible infants and toddlers in classroom situations. Even when school districts are involved in the provision of these services, both home-based and center-based activities would not necessarily be classroom-structured. One should not envision "...babies at school desks..." as this report is being read or its recommendations implemented.

Services for children and their families must be rooted in the community. Communities are the worlds within which children and families live and upon which they depend for enrichment and support. Families can be more effectively served where they naturally are--in their communities, through a wide variety of community agencies and institutions. Services based in and created by the community are most likely to reflect cultural values and traditions and to address specific local concerns.

What Services Are Provided Now?

Illinois is currently providing services that are appropriate to eligible children and their families; however, the delivery of these services while located in many communities within Illinois is not comprehensive, coordinated or statewide. All eligible children and their families are entitled to ongoing assessment, case management, and the development, implementation, review and evaluation of an Individualized Family Service Plan.

Examples of early intervention services that are now being provided in Illinois include:

* identification, interdisciplinary assessment and evaluation;
* Individualized Family Service Plan (IFSP) process;
* developmental services;
* family training and counseling;
* home-based component/home visit;
* case management;
* audiology;
* health services;

* medical services for diagnostic and evaluation purposes;
* nursing services;
* nutrition services;
* occupational therapy;
* physical therapy;
* psychological services;
* social work services;
* special instruction;
* speech-language pathology;
* vision services;
* transportation services; and
* respite care services.

Improvement and Expansion of Early Intervention Services

Prior to the initiation of P.L. 99-457, Part H, early intervention services had been provided by several agencies. It was the intent to continue providing funds for programs to improve their services consistent with Part H as Illinois moved towards establishing a statewide system. Illinois had many public and private programs which were identified as providing early intervention services to infants and toddlers with special needs and their families. Therefore, it was decided to use the majority of the Part H funds to improve and expand existing early intervention programs.

A Request for Proposal was issued in early 1988, for the improvement and expansion of early intervention services for infants and toddlers with disabilities. There had been programs operated through communities, but not through local school districts, providing partial services to handicapped infants and toddlers and their families. Applicants for these funds were existing programs (community-based organizations under the auspices of the Department of Mental Health/Developmental Disabilities) or local school districts/cooperatives. Twenty-seven (27) early intervention programs were funded in 1988-89 to serve as "pilot" improvement and expansion programs (22 community-organization based and 5 school-based) across Illinois; they continue to provide services now.

To be in compliance with P.L. 99-457, each early intervention site was to have a core team. This core team consisted of a child development specialist, a family resource specialist, and a medical/health specialist. The Part H grant provided the additional funds needed to meet this federal requirement. These programs were reviewed and monitored.

Prior to 1987 and continuing to the present, the Department of Mental Health and Developmental Disabilities has been contracting $8 million annually to support 75 community-based early intervention providers across the state serving the birth to three at-risk and developmentally delayed infants, toddlers and their families. The amount and types of services, as well as

program and personnel standards used, varies from provider to provider.

Regional Diagnostic Centers

The State has also funded two diagnostic programs with Part H funds. The goals of these diagnostic programs were to identify, diagnose and monitor, on a regional basis, infants and toddlers with handicaps or developmental delays; assess their health, development and family strengths and needs; and coordinate services with medical and developmental service providers. The diagnostic programs were also to develop effective and efficient service delivery models that were cost effective and could be replicated in other areas of the state. These centers, operated through Lutheran General Children's Medical Center in Park Ridge and LaRabida Hospital in Chicago, provided information regarding the efficacy and cost effectiveness of regional diagnostic centers, as well as incidence rates of infants and toddlers with handicaps and developmental delays on a regional basis.

Illinois Technical Assistance Project

The Illinois Technical Assistant Project (ITAP) grant is a statewide initiative to provide technical assistance/inservice training to those professionals working with special needs children, birth to three. The project has provided up-to-date two day training seminars in topics identified through state initiatives and needs assessment. These topics include:

* a family systems approach for individualizing services;
* assessment of infants and toddlers;
* building better teams;
* case management/interagency collaboration;
* infant and toddler development; and
* medical/health issues affecting children ages birth to three.

ITAP is supported by a combination of funds from Part H under P.L. 99-457 and federal Preschool Discretionary funds. Services are provided without cost to early intervention programs.

The intent of ITAP is to provide consistent and current training across the state to professionals. Over 700 individuals were trained in 1989; over 800 were trained in 1990. It is administered by the South Metropolitan Association of Flossmoor, under contract to the Illinois State Board of Education for this purpose.

Illinois Early Childhood Intervention Clearinghouse

The Illinois Early Childhood Intervention Clearinghouse has provided information services to Illinois residents interested in early intervention and childhood disability issues. The core of the project, the Clearinghouse library, maintained professional

and parent education literature relating to early childhood and family life. Materials related to developmental disabilities, diseases of early childhood, neonatal and prenatal intervention, family support, parent education, nutrition, early childhood education and child development were emphasized.

The Clearinghouse publishes a free quarterly newsletter, *Early Intervention*, featuring early intervention activities throughout the state, reviews of materials available through the project, and a bibliography series. Other services included a bibliographic database (with more than 5,500 items), interlibrary loan services, professional development catalog files, reference services, exhibits and presentations, and access through a toll-free number (800/852-4302).

Central Directory

Direction Service of Illinois is the only comprehensive, statewide data base with information on services to people with disabilities. It has recently been expanded to address the birth to three population, using Part H funds to do so. Via a toll-free telephone number (800/634-8540) and three local sites, consumers and professionals may access information on over 3,000 local support services which enable them to meet child/consumer/family needs. The "one-stop" call eliminates the frustration people with disabilities often face when trying to negotiate the confusing maze of service delivery systems in Illinois.

Accessibility is a priority at Direction Service of Illinois: information may be related with a telecommunication device (TDD) for people with hearing impairments; in braille or enlarged print for those with vision impairments; and in Spanish. Another way it is accessible is by having sites in East St. Louis and the Southeast side of Chicago.

Unique in that the data base includes services to people of all ages and all disabilities, Direction Service of Illinois has steadily gained respect as the leading directory for consumers with disabilities in Illinois.

The activity of the central directory needs to be further expanded when a final statewide system is instituted. The Committee discussed at length, based on testimony and their own experiences, the need to inform families early and sensitively of the nature of the child's needs and the services available to each family and child. This must be accomplished with input from pediatricians, hospitals and prenatal clinics.

Interagency Staff Team

The Part H grant funds a professional staff team which assists the lead agency in the development of policies and documents required for this endeavor. All nine (9) agencies are

represented on the staff team. Their primary role is to ensure representation of their agency's policies and regulations in the statewide system. The Interagency Staff Team reviews and provides technical assistance to the early intervention programs cited earlier.

Now That We Know What Early Intervention Is, Who Are the Infants and Toddlers of Illinois Who Need the Services?

You could probably say, and be accurate, that all children and families would benefit from additional assistance, be it training or support or financial aid or direct therapeutic services. That would hold true for wealthy or poor families, for those from Golconda to Freeport.

As the theme of the parenting education program called Parents As Teachers says, "If They Came With Instructions, You Wouldn't Need Us." Babies don't come with instructions of any sort. All parents, especially new ones, could use help. The needs of some families cry out for help immediately and intensively; it is those families we wish to focus attention on in this report.

Categories of Eligibility

The following children and their families would be eligible to receive needed support through appropriate early intervention services. Children who are eligible for these services are infants and toddlers, from birth to thirty-six months of age, with disabilities due to developmental delay, or a physical or mental condition which has a high probability of resulting in developmental delay, or are at risk of having substantial developmental delays.

* "Developmental delay" means a delay in one or more of the following areas of development; cognitive, physical, including vision and hearing; language, speech and communication, psycho-social or self-help skills, as measured by appropriate diagnostic instruments and standard procedures.

* "Physical or mental condition which has a high probability of resulting in developmental delay" is exemplified by children with disabilities such as cerebral palsy, epilepsy, Down Syndrome or fetal alcohol syndrome who are eligible for services even if their early development appears normal.

* "At risk of having substantial developmental delays" means the presence of *at least three at risk conditions* plus the clinical judgement of a consensus of the interdisciplinary team including the parents. At risk conditions may include:

  * admission to a Neonatal Intensive Care Unit;

* family history of developmental disability, developmental delay or severe emotional disturbance;
* family history of abuse or neglect;
* family history of alcohol or substance abuse;
* family history of genetically transmissible conditions known to cause developmental delay;
* alcohol or substance abuse by the mother during pregnancy;
* homelessness;
* child is a ward of the state;
* mother had a transmissible disease known to cause developmental delay during pregnancy;
* mother less than 18 years of age;
* inadequate prenatal care;
* mother took medication known to pose a risk of developmental delay during pregnancy;
* families who are economically depressed;
* families with limited English proficiency; or
* maternal/paternal level of education equal to or less than 10th grade.

Numbers

Projected numbers of infants and toddlers eligible for early intervention services have been documented by the Illinois Department of Public Health. This estimate is based on data that is available from Vital Statistics, 1988, and/or the Adverse Pregnancy Outcomes Reporting System (APORS, 1988).

Of the 180,000 number of live births a year, it is estimated that a maximum of 10,800 infants a year or 32,400 birth-to-three year olds are eligible for early intervention services based on the Council's definition of developmental delay or as having a high probability of delay.

* Specific factors relating to biological risk which could include children with: a birthweight of less than 1500 grams; APGAR at 5 minutes of less than 5; gestational age at less than 32 weeks; complications in pregnancy, delivery and labor (Vital Statistics, 1988, Illinois Department of Public Health). This accounts for about 5000 children a year.

* Specific factors relating to established risk could include children with: spina bifida; down syndrome; microcephalus; trisomy 13; trisomy 18; toxoplasmosis; rubella; maternal substance abuse (about 2% of live births); and infants with post-neonatal developmental disability diagnosis (about 1% of live births) (Congenital Anomalies-APORS, 1988, Illinois Department of Public Health).

Additionally, an estimated 24,000 birth-to-three year olds would be eligible for services based on the Council's definition of "at risk of substantial developmental delay", an estimated 8,000 new infants a year. Risk factors here were noted above.

Overall, 56,400 children and their families would be eligible for early intervention services annually when the child find and service systems are in full operation. A phase-in plan is noted on page 18 of the report.

An Additional Factor

The Committee members have heard of the numbers of youngsters who are drug-exposed, and what that may mean for the future. No statistics are hard and fast. No one knows for sure how many cocaine-exposed children are being born each year, for example. The President's National Drug Control Strategy report estimates 100,000. Other estimates run upwards of 200,000. A more realistic estimate has been stated as between 1%-2% of all babies born in the United States.

As said in *The Shadow Children: Preparing For The Arrival of Crack Babies In School*, Phi Delta Kappa (July 1990):

> What cocaine-exposed newborns go through during the days and weeks after birth is a rocky start on life. Some have birth defects attributed to cocaine exposure in the uterus. Most are small and underweight...Many suffer neurological damage from prenatal drug exposure. For them, coping with the normal activities and stimuli of daily life will be difficult...Child development experts who try to paint a more hopeful picture say these children need special attention right from birth to overcome difficulties ranging from congenital problems to learning disabilities...The need for early intervention and treatment is clear to those who work with infants born suffering the effects of cocaine exposure.

What Is Our Vision?

As paraphrased from testimony from Voices for Illinois Children, a statewide group advocating on behalf of young children:

> *Ideally...Illinois will be able to identify and serve every family in the state, no matter where they live or what their economic circumstances, that has a child between birth and age three who falls within any category of eligibility.*
>
> *Illinois will find these families through a statewide child find system of trained and designated primary and secondary referral sources. The primary referral sources will cue in as closely as possible to the child's birth and parents, and will include hospitals, pediatricians, and other health care providers.*
>
> *The secondary referral sources will be community-based and include childcare providers, churches, social service*

providers, and community-specific efforts. These vital secondary referral sources will be coordinated in each community through a broad-based local coordinating council made up of local health providers, education providers, public officials, parents, state agencies, and ccmmunity representatives. The local coordinating council will be organized and staffed by an independent agency.

Each designated referral source will know how to introduce the family to the diagnostic and treatment parts of the system within two days after a child is identified as potentially eligible. Coordination with the family, known as case management, will begin as soon as a child is identified to ensure that families don't fall through the cracks.

Every designated referral source will refer the family directly to their community's core early intervention provider. This core provider will determine whether or not the child is eligible for an Individual Family Service Plan (IFSP) under the broad categories of eligibility ("eligibility" in this case means eligibility for an IFSP rather than for any particular services).

The decision on eligibility and the creation of the family's specific IFSP will be the responsibility of an interdisciplinary team which must complete its work within 45 days. The team will combine health, education, and social service professionals along with the family. The team will be backed up when necessary by specialized diagnostic services.

If the team finds that the child is eligible, it then prepares an IFSP which defines in detail the child's services. The family is a full member of the team and has the final right of refusal on any and all aspects of the IFSP. A child will not be "labeled" by being found eligible for an IFSP. For children whose needs are clear, early intervention can begin immediately while the final details of the IFSP are being worked out. The core provider is then responsible for fulfilling the IFSP either directly or through contracted professional services. There will be no waiting lists.

The IFSP will be a living document which will change in tune with each individual child's first three years of life. There will be a wide variety of IFSPs. Some will simply provide for continued monitoring of the child and some basic information for the family. Others will call for specific developmental therapies. Most will begin with services in the infant's home and progress to services at designated centers. Throughout the family's experience with the Illinois early intervention system, they will be assisted by a sort of tour guide, officially their case manager, who

will ensure on the one hand that the family's needs are met and, on the other hand, that the family is able to participate in the system.

Whenever children graduate from early intervention, their IFSP will define how they will transition to other community services. For those children who will need to begin special education [at age 3], the IFSP will ensure that special education will begin promptly upon their third birthday. The child and family will be protected by a formal set of procedural safeguards at every stage in the early intervention process.

Family involvement will also be enhanced through the creation of a statewide central directory of early intervention services. The central directory will be accessible via telephone, computer, and mail and in the family's native language. The central directory will provide specific information on early childhood development, the various causes of developmental delay, and local early intervention resources. The central directory will be able to respond promptly and specifically to parent and public inquiries.

The core provider will receive timely reimbursements for all services provided under a proper IFSP from a single Illinois state source which will then bill in turn the applicable final financial source which may be Medicaid or a particular state agency. Each part of the Illinois early intervention system, identification, assessment, and service provision will be interdependent.

We feel implementing the recommendations of this report will bring about that vision.

What Does The Special Joint Committee Recommend Be Done?

From the background information on children, families and their needs, we feel that early intervention must become an integral element in Illinois' future. Like the current focus on preschool education and the occasional focus on prevention, early intervention must become a priority issue for our collective future.

We acknowledge that no single model of intervention services will work in all parts of our diverse state. However, we do agree that services must have the following component parts, wherever and however they are delivered in the State:

* community-based;
* family-focused;
* with qualified personnel;
* based on quality standards;
* physically and geographically accessible;

* affordable;
* with sufficient family support; and
* coordinated across local and state agencies as applicable.

We feel the delivery of such services has to be created at the community level, with the administering agent determined by local factors, and supported at the State level.

Among the recommendations the Committee offers to colleagues in the General Assembly is a call for legislation in 1991 which would:

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

- Adopt a definition of eligibility.

- Define a State structure to provide early intervention services--geographic boundaries of the local structure as well as creating and empowering local interagency councils.

- Assure collaborative local child find and public awareness efforts, in conjunction with the local councils.

- Create in state statute an Illinois Interagency Council on Early Childhood Intervention.

- Mandate agreements between and among the lead agency and the other relevant state agencies, in order to assure coordination of current spending.

- Define the local structure in accord with the provisions of the State Interagency Council on Early Childhood Intervention's system.

  ** a core provider responsible for assessment of eligibility and services;

  ** a local interagency council responsible for coordination and design of child find and public awareness; and

  ** a coordinating/advocacy provider responsible for staffing the local council, carrying out child find and public awareness activities and providing advocacy for eligible families within the given area.

- Assure that there will be a state agency appointed as the lead agency for early childhood intervention services, with the 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.

- 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.

- Set procedural safeguards for families, in accord with the provisions in Illinois for special education pursuant to Individuals with Disabilities Education Act (IDEA).

- Examine the existing system and expand it into a comprehensive statewide system of opportunities for parent information on early development and advocacy, in order to empower families.

- Assure the use of the current statewide program of home visiting and follow-up services currently available for newborn infants through APORS, through local public health departments and/or community-based organizations.

- Assure linkage of prenatal initiatives to high risk pregnant women.

- Build linkages between at risk programs and local literacy programs.

- Mandate maximum use of federal resources, e.g., Medicaid, Healthy Kids funds, etc.

- Create a central billing office within the lead agency in order to assure that maximum federal resources are utilized and providers receive funds with minimum problems.

- Create a resource review committee on use of public and private sector resources.

- Appropriate sufficient new state funds, e.g., GRF, for start-up and increase of the current effort, with a call for further increases for each year of the five year phase in period.

- Require all early childhood intervention staff to hold the highest entry requirement necessary for that position.

- Assure that rules will be developed by the lead agency which will ensure quality personnel and program standards.

The Committee's work of 1990-91 followed the State Interagency Council's endeavors since 1988. We now propose the next stage--a broad and comprehensive statewide system, implemented in full, over five years. We acknowledge that personnel, space and

financial resources will not all be available in Year 1 of the program recommended, and that a phased in approach will be necessary in order to assure quality services for eligible children and their families.

Due to those restrictions, we would envision Year 1 to be organizational--establish the infrastructure statewide (additional local councils, needs assessment, expanded child find plans written), and report on same. Year 2 would see implementation of that expanded child find plan, establishment of local interagency agreements, and beginning to develop and/or continuing and expanding they delivery of local services. Years 3-5 would see continual expansions, until all eligible children and families would be receiving full service at the end of Year 5. An annual report to the General Assembly should be submitted by the lead agency.

What Can The General Assembly and Governor Do To Assure Such Services Be Provided?

As Voices for Illinois Children said in *Building At The Frontier: Policy Choices For Young Children At Risk*, "...a plan, no matter how ingenious, is no more than an idea until the legislative and executive branches of government decide to breathe life into it..."

We feel that the first task is for members of the General Assembly and the Governor to familiarize themselves with the issue of early intervention, and then move forward on the vision and recommendations cited above. A specific legislative proposal has been prepared to match these recommendations.

Not only will an entitlement be necessary; so will adequate funding on an annual basis. Without that, an entitlement is but an empty promise to the next generation of Illinois citizens.

Another major element that must be provided by the General Assembly and the Governor is that of strong state leadership. This is a necessary prerequisite for the State in order to ensure effective implementation of an entitlement for early intervention.

The plan, from the State level down, **must** assure that the Governor is fully supportive. Further, each state agency director involved in the coordinated provision of this comprehensive service system must be an active participant, and held accountable for his or her actions in this regard annually.

How Can Early Intervention Services Be Funded?

The question that frequently arises is how can we pay for these services. The alternative is how can we afford not to provide them. We will pay much more in the end if we do not do so now.

Facts and Figures

Past studies may help us understand the issue Illinois is now facing.

* In 1980, the Perry Preschool Project in Michigan reported the results of its longitudinal study. The report documented this cost effective fact...*children who had received early intervention services were found to have a 50% reduction in their need for special education services during their secondary education.*

* In addition, a second study in 1980 by Dr. Mary Wood of the University of Georgia found that *the cost of providing special education services for children with developmental delays through the age of 18 was $37,273, IF the children had received early intervention services. However, in comparison, the study noted that if a child had NOT received any early intervention services, the cost of their education through the age of 18 totalled $53,340.*

  Dr. Wood concluded that early intervention services reduced school age special education allowing for immediate recovery on the early intervention investment. However, the biggest savings in our tax dollars will undoubtedly be found during the adult years. Having nurtured a more independent adult as a result of early intervention, these individuals will more likely be tax-paying citizens rather than dependent upon tax-supported systems for the rest of their lives.

* A 3 year follow-up study in Tennessee showed that *for every $1 spent on early treatment, $7 in savings were realized in 36 months.* This savings resulted from deferral of special class placement and institutionalization for severe behavior disordered children.

Findings noted in *Children 1990, A Report Card, Briefing Book, and Action Primer*, by the Children's Defense Fund, are:

* $1 invested in the prenatal component of the Women Infants and Children [WIC program] saves as much as $3 in short-term hospital costs. Improved early nutrition has been shown to be effective in preventing retardation and consequent costs.

* $1 spent on comprehensive prenatal care saves $3.38.

* Annual health care costs are 10 percent lower for children receiving EPSDT services.

* Early educational intervention has saved school districts $1,560 per pupil with disabilities.

* $1 spent on the childhood immunization program saves $10 in later medical costs.

* Investment of $600 for a child for one year of compensatory education can save $4,000 in the cost of a single repeated grade.

* $1 invested in quality preschool education returns $4.75 because of lower costs for special education, public assistance, and crime.

Current Dollars Expended

The Federal government has and continues to play a role in funding early intervention. To date Part H funds have paid about $3 million a year for the last three years to Illinois for planning and initial services.

The following is a chart of Part H dollars for early intervention:

	National Authorization	Illinois Award of Part H
1986-87	$50,000,000	$ 175,145
1987-88	$67,000,000	$2,268,995
1988-89	$69,830,000	$2,996,565
1989-90	$79,520,000	$3,037,449
1990-91	$117,100,000	$3,345,000

Illinois estimates receiving $5,074,652 in 1991-92, for fifth year funding from Part H.

In terms of other federal funds, Illinois counted youngsters birth to three for the first time in December 1989 for purposes of the Chapter 1, 89-313 count. Dollars were received in 1990-91 as a result. The $800,004 for this year was generated by 1495 youth being served with Individual Family Service Plans and therefore counted by the Department of Mental Health and Developmental Disabilities system, with their general revenue funds allowing us to count these youth as "state supported" for the first time. Chapter 1, 89-313 dollars should be able to be used in future years for additional counted children, as long as that dollar source continues at the federal level.

Preliminary Cost Estimates Relating to PL 99-457, Part H Services To Children and Their Families, dated November 5, 1990, prepared by Deloitte and Touche at the request of the State Board of Education, stated that Illinois is **currently** spending about $17.6 million annually for about 8500 eligible youngsters and their families. That is **estimated** for each Illinois State agency as follows:

*	Mental Health/Developmental Disabilities:	$8.9 million
*	Public Aid:	2.2 million
*	Public Health:	1.6 million
*	State Board of Education:	3.4 million

*	Children and Family Services:	1.0 million
*	Services for Crippled Children	.1 million
*	Alcoholism and Substance Abuse:	.2 million
*	Rehabilitation Services	.2 million

These are estimates of expenditures from the State agencies involved. Final figures may indicate that the expenditures were less than anticipated when the data was originally collected.

That table does not take into account funds that the State is expending, from general revenue funds, for what is termed the "prevention initiative". The Illinois State Board of Education has allocated up to $2 million a year to assist infants, toddlers and their families who are deemed at risk. These programs are located in high infant mortality areas and must provide families with services aimed to prevent later school failure. The personnel costs for these programs is the major item. Staff provides family support and education in addition to activities for parent and child together. All of these activities are appropriate for families with children with disabilities as well as for families deemed at risk. Much of these costs can overlap between the two populations, should programs be available statewide.

Current early intervention programs in Illinois, operating in compliance with PL 99-457 service requirements, are spending about $4000 per child. This is in contrast to expenditures in other states which are at varied levels, e.g., $2200 in South Carolina versus $10,000 in New York.

In terms of what other states are spending or estimating spending, ten other states are similar to Illinois in terms of having fourth year Part H applications approved by the federal government. Those states are Maryland, Idaho, Hawaii, Texas, Maine, Nevada, Nebraska, Colorado, North Carolina and Montana. Information from some of them follows:

* Nevada: Their *definition of eligible youngsters does not include services to children who are at risk* of having substantial developmental delays. No cost estimates were available.

* Idaho: The Idaho Infant/Toddler Council estimated *the costs for early intervention services may run as high as $3800 per child/family. Their definition does not seem to include those youth who are at risk of substantial delay.*

* Texas: *They have a narrow definition. If funding is available and all eligible children are being served in the state, children "at risk" can also be served.* They estimate that the *average cost will be $4,700 per child/family.*

* Hawaii: They estimate their *average cost of early intervention services will be $1,700 per child/family.*

* Montana: They feel they have a *conservative definition of developmental delay*. They anticipate serving about 1.5% of the birth through 36 month population of the state, or about 550 to 600 children. The *annual cost* estimated for providing the services required through Part H range from $4,100-$6,400, with *$5,400 being the average*. They are currently serving 250 youth.

* Maryland*: Their Council's *definition of eligible youth is a narrow one*, not including the at risk youth as in recommendations here. They have estimated total costs of early intervention services at about $30.6 million, with a gap of about $6.7 million in the Statewide Early Intervention System. To address the costs, they have identified resources of Medicaid (22.46%); education (25%) for those children currently being served under the existing law and regulation; medical services like Illinois' DSCC (2.5%); local health departments (10%); and social services (20%). Private insurance was considered as well, based on enrollment data and demographic data.

* Nebraska*: They have 572 youngsters eligible per their *current narrow definition*, out of a total population of 1.5 million. They fully provide 6 of the 14 service components required, with the other 8 being partially provided. *They currently spend $6437 per child and estimate a full service per child cost of $13,155.*

Indiana is also in the planning process, although not in its fourth year of funding. Indiana enacted the establishment of a comprehensive coordinated multidisciplinary interagency program in 1989, effective July 1, 1991. The State is the payor of last resort for an eligible child who is not currently entitled to other funding. *Their definition appears to be similar to that used by the Illinois Council.* They estimate enrollment at 4500 in year 1, up to 10,000 in year 5. Currently 1500 children are served. Their program is called First Steps. *Their demonstration projects have spent about $3200 per child for local service delivery costs. They estimated $4300 is more realistic.* They anticipate costs of $21.5 million for FY 92 and $28 million for FY 93. For FY 92, they anticipate $13.5 million is in place from a variety of sources, so $8 million new is needed.

The states marked with an asterisk (plus Michigan, Iowa and Minnesota) are "birth mandate" states, meaning a legislative mandate was enacted several years ago for birth to three services.

Projection for Illinois Funding Needs

The maximum number of youngsters estimated as eligible is 56,400 birth to three year olds in a given year. Again, this would be at a full service level, after the program is fully phased in and

all personnel in place with a maximum child find effort implemented.

The figure cited earlier, $4000 per year per child, reflects a rounded-off figure from data from the 27 early intervention sites from 1989-90. It also does not include those youngsters who were being counted as eligible yet their needs were only being met in part, as described for Nebraska above. It does not account for children whose needs may be able to be met at a lesser dollar amount, e.g., those who are at risk of developing a substantial delay, since they had not been included as eligible youth in that year. Using $4000 per family/child is a reasonable estimate considering "at risk" families need fewer high cost therapy services and might need only $2000/year in services, while medically fragile children might need $6000/year in services.

What are the resources we could plug in when 56,400 children would be able to be served?

* State funds: now $20 million;

* Part H funds: $5+ million in FY 92 (to increase annually);

* Medicaid funds (estimating 1/3-1/2 of the families as eligible for the bulk of the services on an IFSP, and dollars per family at $2,000): $98 million (which would need to be specifically appropriated for this purpose and is not currently in the budget); and

* Chapter 1, 89-313 at $500 per child: $28 million.

Those resources add up to $150+ million in known funds, **at current levels.** Additional but less tangible resources to us are:

* Local dollars (county, township, municipal funds): based on 9.1% of the 74 Department of Mental Health and Developmental Disabilities programs receiving these dollars: about $1.4 million now;

* Private resources (contributions, third party, sales, etc, based on 5% of the 74 Department of Mental Health and Developmental Disabilities programs receiving those dollars): about $800,000 now; and

* Family fees on a sliding scale: about $500,000 now in the Department of Mental Health and Developmental Disabilities programs.

We would estimate the known state and federal resources as at least $150+ million and the remaining need as $75 million, to reach the goal of $225,000,000 in any given year as the outside figure (56,400 families/youth at $4000 each). If we consider a

phase-in over five years to a full service goal, that would mean about $15 million new State dollars in any given appropriation year.

Infants and toddlers with disabilities in families with limited means may be eligible for Supplemental Security Income under new rules issued by the Social Security Administration. Children who are eligible can receive from $1 to $407 a month, based on family income. In most states, they are also automatically eligible for free health care through Medicaid. SSI clearly can be a valuable resource for low-income families with Part H eligible infants and toddlers. And virtually all SSI-eligible infants and toddlers will also be eligible for Part H. Part H child-find and case management are therefore natural channels for SSI outreach.

While this figure for comprehensive early intervention services may initially seem unreachable, we feel it is an attainable goal. We can consider this goal in the light of the experience Illinois has had in providing the preschool program for at risk youngsters, ages 3-5. The target there, in 1985, was serving 112,000 youngsters. The appropriation began on a small basis, $12,100,000 in FY 86, and has grown due to the recognized need to a level of $60,000,000. It is a similar task for our youngest population. Perhaps, with early intervention, the overall need for preschool services for some of these youngsters will diminish, as will the resources needed from the State.

Are There Consequences To Not Providing Early Intervention Services?

Of course. There are human repercussions to the lack of service, alluded to at the beginning of the report. A lack of services equates to children and their families being more, not less, dependent on the State for services, now and especially later. Medical and educational costs will increase when a prevention approach is not used. Families who could have been strengthened, and supported, will not be. When no or inadequate services are being provided, the consequences of divorce and/or abuse are frequent outcomes of having a child with disabilities.

Again, in regard to drug-exposed babies, it is said "...waiting to identify and treat drug-exposed children when they're enrolled in kindergarten is a mistake that could add substantially to the overall cost...early intervention is the key to success..." (*The Shadow Children: Preparing for the Arrival of Crack Babies in School*).

What Can Illinois Citizens Do?

The planning period for the P.L. 99-457 infant-toddler program is nearly over. State agencies and the interagency council have invested great energy in creating this important and complex program. Will children and families be entitled to nonexistent services? Will states opt out of the program because funding is

insufficient? Various state officials have implied that the services will be too costly to provide. The reality of this or any other new entitlement program is that the program may never exist unless parents and other advocates apply enough pressure on decision-makers.

The fate of the state's infant-toddler program ultimately will depend on citizen interaction with elected officials. If the Governor and state legislators don't understand and value early intervention and don't know that their constituents care about it, they won't provide support now, when it's needed.

First, state funding will be needed in addition to the various sources of federal funds that can help pay for early intervention services. State agency administrators must request funds for early intervention in their FY 92 budgets; elected officials must agree to come up with the dollars. State budget processes must begin now, even with a phased-in entitlement.

Second, since each state that intends to implement the Part H program must show that it has in place a policy to carry out the federal requirements, Illinois must pass legislation to establish State early intervention entitlements and authorize the program. Advocacy is needed to accomplish what has been started.

Third, the current political climate is ripe for embracing the concept of early intervention. However, it always takes time and effort to overcome some state officials' fears of a new entitlement program, particularly any with a price tag attached. A dynamic advocacy campaign by an aroused constituency can determine whether or not the state will participate in the early intervention entitlement program.

Where Do We Go From Here?

We seek statewide assistance from Illinois citizens to assist us, the Special Joint Committee on Early Intervention. Critical next steps are legislation to enact this entitlement, and subsequent funding on an annual basis. From there, relevant state agencies will have to develop rules and regulations to allow the law to be implemented in fine detail.

Even with an entitlement in place, Illinois must work to develop a specific plan to phase in the system of services statewide over the next five years. Such a plan must include a careful look at all local community areas where no services are available.

In summary, PL 99-457 is a "window of opportunity" for Illinois to set aside rhetoric. A fragmented system **can** become coordinated; a family **can** face tomorrow because of support and service; a child **can** reach his/her potential because intervention began early. Together, Illinois **can**.

Appendices

STATE OF ILLINOIS

EXECUTIVE DEPARTMENT

SPRINGFIELD, ILLINOIS

EXECUTIVE ORDER NUMBER 4 (1987)

AN EXECUTIVE ORDER
CONCERNING THE
STATE INTERAGENCY COUNCIL ON EARLY EDUCATION

WHEREAS, Congress, in 1986, enacted and the President signed Public Law 99-457, which authorizes an early intervention program under the Education of Handicapped Act for handicapped infants and toddlers and their families; and

WHEREAS, studies have determined the effectiveness of preschool education for handicapped persons and have demonstrated beyond doubt the economic and educational benefits of programs for young handicapped children; and

WHEREAS, these studies have also shown that the earlier intervention is started, the greater the ultimate dollar savings and the higher the rate of educational attainment by these handicapped children; and

WHEREAS, it is desirable to develop and implement a statewide, comprehensive, coordinated, multi-disciplinary, interagency program of early intervention services for all handicapped infants and toddlers and their families; and

WHEREAS, the provisions of Part H of PL 99-457, the Education of the Handicapped Act Amendments of 1986, call for the designation by the Governor of a lead agency to insure a coordinated, comprehensive system to provide early intervention services to handicapped infants and toddlers and their families; and

WHEREAS, it is good public policy to assure direct and ongoing comprehensive coordinated prevention services for the Class of 1999 and their families;

THEREFORE, I, James R. Thompson, order the following:

1. The designation of the State Board of Education as the lead agency in compliance with Part H of the Education of the Handicapped Act Amendments of 1986.

2. The establishment of a State Interagency Council on Early Education to advise and assist the State Board of Education as lead agency in the performance of its responsibilities.

The lead agency will be responsible for the following activities:

1. The general administration, supervision and monitoring of the programs and activities requiring assistance under Part H of the Education of the Handicapped Act Amendments of 1986;

2. The identification and coordination of all available resources within the state from federal, state, local and private agency resources;

3. The assignment of financial responsibility to appropriate agencies;

4. The development of procedures to ensure that services are provided to handicapped infants and toddlers and their families in a timely manner pending the resolution of any disputes among public agencies or service providers;

5. The resolution of intra- and inter-agency disputes; and

6. The entry into formal inter-agency agreements that define the financial responsibility of each agency for paying for early intervention services, consistent with state law; procedures for resolving disputes; and all additional components necessary to ensure meaningful cooperation and coordination.

1. Council Membership

   a. The Council shall be composed of fifteen members appointed by the Governor, selected to reflect the intent of Part H of PL 99-457.

   b. The membership of the Council shall include the Director or his/her designee from the following state agencies involved in the provision of or payment for early intervention services to handicapped infants and toddlers and their families:

      1. Illinois State Board of Education;

      2. Department of Rehabilitation Services;

      3. Department of Mental Health and Developmental Disabilities;

      4. Department of Children and Family Services;

      5. Division of Services for Crippled Children;

      6. Department of Public Health; and

      7. Department of Public Aid.

   c. The remaining eight members shall have the following qualifications:

      1. 3 parents who have handicapped children younger than age 6;

      2. 3 public or private providers of early intervention services;

      3. 1 representative of the Illinois Legislature; and

      4. 1 person involved in the preparation of professional personnel to serve preschool handicapped children.

   d. No member shall cast a vote on any matter which would provide direct financial benefit to the member or otherwise give the appearance of conflict of interest under state law.

   e. The following state agencies shall serve in an ex-officio capacity, without vote:

      1. Department of Alcohol and Substance Abuse; and

      2. Governor's Planning Council on Developmental Disabilities.

2. Terms of Membership

   a. The terms of all members of the Council shall be three years, expiring on January 1, but members shall continue in service to the Council until their successors are appointed. No member shall serve more than three successive terms.

b. Upon the occurrence of a vacancy, the Governor shall make an appointment to fill such vacancy for the remainder of the unexpired term, effective immediately upon appointment.

c. In making initial appointments to the Council, the Governor shall appoint half the membership to terms of office expiring January 1, 1990, and half the membership to terms expiring January 1, 1991. Initial appointment shall be effective upon the effective date of this Executive Order.

3. General Membership Provisions

a. The Governor shall designate a chairperson from the members appointed under this Executive Order. The Governor shall also designate two vice-chairpersons from the membership of the Council. One of the vice-chairpersons shall be a state agency representative.

b. Members of the Council who miss three consecutive council meetings will forfeit their seat on the Council unless there are mitigating circumstances approved by the Council's Executive Committee.

4. Executive Committee

a. The Council shall designate an Executive Committee composed of the chairperson, the two vice-chairpersons and two additional members.

The Council shall operate in the following manner:

1. The functions of the Council shall include, but not be limited to, the following:

a. Advise and assist the lead agency in the performance of the designated responsibilities, particularly the identification of the sources for early intervention programs, assignment of financial responsibility to the appropriate agency, and the promotion of interagency agreements;

b. Advise and assist the lead agency in the preparation of applications and amendments thereto; and

c. Prepare and submit an annual report to the Governor and the Secretary of the U.S. Department of Education on the status of early intervention programs for handicapped infants, toddlers and their families operated within Illinois.

2. The Council shall perform such other functions as are necessary to fulfill its duties under federal law and this Executive Order:

a. Promote prevention services statewide through public education on the value of and need for such services;

b. Oversee the monitoring and evaluation of state and federal resources used for all programs serving both handicapped and environmentally at risk children ages 6 and younger.

3. The Council shall be provided professional, technical and necessary support services to carry out its function under this Executive Order.

This Executive Order Number Four (1987) shall become effective upon filing with the Secretary of State.

James R. Thompson
GOVERNOR

Dated: June 8, 1987

STATE OF ILLINOIS

EXECUTIVE DEPARTMENT

SPRINGFIELD, ILLINOIS

EXECUTIVE ORDER NUMBER 3 (1989)

AN EXECUTIVE ORDER
AMENDING EXECUTIVE ORDER NUMBER 4 (1987)

On June 8, 1987, I executed an Order establishing a State Interagency Council on Early Education to advise and assist the State Board of Education's implementation of the provisions of the federal Education of the Handicapped Act. One provision of the Order designated the Department of Alcohol and Substance Abuse and the Governor's Planning Council on Developmental Disabilities as non-voting, ex-officio members of the Council. Over the last year and a half that the Council has been in operation, the two named agencies have provided invaluable assistance to the State Board of Education and other members of the Council. At the suggestion of the Council Executive Committee, I am persuaded that those agencies should participate in the work of the Council as full voting members.

Furthermore, so that it is clear that the Council should focus on all manner of aiding early childhood growth and development, and not just Education, I shall rename the Council as the State Interagency Council on Early Intervention.

THEREFORE, I, James R. Thompson, pursuant to the authority vested in me as Governor by Article 5, Section 11 of the Illinois Constitution, order the following:

- That Executive Order Number 4 (1987) be and hereby is amended to redesignate the Illinois Department of Alcohol and Substance Abuse and the Governor's Planning Council on Developmental Disabilities as full, voting members of the State Interagency Council on Early Education.

- That Executive Order Number 4 (1987) be and hereby is further amended to rename the State Interagency Council on Early Education as the State Interagency Council on Early Intervention.

This Executive Order Number 3 (1989) shall become effective upon filing with the Secretary of State.

JAMES R. THOMPSON
GOVERNOR

Date: May 30, 1989

Appendix B

Members of the State Interagency
Council on Early Intervention
January 1991

Parents

Linda Colson Perlstein
466 Ridgewood
Glen Ellyn, IL 60137

Susan Walter
150 Sunflower
Highland, IL 62249

Providers

Maureen Patrick, Executive Director
Family Focus
310 South Peoria, Suite 401
Chicago, IL 60607

Vincent Alioco, Executive Director
El Valor Corporation
1850 West 21st Street
Chicago, IL 60608

Betsy Voss-Lease
South Metropolitan Association
800 Governors Highway
Flossmoor, IL 60422

Legislator

Representative Lee Daniels
(R-46th)
50 East Oak, Suite 250
Addison, IL 60101

Dr. Race Davies (designee)
House Republican Staff
221 Capitol Building
Springfield, IL 62706

Higher Education

Dr. Jeannette A. McCollum, Associate Professor
University of Illinois
Department of Special Education
288 Education Building
1310 South Sixth Street
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State Agencies

James Long, Director
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State of Illinois Center
100 West Randolph, 5-600
Chicago, IL 60601

Barbara Cimijlio (designee)
Acting Administrator
Prevention Division
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Michael Horstman, Executive Deputy Director
Dept. of Children and Family Services
406 East Monroe, 7th Floor
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Sue Howell, Chief (designee)
Office of Child & Family Development
Dept. of Children & Family Services
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Springfield, IL 62701-1498

Robert Leininger, Council Chair
State Superintendent of Education
Illinois State Board of Education
100 North First Street
Springfield, IL 62777

Gail Lieberman (designee)
Assistant Superintendent
Department of Special Education
Illinois State Board of Education
100 North First Street

Cathy Ficker Terrill, Executive Director
Illinois Planning Council on
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100 West Randolph, 10-600
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Rene Christensen Leininger, Deputy Director (designee)
Illinois Planning Council on Developmental Disabilities
820 South Spring Street
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William Murphy, Director
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401 Stratton Office Building
Springfield, IL 62765

Lynn Handy, Assistant Associate Director (designee)
Dept. of Mental Health and Developmental Disabilities
405 Stratton Office Building
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Stephen Spence, Special Assistant to the Director (designee)
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100 South Grand Ave. East, 3rd Floor
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Dr. John Lumpkin, Director
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535 West Jefferson, 5th Floor
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Dr. Stephen Saunders, Chief (designee)
Division of Family Health
535 West Jefferson, 1st Floor
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Carl Suter, Assistant Director
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623 East Adams
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Larry Rau (designee)
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623 East Adams, First Floor
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Dr. Robert F. Biehl, Acting Director
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2040 Hill Meadows Drive, Suite A
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Wanda Thompson (designee)
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Division of Services for Crippled Children
2040 Hill Meadows Drive, Suite A
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APPENDIX C

STATE OF ILLINOIS
EIGHTY-SIXTH GENERAL ASSEMBLY
HOUSE OF REPRESENTATIVES

House Joint Resolution No. 114

Offered by Representatives Daniels - Steele - Didrickson - LeFlore

WHEREAS, Congress, in 1986, enacted and the President signed Public Law 99-457, which authorizes an early intervention program under the Education of the Handicapped Act for handicapped infants and toddlers and their families; and

WHEREAS, Governor James R. Thompson, in accordance with provisions of Part H of P.L. 99-457, designated, in 1987, the State Board of Education as the lead agency to insure a coordinated comprehensive system to provide early intervention services to handicapped infants and toddlers and their families, and created the State Interagency Council on Early Intervention to advise and assist the State Board of Education; and

WHEREAS, Illinois infants and toddlers who are handicapped receive early intervention services from various public and private providers, yet these services are just beginning to become coordinated, comprehensive and statewide; and

WHEREAS, the State Interagency Council in accordance with requirements for federal funding received for three years, adopted a policy in 1989 containing all specified components of a plan to develop and implement a statewide early intervention system; and

WHEREAS, the State Interagency Council will have by June 30, 1990 designed a coordinated comprehensive system to provide intervention services to infants and toddlers who are handicapped and their families; and

WHEREAS, the State Interagency Council will have by June 30, 1990 identified initial technical, personnel, administrative, financing and other problems involved in establishing a statewide early intervention system; and

WHEREAS, The State Interagency Council will have by June 30, 1990 prepared legislation to implement a statewide early intervention system; and

WHEREAS, the State Interagency Council will have by June 30, 1990 prepared preliminary estimates of costs of funding a statewide early intervention system; and

WHEREAS, to be considered for fourth-year federal funding under P.L. 99-457, the State of Illinois must adopt by October 1, 1990 a comprehensive early intervention system with a timetable ensuring that early intervention services will be provided to all handicapped infants and toddlers in the State by the beginning of the fifth year of federal funding; therefore be it

RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE EIGHTY-SIXTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, THE SENATE CONCURRING HEREIN, that a Special Joint Committee on Early (Childhood) Intervention be appointed, the committee to consist of 11 members, the Speaker of the House to appoint 2, a member of the House and a member of the public; the Minority Leader of the House to appoint 2, a member of the House and a member of the public; the President of the Senate and the Minority Leader of the Senate each to appoint 2, a member of the Senate and a member of the public; the Governor to appoint 2, both from the public; and the State Superintendent of Education, or his designate, to be a member; with one co-chair each to be appointed from the committee by the Speaker of the House and the President of the Senate; and be it further

RESOLVED, That the Special Joint Committee review all policies adopted, plans developed, and problems identified by the State Interagency Council on Early Intervention with respect to the adoption and implementation of a statewide early intervention system; and be it further

RESOLVED, That the Special Joint Committee conduct whatever hearings the committee deems to be necessary to gather information regarding adoption and implementation of a statewide early intervention system; and be it further

RESOLVED, That before ceasing to exist on January 1, 1991, the Special Joint Committee report to the General Assembly its findings, conclusions, and recommendations, including any recommended legislation and specific necessary funding regarding the creation and implementation of a statewide, mandatory early intervention system.

Adopted by the House of Representatives on May 11, 1990.

John F. O'Brien, Clerk of the House

Michael J. Madigan, Speaker of the House

Concurred in by the Senate on June 13, 1990.

Linda Hawker, Secretary of the Senate

Philip J. Rock, President of the Senate

Appendix D

Members of the Special Joint Committee on Early Intervention

Senator Joyce Holmberg
825 N. Main Street
Rockford, IL 61103

Senator Joyce Holmberg of Rockford serves as co-chair of the committee. She represents the 34th District in the Senate and was appointed by Senator Rock.

Representative Terry A. Steczo
15958 Cicero Ave., Suite 2B
Oak Forest, IL 60452

Representative Steczo of Oak Forest serves as co-chair of the committee. He represents the 78th District in the House and was appointed by Representative Madigan.

Representative Loleta Didrickson
2023 Ridge Road, Suite 2NW
Homewood, IL 60430

Representative Loleta Didrickson of Flossmoor represents the 37th District of the House and was appointed by Representative Daniel.

Elizabeth Hoeft
614 Center Street
Elgin, IL 60120

Elizabeth (Libby) Hoeft of Elgin was appointed by Governor James Thompson and is a speech/language pathologist for Elgin District #46.

Robert Leininger
State Superintendent of Education
Illinois State Board of Education
100 N. First Street, S-404
Springfield, IL 62777-0001

Robert Leininger is State Superintendent of Education. House Joint Resolution 114 mandated his membership on the committee.

Blanca E. Almonte
435 North Lombard
Oak Park, IL 60302

Blanca E. Almonte of Oak Park is the Center Director, West Town, for Family Focus-Chicago. She was appointed to the committee by Governor James Thompson.

Betsy Voss-Lease
South Metropolitan Association
800 Governors Highway
Flossmoor, IL 60422

Betsy Voss-Lease of Flossmoor is the Program Director for South Metropolitan Association and was appointed by Representative Daniels. She serves as a provider representative on the State Interagency Council on Early Intervention.

Thomas Gott
1824 North 24th Street
Quincy, IL 62301

Thomas Gott of Quincy is the Director of the Head Start Program. He was appointed by Representative Madigan.

Erika Marshall
205 S. Humphrey Avenue
Oak Park, IL 60302

Erika Marshall is an early intervention teacher at Skinner School, Chicago District #299, and lives in Oak Park. Erika was appointed by Senator Rock.

Susan Walter
150 Sunflower
Highland, IL 62249

Susan Walter is the representative for parents on the State Interagency Council on Early Intervention and lives in Highland. She was appointed by Senator Philip.

Appendix E

Special Joint Committee on Early Intervention
Meetings Dates and Sites

Chicago
State of Illinois Center
October 31, 1990
Initial Meeting and Briefing on Early Intervention
9:30 a.m.-2:30 p.m.

Chicago
State of Illinois Center
November 19, 1990
Public Hearing on Adoption and Implementation of a Statewide System of Early Intervention Services
1:00 p.m.-5:00 p.m. and 5:30 p.m.-7:30 p.m.

Springfield
State Capitol
November 27, 1990
Public Hearing on Adoption and Implementation of a Statewide System of Early Intervention Services
1:00 p.m.-3:00 p.m. and 5:30 p.m.-7:30 p.m.

Chicago
State of Illinois Center
December 14, 1990
Discussion of Findings and Initial Recommendations
9:30 a.m.-2:30 p.m.

Chicago
State of Illinois Center
December 19, 1990
Discussion of Recommendations
9:30 a.m.-2:30 p.m.

Springfield
State Capitol
January 7, 1991
Finalize recommendations and report to General Assembly and Governor
12:00 p.m.-4:00 p.m.

Springfield
State Capitol
January 8, 1991
Discuss recommendations with the Governor-elect's Transition Team Director
9:00 a.m.-10:00 a.m.

Appendix F
LIST OF PARTICIPANTS -- PUBLIC HEARINGS ON EARLY INTERVENTION
11/19/90 AND 11/27/90

Grace S. Fiorenza	Speech/Language Pathologist
Josephine Pappgeorge	Relative
The Barone Family	Parents
Sherry Humphries	Hearing Impaired Interventionist
Rosann Mazzauti	Parent
Kathy Newhall	Family Health Coordinator
Barb Tracy	Parent
Marlene Sheehan	Parent
Carmen Hembie	Parent
Bill/Joelle Kelly	Parent
Patti Luplow	Parent
Karen D. Brejcha	Parent
Kimberly G. Sipple	Parent
Cheryl Friebus	Early Intervention Director
Carl R. Hall	Special Education Director
Lynda Myers	Early Intervention Professional
Michael O'Hart	Parent
Karen Grace	Parent
Linda Shambee	Child Development Specialist
David Misewicz Family	Parents
Mary Denato	Social Worker
Kozak Family	Parent
Marie A. Huff	Parent-Infant Educator
Elmer/Leona Kocher	Relative
James Vanderbosch	Head of Mental Health Services Hospital
JoAnn Hart	Parent
David N. Sheftel, M.D.	Director, Neonatal Development Follow-up Program, Lutheran General
Marilyn LaMarca	Parent
Lisa Gutowski	Parent
Nancy Romine	Early Intervention Administrator
Charlene O'Hart	Parent
Richard S. Willey	Parent
Thomas O'Hart	Parent
Alice R. Johnson	Parent
Karen A. Silmers	Parent
Robin McHugh	Parent
Becky R. Harding	Parent
Barbara A. Hasie	Parent
Cleonne O'Hart	Parent
Karen Willey	Parent
Leonard M. O'Hart	Parent
Robert Heinn	Parent
Francene Heinn	Parent
Robin Heinn	Parent
Bonnie Hayes	Parent
Ethel Melton	Parent
Gail Shaffer	Parent
Richard B. Hayes	Parent
R.L. Melton	Parent

Edith Paschke	Parent
Frank C. Paschke	Parent
Tina Bria	Parent
Bill Peters and Staff	Special Education Director
Tom Rosene	Superintendent of Schools
Dr. Philip Pogue	Superintendent of Schools
Teri Litavsky	Parent
Mr./Mrs. Stephen Seper	Parent
Jim Brotheridge	Principal
Debra Kibort	Therapy Center Director
Dubois Family	Parent
Carmen Gillard	Parent
Amy Koester	School Psychologist
J.L. McCall	Audiologist
Lisa Mann	Teacher - Hearing Impaired
Cheryl Miller	Parent
Dr. Joe Bocke	Special Education Director
Georgia Crabtree	Parent
Angela W. Roberts	Deaf Services Coordinator
William A. Ortiga	Manager, Community Residential Alternative
LeCleta Hall	Parent
Genie White	Early Childhood Special Education
Charlene Hartfield	Child Welfare Specialist
Linda Bertani	Speech and Language Therapist
Amy K. Lauesen	Parent
Alice Spaulding	Early Intervention Coordinator
Barb Yerkes	Parent
David L. Fael	Parent
Rosemary Jesper	Parent
Dawn Nagy	Relative
Susan Mussatt	Parent
Myron T. Dagley	Executive Director, Regional Special Education Association
Cynthia Mazuk	Parent
Lynn Bastuk	Parent
James/Mary Lou Miller	Parent
Ann Becker	Volunteer
Vicki/Bill Morton	Parent
Mary Ann Lawinger	Secretary/Substitute
Nancy M. DeBuono	Parent
Suzanne Iacovelli	Early Intervention Director
Ken Jackson	Parent
Schliemann Family	Parent
Sue Epich	Educational Interventionist
Mr./Mrs. Clark Sell	Parent
Robin Thompson	Early Intervention Professional
Herease Frazier	President, Speech-Language Hearing Association
Penny Loft	Chapter I Teacher
Mary Pritchard	Parent
Larry Pritchard	Parent

Peggy O'Connor	Parent
Catherine T. Belt	Parent
Theresa Jabaley	Representative, Illinois Speech Language Hearing Association
Dr. Ira Chasnoff	President, National Association for Perinatal Addiction, Research and Education
Sharon Kettinger	Parent
Beth Robinson	Parent
Ann Patla	Executive Director, Early Intervention
Lori Mackenzie	Parent
Raquel Reyes	Coordinator, Diagnostic Program
Patricia Singler	Parent
Pamela Northrop	Social Worker
Pamela Richards	Child Development Specialist
Nancy Murray	Student
Karen Campbell	Chairperson, Division on Child Health
Wanda E. Black	Early Childhood Program Coordinator
Margaret White	Parent Training Program Coordinator
Judy Motykowski	Perinatal Discharge Planning
Kathryn Erlenbaugh	Early Intervention Director
Colleen B. Wilcox	Special Education Director
Susan Deaton	Principal, Early Childhood Center
Joe/Michelle Annarino	Parent
Mr./Mrs. Richard Rogers	Parent
Rosemary M. Jung	Parent
Steven/Judy Groner	Parent
Mrs. Craig Montgomery	Parent
Craig/Helen Finnicum	Parent
Keith/Jackie Kissane	Parent
Susan Lennon	Parent
Susan Stefanski	Parent
Colleen Dearth	Parent
Sandy Ellis	Parent
Delores Hollingsed	Parent
JoMarie Lypon	Parent
Donna MoLony	Parent
Joan Morris	Parent
Janine Fletcher	Parent
Paula Jones	Parent
Faye Eldar	Parent
Kathy Pluymert	President, Illinois School Psychologist's Association
Maryanne Dzik	Early Intervention Director
Nob Bordent	Administrator, Developmentally Disabled Program
John Steffey	Parent
Ann Jackson	Parent

Kathy Faulkner	Parent/LSC Member
Heidi Biederman	LUDA
Mary Enck	School District #U-46
Nancy MacDonald	Parent
Carol Melby	Clearbrook Center
Kathy Schrock	Clearbrook Center
Linda Gilkerson	Evanston Hospital and Erikson Institute
Jerry Stermer	Voices for Illinois Children
Nancy A. Cheeseman	Illinois Planning Council on Developmental Disabilities
Gloria Estrada	Parent
Karen Culberg	Illinois Council on Teen Pregnancy
Cathy Belt	SMA P/I Park Forest
Nancy Kuglin	SMA P/I
Nancy Shier	Kids PEPP
James Webster	SMA P/I
Larry Ehman	Parent - SMA
Nancy Carlson	La Rabida - Univ. of Chicago Research and Policy Center
Daisy D. Dowell	Skinner PIE
Donna Sassaman	Healthy Mothers and Babies CARC
Sharon Paris	SMA - PI
Liese DeVries	SMA - PI
Timmy Backe	Child
Kim Backe	Parent for Early Intervention
Dorothy Longfellow	Lakeview Early Intervention Parent
Judi Burnison	NAPARE
Pat Brady	CSCD
Theresa Jabaley	Illinois Speech Hearing Association
Richard Brinker	UIC, ISDD
Mon Ray's Family	El Valor
Hernandez Family	El Valor
Azala's Family	El Valor
Rosa Marie DeLopez	El Valor
Patricia Castro	El Valor
Doug Brandow	Chicago ARC
Kate Van Lowe	0-5 IAC Winnebago/Boone/Ogle
Kathy Kloppenburg	Christopher House
Karen Carroll	Illinois Nurses Association
Doris Taylor	Easter Seals
Carey Schmerman	Parent
Michael N. Nelson	INDFA
Mary Jane Chainski	Infant Welfare Society of Evanston
Matthew Cohen	Monahi[illegible], Cohen, and Derskie
Joan Katz	Lakeview
Paul Weaver	Prairie State College
Brigide Cornejo	Mother
Terri Jenkins	Parent/Prevention SMA

Martha Robles	Parent/Prevention SMA
Mary Davis	Parent/Prevention SMA
Araceli Alvarado	Parent/Prevention SMA
Dorothy B. Groh	Marissa District #40
David Stover	Illinois Association of Rehabilitation Facilities
Sheri Sauehoff	PRIME/CARE
Patricia Swagler	PRIME/CARE
Kathleen Cullen	PRIME/CARE
Lisa Noyes	PRIME/CARE
Raymond/Lisa Flaiz	PRIME/CARE
Robin Thompson	Direction Services
Brenda Hilliard	Head Start
Sandy Heins	Central Illinois Downs Syndrome
Sandy Heins	Illinois Alliance for Exceptional Children and Adults
Sandy Heins	Parents for Inclusive Communities
Pat Curtis	ARC/Illinois
Kristine Weisenberger	Lake Parent Infant Center
Johnnie Pendleton and Parents	Lessie Bates Davis
Pam Dimmlich	Malcolm Eaton Enterprises
Richard Blakeley	Springfield Center for Independent Living
Drew Akason	Voices for Illinois Children
Connie Luthe	Wabash and Ohio Valley Special Education
Chet Brandt	Illinois Early Childhood Intervention
Lora McCurdy	Illinois Assocation of Rehabilitation Facilities
Mark Noyes	Prime Care of Illinois
Mark Gerbinding	St. John's Hospital
Ruth Dove	West Central Special Education Cooperative
Wanda Black	West Central Special Education Cooperative
Debra Heckenkamp	ARC/Springfield
Keri Cottrell	Community Counseling
Barbara Bodda	Malcolm Eaton Enterprises
Terri Hendrickson	Malcolm Eaton Enterprises
Sue Fridel	Malcolm Eaton Enterprises
Marybeth Arduin	Peoria Association for Retarded Citizens
Mary Ann Castaneda	Peoria Association for Retarded Citizens
Bev Johns	ISELA
Syndi Parks	Community Counseling
Susan Mussatt	Parent
Tom Mussatt	Parent
Terri Hall	Parent
Ron Hall	Parent
Les Dollinger	Hillsboro Supterintendent of Schools
Connie Shugart	JAARC
Mary Jo Jarzen	Parent
Pat Paul	

Sharon Winnett	Hillsboro Pre-Kindergarten
Jonah Deppe	ILCEC/DEC
Jonah Deppe	IDPH
Margaret Aylesworth	Illinois Speech-Language Hearing Association
Lisa Henning	Pioneer Center
Maryann Barnett	Parent
Mary Zabelski	Chicago Lighthouse for the Blind
Joyce Poll	Easter Seal
Anita Hermann	Student
Thubi Kolobe	University of Illinois at Chicago
Sheila Bastyo	
Georgia Pecenrad	
Catherine Varnow	Parent
Eileen/Kevin Dunleavy	Parents
Norbert A. Simon	Illinois Association of School Social Workers
Jean LeBlond	Independent
Carl Wanzung	Parent
Jill Droge	LaRabida 0-3 Diagnostic Center
Lindy Mika	Parent
Jill Tatz	Parent/Early Intervention Specialist
John A. Bartel	Parent
Frannie Mitchell	Parent
Glorie Ruelez	SASED
Haroldine Bouruz	Center for Successful Child Development
Sandra Breckenridge	Center for Successful Child Development
Kate Sachnoff	Chicago Department of Human Services
Linda Laiss	CARC
Deborah Silverglade	CARC
Alice Kusmierek	SMA Prevention
Esperanza Argueta	CARC LaPaz
Celia Barrera	CARC LaPaz
Marie Izzuerdo	CARC LaPaz
Peter Leonis	DORS
Paulette Blackshire	Center for Successful Child Development
Maxine Muris-Jones	Center for Successful Child Development
Alphonzo White	Center for Successful Child Development
Leslie Lewis	UIC - MCH Project
Susan R. Miller	Kids PEPP
Kathleen Kennedy	State Senate Democratic Staff
Cheryl Rush	Oak-Leyden Developmental Services
Julie Elsen	South Metropolitan Association
Pamela Sursu	Michael Reese
Nancy Egger	Children's Developmental Center
Mary Ann Witvoet	Illinois Technical Assistance Project
Heather Courtney	Voices for Illinois Children
Lynn Liston	Rockford Memorial Hospital

Gail Russell	Healthy Mothers and Babies Coalition
Melinda Stengel	Michael Reese Hospital, Siegel Institute
Briseida Gurrola	El Valor
Nick Wechsler	
Eldona Rozenas	Helping Hand Rehabilitation Center
Vincent A. Allocco	El Valor
Bertha Razo	El Valor
Aldonza Palrua	El Valor
Lynae Goleb	Lakeview
Anne Campbell	Family Focus
Natalia Salces	Easter Seal Society
Phyllis Wielgoricki	SMA
Michelle Palazzetti	Division of Services for Crippled Children
Ricky Ehman	SMA
Jane VanBreman	NAPARE
Ruth Mohive	El Valor
Bertha Murray	ISBE
Faye Osken	LaPaz
Mavis Izguerto	LaPaz
Sharon Jackson	LaPaz
Stephanie Windag	LaPaz
Linda Bowers	LaPaz
Rosa Rodriquez	LaPaz
Patricia J. Husband	University of Illinois
Sheryl Covitt	CARC
Tera Lynch	CARC
Carolyn Shapiro	DCAC
Julie Larsen	University of Illinois
Mary K. Tanka	Edward Hospital
Bessie Tritsopoulas	Bearon Therapeutic
Jeanne Maison	Loyala Univerisity
Andre Bush	Bethel New Life
Diane Wright	Bethel New Life
Brenda Wolf	La Rabida Children's Hospital
Gloria Estroda	Parent
Barbara Myers	DePaul University
Betty Babcock	Kinzie School
David Taylor	Kinzie School
Mary Pawlicki	Oak Leyden Developmental Services
Judy Walker	SMA
Kitty Cunningham	SMA
Lorry Ehman	Parent - SMA
Barbara Zawacki	Easter Seals
Karen Sullivan	SMA
Dr. Paul Gallagher	Illinois Assocation for Community Mental Health Agencies
Cathy Leonis Muno	Department of Alcohol and Substance Abuse
Michelle Gilbert	Legal Assistance Foundation
Peggy Muetterties	Easter Seal Rehabilitation Center
Cheryl Friebus	Easter Seal Rehabilitation Center

Appendix G

MEMORANDUM

TO: Special Joint Committee on Early Intervention

FROM: Gail Lieberman, Pat Koch, and Chris Lehl

DATE: December 7, 1990

SUBJECT: Synopsis of Public Testimony Comments at Public Hearings; November 19 and 26, 1990

Synopsis

The attached report is an initial synopsis of oral testimony and written comments presented at the public hearings in Chicago and Springfield. All written comments received by mail at the Illinois State Board of Education were also included. Because of the time constraint, a *best effort* was made to provide you with the enclosed summary prior to the December 14th meeting.

Dates

The next meetings are as follows:

December 14th	Chicago - State of Illinois Center - Room 16-504 - 9:30 -2:00
December 19th	Chicago - State of Illinois Center - Room 16-504 - 9:30 -2:00
December 28th	Chicago - State of Illinois Center - 16th Floor - 11 a.m.-noon Governor's Office with Paula Wolff, head of Governor-Elect Edgar's transition team
January 7th	Springfield

Please let us know if you need arrangements made or have questions (Gail 217/782-3699; Audrey, Chris and Pat at 217/524-0203).

Attachment

There is a need for services within the local community area. This includes comments that refer to family/child, early intervention services, early intervention service providers and diagnostic services.

A. Family/Child

- Need to know available resources (2)
- Need for respite services (3)
- Vital for parents to be team members (9)
- Parent need for support component and parent options (11)
- Need for appropriate services for child/families [including general as well as special equipment] (5)
- Need for home program and services (8)
- One-stop shopping for services (9)
- Support for **pre-natal** programming and education (3)
- Need for choices (e.g., to participate or not; specific service delivery) to be given to the family (5)
- Coordinate early intervention services (1)

B. Early Intervention Provider

- Individual Family Service Plan should be child/family driven (27)
- Train families to provide therapy (5)
- Language/barrier to therapy and follow-up (2)
- Need for appropriate transition (after age 3) services (8)
- Setting options should be natural settings and community-based (10)
- Need for appropriate physical space for services (1)
- Need for integration of children without disabilities with children with disabilities (3)
- Should not be prime contractors - conflict of interest (1)
- Include pediatrician in the Individual Family Service Plan (1)
- Need to assure staff safety in service delivery (2)
- Avoid labeling of child (5)
- Priority need for interdisciplinary effort at all levels (2)

C. Services Which Should Be Provided

- Transportation (9)
    - enough vehicles
    - available to meet needs (including rural)
    - early intervention (EI) on wheels - southern Illinois (1)
- Speech and language (1)
- Public awareness (9)
- Need for services to be culturally sensitive and flexible (5)
- Need for respite care (2)
- Audiological evaluation and Tympanometry as a required diagnostic service (2)
- Day care for siblings so parents can participate in eligible child services (2)

D. Diagnostic Services

- Independent from EI provider (3)
- Early diagnosis (10)
- Include diagnostic clinics as medical component of overall plan (4)
- Need for availability of developmental pediatricians (4)
- Need for appropriate diagnostic services (9)
- Need for support of diagnostic services for hearing impaired (5)
- Need for satellite diagnostic clinics/services (5)

E. Local Interagency Coordinating Council and Coordinating Advocacy Provider

- Local control for disbursement of funds based on local population
- Need for ombudsman

Services must be coordinated, both organizationally and financially, to assure a coordinated comprehensive program across Illinois. This includes comments on local agencies, State Interagency Council on Early Intervention (SICEI), Special Joint Committee on Early Intervention, and the State Legislature.

A. State Configuration

- Positive support for EI program continuation (20)
- Mandate for comprehensive services (126)
- Implement and fund statewide service system (46)
- Service needs greater than available resources (34)
  - waiting lists
  - insufficient service
- Build system on existing services (17)
- Competitive review process for all to apply to be provider (1)
- Geographical access to services (22)
- Need for appropriate catchment areas (1)
- Expansion of eligibility criteria (26)
- Need for effective child find (9)
- SICEI define clear objectives (1)
- Need for effective and reliable data collection system (2)
- System must be comprehensive and family-focused (15)
- Need for available qualified personnel (23)
  - $ issues - salary level inequities
  - total communication [e.g., sign language a must] (2)
- Need for tracking system of eligible clients (3)
- Interagency approach demands removal of turf issues (6)
- Need for strong working citizens advisory committee to the lead agency (1)
- Support for interagency effort regarding system (3)
- *Prevention* programs make a positive difference (16)
- Change lead agency to Illinois Department of Public Health and Department of Mental Health and Developmental Disabilities to become co-lead agencies (1)

- Prevention and EI programs can benefit the economically depressed with job training, literacy training (3)
- Use day care settings for EI (1)
- System must have built-in advocacy (3)
- Department of Public Health has greatest potential to be lead agency

B. System Fiscal Recommendations

- Continued agency commitment to present funding
- Medicaid
- Should be cost-benefit effective (26)
- Additional taxes
- Central Billing Office
- Cost-based reimbursement system
- EPSDT
- Special Task Force on Use of Private Insurance (3)
- Pre-existing medical conditions - barriers to coverage (2)
- Local county boards as source
- New GRF sources (2)
- SSI
- Sliding fee scale/family payment (3)
- Establish advisory committee on coordinating private charitable funds(2)
- EI makes a difference [shows benefits] (87)
- EI services must receive national and state funding support - cannot be a burden of the education system (2)
- 3-5 System will need additional funding and development
- Need for adequate, equal and fair payment system (7)
- Family financial status (DPA eligibility) should not dictate services accessible (5)

C. Statewide Standards

- Strong state standards that are truly monitored (4)
- Support proposed personnel standards (10)
    - parent to parent coordinator
- Support program standards (2)
- Psychological services as described in personnel document can be given by school psychologists (3)
- Quality intervention requires a professional *team* effort [multidisciplinary] (5)
- Support for statewide consistent program and personnel standards (4)

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