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OFFICE OF THE AUDITOR GENERAL
WILLIAM G. HOLLAND

*To the Legislative Audit Commission, the Speaker
and Minority Leader of the House of
Representatives, the President and Minority Leader
of the Senate, the members of the General
Assembly, and the Governor:*

This is our report of the evaluation of the Early Intervention Services System in Illinois.

We conducted this audit at the direction of Public Act 87-680, which became effective September 23, 1991. The audit was conducted in accordance with generally accepted government auditing standards and the audit standards promulgated by the Office of the Auditor General at 74 Ill. Adm. Code 420.310.

The audit report is transmitted in conformance with Section 3-14 of the Illinois State Auditing Act.

A handwritten signature in black ink, appearing to read "W. G. Holland", with a long, sweeping line extending upwards and to the right.

WILLIAM G. HOLLAND
Auditor General

Springfield, Illinois
April 1993



OFFICE OF THE AUDITOR GENERAL
WILLIAM G. HOLLAND

REPORT DIGEST

Evaluation of the EARLY INTERVENTION SERVICES SYSTEM (as required by Public Act 87-680)

SYNOPSIS

Planning for the Early Intervention Services System, a program to identify and serve developmentally delayed infants from birth to 36 months of age, began in 1987. Although the framework being established by the Illinois Interagency Council on Early Intervention should be capable of providing services under federal and State laws, several areas still need to be addressed:

- Services are not available in all parts of the State; however, the Council is adding local councils and expanding provider services.
- Some eligible children are not being served and are on waiting lists.
- Some required federal and State program components have not been fully implemented.
- Tracking or follow-up is not done to determine what progress is made after children leave the program.

Most State agencies do not collect information on the number of children eligible for services, the number served by all programs, or the costs of services per child. Other states are considering whether to continue accepting federal early intervention funding because of fiscal constraints, including the possibility that the federal government will make early intervention an entitlement.

INTRODUCTION

On September 23, 1991, Public Act 87-680, the Early Intervention Services System Act, became effective. This Act established the Early Intervention Services System in Illinois. Section 15 of the Act (Appendix A) requires the Auditor General to "conduct an evaluation of the system established under this Act, in order to evaluate the effectiveness of the system in providing services that enhance the capacities of families throughout Illinois to meet the special needs of their eligible infants and toddlers, and provide a report of the evaluation to the Governor and the General Assembly no later than April 30, 1993." (page 1)

REPORT CONCLUSIONS

Planning for the Illinois Early Intervention Services System, a program to identify and serve infants from birth to 36 months of age with disabilities to minimize their developmental delays, began in 1987. Under the Illinois Interagency Council on Early Intervention, comprised of 10 State agencies with the State Board of Education as the lead agency, Illinois has received over \$24 million in federal funds to plan and implement a coordinated system of statewide councils and service providers.

Overall, we conclude that the framework being established by the Council should be capable of providing services under federal and State laws, but several areas still need to be addressed:

- Services are not available in all parts of the State; however, the Council is in the process of adding local councils and expanding provider services.
- Some eligible children are not being served and are on waiting lists for services.
- Some required federal and State program components have not been fully implemented.
- Tracking or follow-up is not done to determine what progress is made after children leave the program.
- Most State agencies do not collect information on the number of children eligible for services, the number served by all programs, or the costs of services per child.

The effectiveness of the early intervention system in Illinois and the costs to fully implement it are not known. Although State agencies do not collect the information necessary for refined estimates of the number of children eligible for early intervention services and their associated costs, the Council did make some general estimates for 1988. Using the Council's methodology, we estimate that there are about 59,000 children currently

eligible for early intervention services in Illinois: 35,000 considered to be developmentally delayed and 24,000 at risk of developmental delay. Based on our survey of 89 early intervention service providers and Council data, we estimate that:

- Providers served 9,126 (26%) of the estimated 35,000 developmentally delayed children in 1992 and 3,681 (15%) of the estimated 24,000 at-risk children.
- Estimates of the average cost of providing services to developmentally delayed children in Illinois range from about \$4,300 to \$7,500 per child. Thus, the estimated cost of serving developmentally delayed children in 1992 ranges from about \$39 million to about \$68 million. Early intervention services are paid by federal, State, and local funds.
- If all 35,000 children with developmental delays were served, the costs would be in the range of \$150 million to \$260 million. However, it is not expected that all children would participate in the program. The Department of Public Health estimates that no more than about 15,000 children would participate because all children would not be identified as developmentally delayed by their third birthday, some families would choose not to participate, and the average age of children who do participate is about 16 months. Thus, Public Health participation estimates would yield an annual program cost for developmentally delayed children of between \$63 million and \$109 million, which is a 60 percent increase in the cost estimated for 1992.
- The costs of serving children at risk of developmental delay are not known; however, it is assumed that it would be less than those with actual developmental delays.

Other states are considering whether to continue accepting federal early intervention funding because of fiscal constraints, including the possibility that the program will become an entitlement. A federal determination on whether early intervention services will become an entitlement program will probably not be made until 1995. (pages 1-2)

BACKGROUND

Various studies have shown the effectiveness and importance of early intervention services. The National Conference of State Legislatures reports that each dollar a state spends on early intervention services may save between three and seven dollars by reducing expenditures for special education, institutionalization, and welfare.

To be eligible for early intervention services, a child must be between birth and 36 months of age and must be identified as developmentally delayed or have a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay. Developmental delay means a delay in one or more areas of childhood development: cognitive; physical; language, speech, and communication; psycho-social; or self-help skills.

States may, at their discretion, elect to serve a third category: children considered at risk of developmental delay if services are not provided. (pages 3-4)

EARLY INTERVENTION INITIATIVES

In 1986, Congress passed Public Law 99-457 (Part H) to amend the Individuals with Disabilities Education Act (20 U.S.C. 1471 *et seq*). Part H set forth minimum requirements for state early intervention systems and allocated funds for their development and implementation.

Illinois has received about \$24 million in Part H funds since federal Fiscal Year 1987. These funds are designed to supplement, rather than replace, state and local funds expended for infants, toddlers, and their families. Other sources of early intervention service funding include other State agencies, federal Chapter 1 funds, community support organizations, local and county governments, parents and other private sources, and other third-party payors.

Illinois was already providing early intervention services through numerous public and private programs when Congress passed Public Law 99-457 (Part H). However, the system was neither comprehensive nor coordinated among State agencies. In 1987, Illinois created the State Interagency Council on Early Intervention (Council). In September 1991, the Early Intervention Services System Act (325 ILCS 20/1 *et seq*; formerly Ill.Rev.Stat.1991, ch. 23 par. 4151 *et seq*) (Act) solidified the Council's framework and functions. With the State Board as lead agency, the Council is to develop, implement, and evaluate a comprehensive early intervention system in Illinois. (pages 3-6)

AVAILABILITY OF SERVICES

Digest Exhibit 1 shows that an estimated 34,920 children would be developmentally delayed or have a high probability of delay based on 1991 live birth data. Adding the 24,000 estimated at-risk children yields a total of 58,920 children eligible for early intervention services in Illinois in 1991.

Digest Exhibit 1 ESTIMATE OF THE NUMBER OF CHILDREN ELIGIBLE FOR SERVICES IN ILLINOIS				
Year	Number Live Births	Children w/delays	At-Risk Children	TOTAL
1990	196,000	35,280 +	24,000 =	59,280
1991	194,000	34,920 +	24,000 =	58,920

Source: OAG analysis of information supplied by the State Board of Education and the National Center for Health Statistics

Most State agencies on the Council did not collect the information necessary to determine the total number of children and families served in Fiscal Years 1991 or 1992. Only three agencies (State Board, Department of Mental Health and Developmental Disabilities, Department of

Rehabilitation Services) kept figures specifically for the birth to 36 month population. Providers responding to our survey reported serving 11,756 children from 9,991 families in 1991 and 12,807 children (9,126 with delays and 3,681 at risk of developing delays) from 11,077 families in 1992. Fifty-two providers responding to our survey reported having a total of 1,048 children in need of early intervention services on waiting lists as of November 1, 1992. Providers reported that children spent from 2 weeks to 12 months on waiting lists before receiving services. (pages 39-46)

POTENTIAL COSTS

Previous studies funded or conducted by the Council estimated the average cost of serving a developmentally delayed child. Estimates ranged from \$4,287 to \$7,452. Using these estimates, serving the 9,126 children with actual delays in Fiscal Year 1992 would have cost between \$39 million and \$68 million. Data were not available to estimate how much of the total cost would be paid by State or federal funds.

Digest Exhibit 2 shows that the estimated total cost of providing early intervention services to all children with developmental delays in Illinois would range from nearly \$150

million to over \$260 million. Adjusting these figures to account for children who are not identified as delayed by their third birthday, for children whose families choose not to participate, and for children who will not participate for the entire 36 months, results in an potential range of costs from about \$63 million to \$109 million for 1991.

The additional costs of serving the estimated 24,000 children at risk of developmental delay is not known. It is assumed, however, that the costs of serving an at-risk child would be less than serving a child with a diagnosed delay because the at-risk child would require fewer, less intensive services. (pages 39-49)

Digest Exhibit 2 POTENTIAL COSTS FOR CHILDREN WITH DELAYS USING TOTAL AND ADJUSTED FIGURES			
TOTAL POTENTIAL ELIGIBLES			
Year	Eligible Children	Projected Costs	
		\$4,287 Per Child	\$7,452 Per Child
1990	35,280	\$151,245,360	\$262,906,560
1991	34,920	\$149,702,040	\$260,223,840
ADJUSTED FIGURES			
Year	Eligible Children	Projected Costs	
		(at \$4,287)	(at \$7,452)
1990	14,818	\$63,524,766	\$110,423,736
1991	14,666	\$62,873,142	\$109,291,032

Source: OAG summary of State Board and Public Health data.

ENTITLEMENT QUESTIONS

Other states have expressed concerns about early intervention services becoming an entitlement program, since it could escalate the costs of providing services in the states. If the services are declared an entitlement under federal law, the costs to Illinois could be more than the amounts estimated above due to the eligibility of at-risk children in Illinois.

Illinois could continue receiving federal Part H funds until the services are declared an entitlement and then discontinue participation by notifying the U.S. Department of Education. Part H funds represented only 22 percent of the identifiable funds spent in Illinois on early intervention. Thus, while losing Part H funds may not be a desirable choice, other early intervention programs and funding sources would continue. (page 49)

MATTER FOR CONSIDERATION BY THE GENERAL ASSEMBLY

The General Assembly may wish to consider amending the Illinois Early Intervention Services System Act (325 ILCS 20/4; formerly Ill.Rev.Stat.1991, ch. 23 par. 4154 (b)) to require the Interagency Council to include in its annual report to the Governor and General Assembly the estimated number of children in Illinois with developmental delays and at-risk of developing delays, the number of children served and the related expenditures, and the estimated cost to serve all eligible children in Illinois. This information can be used to evaluate Illinois' participation in the federal Part H Early Intervention Program. (page 50)

RECOMMENDATIONS

We made seven recommendations to the State Board of Education as lead agency of the Illinois Interagency Council on Early Intervention. See Appendix G for the responses of the State Board and other agencies on the Council.



WILLIAM G. HOLLAND
Auditor General

JK
April 1993

TABLE OF CONTENTS

Auditor General's Transmittal Letter	i
Report Digest	iii
CHAPTER ONE: INTRODUCTION	1
REPORT CONCLUSIONS	1
BACKGROUND	3
Federal Early Intervention Initiative	3
Illinois Early Intervention Efforts	5
Illinois Accomplishments	6
Access to Services	8
Other Programs Serving the Eligible Population	9
SCOPE AND METHODOLOGY	9
REPORT ORGANIZATION	11
CHAPTER TWO: FUNDING AND SERVICES	13
FUNDING FOR EARLY INTERVENTION SERVICES	13
Part H Funding and Services	13
Additional Funding Sources and Services	17
AVAILABILITY OF EARLY INTERVENTION SERVICES	19
Pilot Sites	21
Review of Cases Selected	25
Diagnostic Centers	25
CHAPTER THREE: SYSTEM IMPLEMENTATION	27
IMPLEMENTATION OF FEDERAL REQUIREMENTS	27
Timetables for the Availability of Services	30
Council Chairperson	31
IMPLEMENTATION OF STATE LAW	31
State's Five-Year Plan	31
Individualized Family Service Plans	33
Interagency Agreement	34
Rules and Regulations	34
Agency Recommendations	36

CHAPTER FOUR: EFFECTIVENESS	39
EFFECTIVENESS	39
Council Studies	40
Need to Monitor Child Development	40
Agency Recommendation	41
Estimating the Number of Eligible Children	42
Number of Children Served	44
Potential Costs	46
Other States Survey	47
Entitlement Questions	49
MATTER FOR CONSIDERATION BY THE GENERAL ASSEMBLY	50

APPENDICES

APPENDIX A	Illinois' Early Intervention Services System Act (Section 15)	53
APPENDIX B	Methodology	57
APPENDIX C	Provider Survey Summary	65
APPENDIX D	Other States Survey	71
APPENDIX E	Providers Receiving State or Federal Funds	81
APPENDIX F	Number of Services Provided By County	87
APPENDIX G	Agency Responses	91

EXHIBITS

EXHIBIT 1	Early Intervention Allocations To States	4
EXHIBIT 2	Development Of The Early Intervention System In Illinois	7
EXHIBIT 3	Part H Allocations For Early Intervention	14
EXHIBIT 4	Part H Expenditures In Illinois - Fiscal Years 1991 & 1992	15
EXHIBIT 5	Part H Providers	16
EXHIBIT 6	State Agencies, Early Intervention Programs, And Identified Expenditures State FY 1992	17
EXHIBIT 7	The 16 Services and Providers In Illinois Who Furnish The Service	19
EXHIBIT 8	Number of Services Provided By County	22
EXHIBIT 9	Twenty Existing Local Interagency Councils And Their Local Community Areas	24
EXHIBIT 10	Summary Of Illinois Progress Toward The 14 Components Required By Federal Law	28
EXHIBIT 11	Estimate Of The Number Of Children Eligible For Services In Illinois	43
EXHIBIT 12	Adjusted Estimate Of Participants	44
EXHIBIT 13	Number Of Children Served By State Agencies	45
EXHIBIT 14	FY 1992 Estimated Costs In Illinois	46
EXHIBIT 15	Potential Costs For Children With Delays Using Total and Adjusted Figures	47
EXHIBIT 16	State Estimates Of Cost Per Child	48

GLOSSARY

APORS	Adverse Pregnancy Outcome Reporting System. Department of Public Health record of adverse outcomes to identify and track infants requiring services.
ASSISTIVE TECHNOLOGY	Devices, aids, and services designed to develop and promote functional skills.
AT-RISK OF DEVELOPMENTAL DELAY	Diagnosis based on clinical judgment and the presence of at least three of the following conditions: family history of developmental disability, victim of child abuse, mother less than 15 years of age, mother has less than 11th grade education (unless that level is appropriate to mother's age), inadequate parenting/caregiving practices, disruption in meeting child's basic needs, absence of regular professional health maintenance, or growth deficiency and/or nutritional problems. (See DMHDD's response in Appendix G for further information)
CENTRAL DIRECTORY	Information on early intervention services and resources in the State.
CHAPTER 1	Federal program which provides funds for services to educationally disadvantaged children.
CHILD FIND	Service which identifies infants and toddlers in need of early intervention services.
DEVELOPMENTAL DELAY	Delay in development of cognitive, physical, language, speech and communication, psycho-social, or self-help skills. For this report, developmentally delayed refers to children who have an actual delay or have a physical or mental condition which has a high probability of resulting in a developmental delay. (See DMHDD's response in Appendix G for further information)

EARLY INTERVENTION	Services to meet the developmental needs of children from birth to 36 months of age and their families.
EARLY INTERVENTION SERVICES	Proposed rules for Part H of the federal Individuals with Disabilities Education Act list 16 services as early intervention services. Since Illinois is operating under the proposed rules, we used the 16 services for the purposes of this report: assistive technology devices; audiology; family training, counseling, and home visits; health services; medical services; nursing services; nutrition services; occupational therapy; physical therapy; psychological services; service coordination; social work services; special instruction; speech-language pathology; transportation services; and vision services.
FEDERAL FISCAL YEAR (FFY)	Fiscal year of the federal government - October 1 to September 30.
INDIVIDUALIZED FAMILY SERVICE PLAN (IFSP)	Written plan for providing early intervention services to the child and family.
LEAD AGENCY	Illinois State Board of Education is the agency responsible for administering the early intervention system. Its duties include general administration, supervision, and monitoring of programs and activities.
NEC*TAS	National Early Childhood Technical Assistance System. Provides technical assistance to early intervention programs in the country.
PART B	Subchapter II of the federal Individuals with Disabilities Education Act. Provides funding for programs serving children with disabilities from age 3 through age 21.
PART H	Subchapter VIII of the federal Individuals with Disabilities Education Act. Provides funding for early intervention programs serving children from birth to 36 months of age.

PROGRAM 33

Early intervention program administered by the Illinois Department of Mental Health and Developmental Disabilities. Serves children from birth to 36 months of age.

**STATE FISCAL YEAR
(Fiscal Year or FY)**

Fiscal year of Illinois government - July 1 through June 30.

TRANSITION SERVICES

Services to assist families in finding other appropriate programs for their children as or after they reach age 36 months.

CHAPTER ONE INTRODUCTION

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REPORT CONCLUSIONS

Planning for the Illinois Early Intervention Services System, a program to identify and serve infants from birth to 36 months of age with disabilities to minimize their developmental delays, began in 1987. Under the Illinois Interagency Council on Early Intervention, comprised of 10 State agencies with the Board of Education as the lead agency, Illinois has received over \$24 million in federal funds to plan and implement a coordinated system of statewide councils and service providers.

Overall, we conclude that the framework being established by the Council should be capable of providing services under federal and State laws, but several areas still need to be addressed:

- Services are not available in all parts of the State; however, the Council is in the process of adding local councils and expanding provider services.
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- If all 35,000 children with developmental delays were served, the costs would be in the range of \$150 million to \$260 million. However, it is not expected that all children would participate in the program. The Department of Public Health estimates that no more than about 15,000 children would participate because all children would not be identified as developmentally delayed by their third birthday, some families would choose not to participate, and the average age of children who do participate is about 16 months. Thus, Public Health participation estimates would yield an annual program cost for developmentally delayed children of between \$63 million and \$109 million, which is a 60 percent increase in the cost estimated for 1992.
- The costs of serving children at risk of developmental delay are not known; however, it is assumed that it would be less than those with actual developmental delays.

Other states are considering whether to continue accepting federal early intervention funding because of fiscal constraints, including the possibility that the program will become an entitlement. A federal determination on whether early intervention services will become an entitlement program will probably not be made until 1995.

BACKGROUND

Various studies have shown the effectiveness and importance of early intervention services. Children are the direct beneficiaries of these services, which research suggests improve childhood development and educational potential. Early intervention programs also give families the support and skills they need to cope with their children's special needs.

Society also benefits from the favorable cost-benefit ratios associated with early intervention. The National Conference of State Legislatures reports that states may save between three and seven dollars for each dollar spent on early intervention services. The savings are expected to accrue through reduced costs of special education, institutionalization, and welfare. Early intervention could result in greater consumer spending and tax revenues through the higher expected earnings of children receiving these services.

An accepted way to measure the effects of early intervention is by longitudinal studies designed to track the development of children who received services over an extended period of time. Because state early intervention systems are relatively new, Illinois and other states have not studied the long-term effects of programs for the birth to 36-month population. However, longitudinal studies on participants in related programs, such as Head Start for children from three to five years old, have generally confirmed the benefits of early intervention.

Federal Early Intervention Initiative

In 1986, Congress passed Public Law 99-457, which provided funds for a system of early intervention for infants and toddlers with disabilities. Early intervention services are designed to:

- enhance the development of infants and toddlers with disabilities and to minimize their potential for developmental delay;
- reduce the educational costs to our society by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age;
- minimize the likelihood of institutionalization of individuals with disabilities and maximize the potential for their independent living in society;

- enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities; and
- enhance the capacity of state and local agencies and service providers to identify, evaluate, and meet the needs of historically under-represented populations, particularly minority, low-income, inner-city, and rural populations.

The law, which amended the Individuals with Disabilities Education Act (20 U.S.C. 1471 *et seq*), encourages states to develop a statewide, comprehensive, coordinated system of early intervention services. The law also created a federal council on early intervention to oversee the system and to minimize duplication of programs across federal, state, and local agencies.

To be eligible for early intervention services, a child must be between birth and 36 months of age and must be identified as developmentally delayed or have a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay. Developmental delay means a delay in one or more areas of childhood development: cognitive; physical; language, speech, and communication; psycho-social; or self-help skills. States may, at their discretion, elect to serve a third category: children considered at risk of developmental delay if services are not provided.

Subchapter VIII (Part H) of the federal law lists a number of services participating states may provide to eligible children. These services include physical and occupational therapies, family counseling and home visits, case coordination services, and transportation to receive services. The law also sets forth minimum requirements for the statewide system. These requirements include the state's definition of the eligible population, a system for identifying eligible children and referring them to services, a multidisciplinary assessment for each child, an individualized service plan based on the assessment of the needs of the child and family, and a system for compiling data on the numbers of children eligible and served. These components are more fully discussed in Chapter Three.

As an incentive for states to participate, Part H allocated funds to develop and implement the statewide system. Each state received a portion of the funds relative to its population of infants and toddlers. After the system is implemented, the state can continue to receive Part H funds. The total amount of funds awarded to states by the U.S. Department of Education is shown in Exhibit 1.

**Exhibit 1
EARLY INTERVENTION
ALLOCATIONS TO STATES**

FFY	AMOUNT
1987	\$ 50,000,000
1988	67,000,000
1989	69,830,000
1990	79,520,000
1991	117,106,478
1992	<u>175,000,000</u>

TOTAL \$ 558,456,478

Source: OAG summary of Joint Committee on Early Intervention Report and U.S. Dept. of Education data.

As of 1992, all 50 states were receiving Part H funds. The Part H program is specified as payor of last resort; that is, all other fund sources should be used before using Part H funds to provide early intervention services.

The federal law gave states five years to develop and implement the statewide system. The system is to be in place by the beginning of the states's fifth year of participation. Originally, this meant that a state would have to have its system in place by October 1991. Maryland and Hawaii were the first two states to meet the original five year schedule. When the federal law was reauthorized in October 1991, it was changed to allow a state extra time to implement the system. A state requesting extended participation would receive the same amount of funds it received the year before. States may not be in extended participation more than twice.

The programs under Part H are coordinated with other programs required under the Individuals with Disabilities Education Act, including preschool programs set up under Part B. The goal is to ensure that developmentally disabled children over age three continue to receive services until they begin public school or community programs.

Illinois Early Intervention Efforts

Illinois was already providing early intervention services through numerous public and private programs when Congress passed Public Law 99-457 (Part H) in 1986. The Department of Mental Health and Developmental Disabilities awarded grants from General Revenue Funds to a network of providers; local public health clinics were screening and examining children for medical and other problems. However, the system was neither comprehensive nor coordinated among State agencies.

Exhibit 2 shows the significant events in developing the early intervention system in Illinois. In response to the federal law, Illinois created the State Interagency Council on Early Intervention (Council) in 1987. Council membership includes: the State Board of Education (State Board), the University of Illinois' Division of Specialized Care for Children, the Illinois Planning Council on Developmental Disabilities, and the Departments of Rehabilitation Services (DORS), Mental Health and Developmental Disabilities (DMHDD), Children and Family Services, Public Health, Public Aid, Alcoholism and Substance Abuse, and Insurance. The Council also includes: parents of children with disabilities, public or private providers of early intervention services, one member of the General Assembly, and one person involved in the preparation of professional personnel to serve infants and toddlers.

The Early Intervention Services System Act (325 ILCS 20/1 *et seq*; formerly Ill.Rev.Stat.1991, ch. 23 par. 4151 *et seq*) (Act) became effective in September 1991. The Act solidified the framework and functions of the State Interagency Council on Early Intervention. It also created an Early Childhood Intervention Ombudsman in the Governor's

Office to assist families and local parties in ensuring that all State agencies participating in the system do so in a cooperative manner.

According to the Act, the Council's main duty is to advise and assist the lead agency in developing, implementing, and evaluating a comprehensive early intervention system in Illinois. Additionally, the Council is to prepare an annual report for the Governor and the General Assembly on the status of early intervention programs for eligible infants and toddlers and their families in Illinois. The State Board was officially designated as the lead agency in June 1992. The lead agency's duties include general administration and supervision of the programs receiving Part H funds, identification and coordination of available resources within the State, and development of formal interagency agreements which define the financial responsibility of each agency paying for early intervention services.

The Act also requires that the lead agency define from 40 to 60 local service areas to ensure the availability of services statewide. Each local service area is required to have a local council to help resolve local disputes, assist in developing collaborative agreements between providers and agencies, identify and resolve local access issues, and assist in conducting local needs assessments and planning efforts. The State Board has established 20 local councils in the State.

Under the Act, the lead agency and the Council are to prepare a five-year implementation plan to submit to the Governor. This plan is to list the specific activities to be accomplished each year with cost estimates for each activity. The Governor is required to certify that tasks are completed before authorizing State agencies to complete the other tasks.

In December 1992, Illinois became the 20th state to begin the fifth year of participation in Part H. Fifth-year participation was achieved one year behind the federal implementation schedule because the system was not ready for full implementation. Thus, in September 1991, the Council applied for extended participation status for one year.

Illinois Accomplishments

Illinois is in the process of implementing a system that will enable families to access early intervention services in the State. The Council has formed committees to develop and recommend personnel standards and system standards. These standards have been adopted by the Council at three pilot implementation sites. The Council has also developed a list of at-risk conditions that must be met for children in this category to be eligible.

Exhibit 2
DEVELOPMENT OF THE EARLY INTERVENTION SYSTEM IN ILLINOIS

October 1986

Congress amended the Education of the Handicapped Act (now known as the Individuals with Disabilities Education Act - PL 99-457). Part H of the Act established a new state early intervention program for infants and toddlers.

June 1987

Governor Thompson issued Executive Order 4 designating the State Board of Education as the lead agency to implement provisions of Part H. The Order also created the State Interagency Council on Early Education.

July 1988

The State Board and the Council awarded Part H grants to 27 providers to improve and expand existing early intervention services.

May 1989

Governor Thompson issued Executive Order 3, which added the Illinois Department of Alcoholism and Substance Abuse and the Illinois Planning Council on Developmental Disabilities to the Council as voting members. It renamed the Council the State Interagency Council on Early Intervention.

February 1991

The State Board and Council began a pilot implementation program. The pilot sites (Rockford, Chicago, and Jonesboro) test the feasibility of the proposed early intervention system.

September 1991

Public Act 87-680 (Early Intervention Services System Act) became effective. Its purpose was to provide a comprehensive, coordinated, interagency, interdisciplinary early intervention system for eligible infants and toddlers.

October 1991

The federal Individuals with Disabilities Education Act was reauthorized and amended to clarify parts of the original law. Provisions for extended participation were added.

June 1992

Local Interagency Councils were developed in 17 additional areas of the State to coordinate services and planning at the local level.

July 1992

Amendments to the Illinois Early Intervention Services System Act became effective (P.A. 87-847) to make the State law consistent with the changes in the federal Act. It also made the Department of Insurance a member of the Council as required by federal law.

Source: OAG summary of information supplied by the State Board of Education.

The State Board established three pilot sites in 1991. These pilot sites were to set up local councils and implement the early intervention services system in those areas. This included following the standards the Council had adopted for personnel, training, programs, and services. These three sites have progressed toward implementing a comprehensive, community-based system.

Access to Services

There are several ways children in need of early intervention services may enter the system. Most referrals for early intervention services come from physicians, hospitals, social workers, or health clinics. Parents and other individuals may obtain information about the system by calling one of three toll-free numbers or by directly contacting a service provider.

One of the toll-free numbers is a central directory of services in Illinois. This directory has a master listing of the programs providing services to the birth to 36-month age group. Parents receive the names, addresses, and phone numbers of all the providers in their geographic area. If the parents need information about early childhood issues or some specific diagnosis, they can call another toll-free number at the Illinois Early Childhood Intervention Clearinghouse. The Clearinghouse keeps reference material on issues relating to early childhood and medical conditions that lead to developmental problems. It also publishes a quarterly newsletter.

The other toll-free number is for the State's Child Find effort. Child Find is required under Part H and Part B of the Individuals with Disabilities Education Act. School districts are required to identify all children who will need special education services. They conduct mass screenings at least once every year for children from ages 3 to 5 and may conduct individual screenings for children from birth to 3. If the school district screening identifies a developmental delay, the child will be referred to a provider.

If the child is found to have some delay or suspected delay, an in-depth assessment will be completed. This assessment measures the child's speech and language skills, socialization, hearing, motor skills, cognitive abilities, and self-help skills. This assessment is usually performed by a team that may include several disciplines, such as a child development specialist, nurse, social worker, physical therapist, and others as needed. An individualized family service plan is then developed showing all the services needed and how often they should be provided.

According to the State Part H coordinator, Illinois has the largest number of State agencies on its council of the states that have achieved fifth year participation. While few of the State agencies on the Council actually provide direct early intervention services to children, many agencies provide funds for services through local public health clinics, school districts, and other community organizations, or through direct reimbursements. For

example, DMHDD and the State Board give grants to community-based organizations and school districts to provide services. DORS pays for persons to provide in-home care and assistance for the child and the family; Public Aid will pay when a Medicaid-approved provider submits a bill for services such as physical or occupational therapy.

Other Programs Serving the Eligible Population

There are other programs in Illinois not specifically designated as early intervention programs, but which provide services related to early intervention for the birth to 36 month population. For example, the State Board funds the Prevention Initiative program, which targets children at risk of school failure. Many of the children eligible for this program would be eligible for early intervention under the list of at-risk conditions. Public Aid receives funding for a Healthy Moms/Healthy Kids program initially targeted at low income mothers and children in Cook County. An official at Public Aid stated that this program was scheduled to become statewide in April 1993. Additionally, the State's perinatal centers provide hospital care for high-risk infants within the first 30 days after birth. Some of the services children receive through these programs could be defined as early intervention.

Department of Mental Health and Developmental Disabilities Response:

Because P.L. 102-119 gives the lead agency responsibility to oversee all early intervention efforts, any initiatives or projects which affect children in Illinois should be presented to the lead agency and the Illinois Interagency Council on Early Intervention (IICEI) to determine if and how the initiative/project(s) is part of the collaborative, coordinated system for early intervention.



SCOPE AND METHODOLOGY

This audit was conducted in accordance with generally accepted government auditing standards and the audit standards promulgated by the Office of the Auditor General at 74 Ill. Adm. Code 420.310.

The scope of the audit included the period from June 1987 through January 1993, but detailed testing and examination focused on Fiscal Years 1991 and 1992.

We interviewed officials at the State Board of Education, the Departments of Rehabilitation Services, Mental Health and Developmental Disabilities, Children and Family Services, Public Health, Public Aid, Alcoholism and Substance Abuse, and Insurance. We also interviewed the Early Childhood Intervention Ombudsman in the Governor's Office and

officials at the University of Illinois Division of Specialized Care for Children and the Illinois Planning Council on Developmental Disabilities. In addition, we interviewed officials at the Voices for Illinois Children and persons responsible for the State's Central Directory of services, Clearinghouse, and Child Find efforts and contacted a geneticist at Children's Memorial Hospital in Chicago.

Additionally, we contacted the United States Departments of Education and Health and Human Services, including the Centers for Disease Control. We contacted the National Conference of State Legislatures, the March of Dimes, and the National Early Childhood Technical Assistance System. We contacted officials in 32 states to determine if those states had evaluated their early intervention programs; for those states in the second year of extended participation, we asked if they were planning to continue participation in Part H.

We surveyed 99 providers of early intervention services in the State to determine the level of funding received, the services rendered, and other administrative aspects. These providers were identified by the State Board of Education, the Department of Mental Health and Developmental Disabilities, and the Department of Children and Family Services.

We reviewed statutes and administrative rules concerning early intervention for all agencies involved in the Interagency Council. We examined controls over administration of the Part H program at the State Board of Education and the accuracy of EDP-generated data. In addition to our internal control and EDP testing, we relied on the testing done by the Office of the Auditor General's Compliance Audit Division in their audits of the State Board.

In addition, we reviewed Council minutes, committee reports, studies done by consultants and paid for by the Council, other internal documents, the annual reports submitted to the Governor, and the applications for funds submitted to the federal government. We examined pertinent documents at the State Board of Education and Department of Mental Health and Developmental Disabilities. We also examined information from the Office of the Comptroller on appropriations for early intervention by State agencies.

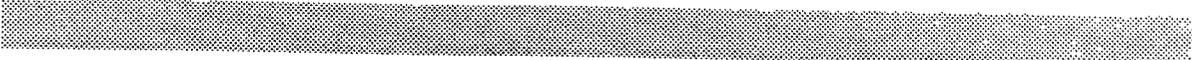
We visited the three pilot implementation sites designated by the Council, where we examined the structure of the local programs and talked with parents, providers of services, and advocacy personnel. Additionally, we sampled 20 cases from a provider at each site.

Appendix B contains the methodology for estimating the number of children eligible for services, estimating the potential costs of the early intervention system in Illinois, and selecting samples at the three pilot sites.



REPORT ORGANIZATION

The remainder of the report is organized as follows:

- Chapter Two discusses the funding and services provided in Illinois for early intervention.
 - Chapter Three presents issues concerning the implementation of federal and State law.
 - Chapter Four examines program effectiveness measures and potential costs of the system.
- 

CHAPTER TWO FUNDING AND SERVICES

Since 1987 Illinois has been awarded over \$24 million in federal Part H funds to plan and implement a coordinated early intervention system. The cost of fully implementing the early intervention system is not known; most State agencies involved in the system do not maintain complete data regarding program expenditures.

There is no complete, centralized source of information on the location or services of early intervention providers. Most providers do not provide all of the early intervention services, and some children in need of services are on waiting lists.

FUNDING FOR EARLY INTERVENTION SERVICES

The two primary sources of identifiable funding for early intervention services in Illinois are Part H program allocations and Department of Mental Health and Developmental Disabilities early intervention (Program 33) funds. Providers can also receive funds from other State agencies, federal Chapter 1 funds, community support organizations, local and county governments, parents and other private sources, and other third-party payors.

Part H Funding and Services

Beginning in federal Fiscal Year 1987, the federal government provided funding to states for a five-year early intervention development effort under Part H of the Individuals with Disabilities Education Act. Part H funds are designed to supplement, rather than replace, the level of State and local funds expended for infants, toddlers, and their families. Since the federal law's inception, Illinois has received over \$24 million of the \$558 million allocated in federal Part H funds (see Exhibit 3). In federal Fiscal Year 1991, Illinois initially received \$3.4 million in federal funds.

Illinois received an additional \$1.4 million for federal Fiscal Year 1991 when the U.S. Department of Education redistributed the funds of the states that were not ready for fifth year status. These states used a provision in the federal law which allowed them to continue functioning at the fourth year level in terms of program development. States may

extend their program development schedule up to two years while continuing to receive Part H funds. States in extended participation receive the same funding as the previous year. Any remaining funds the federal government had set aside for these states are redistributed to other states that applied for the succeeding level of participation. Since Illinois applied for fifth year funds in 1992, it received its original Part H allocation as well as a redistribution of other states' funds.

Exhibit 3
PART H ALLOCATIONS FOR EARLY INTERVENTION

Federal Fiscal Year	Federal Funds Allocated	Illinois Award	Percent of Funding
1987	\$ 50,000,000	\$2,268,995	4.5%
1988	67,000,000	2,996,565	4.5%
1989	69,830,000	3,037,449	4.3%
1990	79,520,000	3,608,771 ¹	4.5%
1991	117,106,478	4,888,032 ²	4.2%
1992	175,000,000	7,626,080 ³	4.4%
TOTAL	\$ 558,456,478	\$24,425,892	4.4%

¹ Includes \$162,923 in redistributed funds.
² Includes \$1,442,184 in redistributed funds.
³ As of January 1993.

Source: OAG summary of Joint Committee on Early Intervention Report (January 1991) and U.S. Dept. of Education data.

Exhibit 4 shows that the State used almost \$3.7 million in federal Part H funds in Fiscal Year 1991 and \$3.2 million in Fiscal Year 1992. These amounts include approximately \$2 million in grants to 27 providers of early intervention services. An additional 29 newly funded providers were added in December 1992 (see Exhibit 5) for a total of 56 Part H providers. The Part H totals also include nearly \$1 million in grants to regional diagnostic centers and the three pilot projects in Fiscal Year 1991. Approximately \$300,000 in Part H funds was spent on general program administration and maintaining a central directory of services during Fiscal Year 1992.

**Exhibit 4
PART H EXPENDITURES IN ILLINOIS - STATE FISCAL YEARS 1991 & 1992**

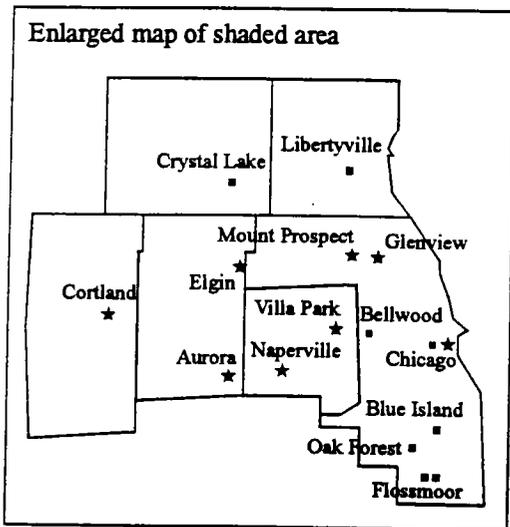
<u>GRANTS TO PROVIDERS</u>	<u>LOCATION</u>	<u>FY91</u>	<u>FY92</u>
Adams County Mental Health Center	Quincy	\$ 52,032	\$ 47,269
Blue Cap Infant-Parent Center	Blue Island	64,050	58,186
Chicago ARC	Chicago	242,140	215,415
Chicago Public School District 299	Chicago	91,671	85,844
Childrens Developmental Center	Rockford	159,958	133,213
Coleman Tri-County	Harrisburg	98,611	93,641
Coles County ARC	Charleston	79,667	71,169
Cook County Hospital	Chicago	99,696	77,166
Delta Center	Cairo	64,151	53,051
Developmental Services Center	-Champaign	154,273	132,642
Easter Seal Society of Metro Chicago	Chicago	66,603	62,655
El Valor Corporation	Chicago	67,608	46,062
Esperanza Community Services	Chicago	24,080	21,838
Fulton County Rehabilitation Center	Canton	17,850	16,218
Good Shepherd Center	Flossmoor	27,930	25,375
Jefferson County Comprehensive Services	Mt. Vernon	26,702	24,259
Lake Parent-Infant Center	Libertyville	74,301	69,362
Malcolm Eaton Enterprises	Freeport	41,782	37,958
McDonough County Rehabilitation Center	Macomb	36,750	33,387
Pioneer Center	Crystal Lake	71,410	64,872
Prime/Care	Belleville	80,644	73,674
Proviso ARC	Bellwood	41,957	38,117
Rehabilitation Institute of Chicago	Chicago	105,000	95,385
South Metropolitan Association	Flossmoor	134,264	121,968
Southwest Cook County Cooperative Assn. for Special Education	Oak Forest	58,000	53,307
Wabash & Ohio Valley Special Education District (WOVSED)	Norris City	159,995	149,539
Warren Achievement Center	Monmouth	42,609	39,007
Subtotal - Grants to Providers		<u>\$2,183,734</u>	<u>\$1,940,579</u>
<u>OTHER SERVICES</u>			
Diagnostic Centers		\$ 550,439	\$ 503,933
Pilot Projects		393,888	496,946
Subtotal - Other Services		<u>\$ 944,327</u>	<u>\$1,000,879</u>
<u>ADMINISTRATION</u>			
General		\$ 380,352	\$ 235,653
Illinois Technical Assistance Project		103,921	N/A ¹
Illinois Planning Council on Developmental Disabilities		46,000	N/A ²
Central Directory		29,775	62,500
Subtotal - Administration		<u>\$ 560,048</u>	<u>\$ 298,153</u>
TOTAL		<u>\$ 3,688,109</u>	<u>\$ 3,239,611</u>

¹ Funded with Part B - Preschool Discretionary Funds in FY92.
² Part H funds provided in FY91 only.

Figures are rounded.

Source: OAG Summary of State Board of Education data.

Exhibit 5 Part H Providers



- Providers Designated in June 1988
 - ★ Providers Added in December 1992
- Chicago has 11 Providers -
7 Original and 4 New

Source: OAG map based on State Board of Education Data

Additional Funding Sources and Services

Only three of the ten agencies on the Illinois Early Intervention Council could identify specific State or federal expenditures for children from birth to 36 months. Many agencies on the Council did not have programs specifically related to early intervention. Many agencies could not isolate information on the birth to 36 month age group from programs that also provided services to children older than 36 months. In addition, many agencies involved in the Council maintained expenditure information by fund, not by program. Exhibit 6 lists the State agencies on the Council, their early intervention programs and services, and the \$14 million in specific early intervention expenditures readily identifiable for Fiscal Year 1992 at three agencies: DMHDD, DORS, and the State Board.

In fiscal year 1992, DMHDD granted \$8.8 million in State General Revenue Funds to the 73 providers participating in Program 33. DMHDD reported that Program 33 provided early intervention services to 6,347 clients statewide during Fiscal Year 1992.

DMHDD awarded Chapter 1 funds totalling \$975,296 in Fiscal Year 1991 and \$1,317,858 in Fiscal Year 1992. The 73 Program 33 providers also receive Chapter 1 grants. DMHDD officials stated that Chapter 1 funds allow these agencies to acquire

Exhibit 6
STATE AGENCIES, EARLY INTERVENTION PROGRAMS,
AND IDENTIFIED EXPENDITURES - STATE FY 1992

<u>Agency</u>	<u>Programs/Services</u>	<u>Expenditures FY 1992</u>
State Board of Education	Part H Part B (Preschool)	\$ 3,239,611 ¹ Cannot identify
DMHDD	Program 33 Chapter 1	\$ 8,837,662 ² \$ 1,317,858 ¹
DORS	Home Services Lekotek	\$ 1,037,031 ² Cannot identify
Public Aid	EPSDT, Healthy Moms/ Healthy Kids, occupational and physical therapies	Cannot identify
Public Health	Newborn screening, medical services, WIC, APORS, Project services	Cannot identify
Alcoholism and Substance Abuse	Treat pregnant women and mothers who abuse drugs - refers infants for services	Cannot identify
Insurance	Role is being developed	No cost
U of I - DSCC	Medical services for congenital conditions, services to children with special health needs	Cannot identify
Planning Council	Grants to pilot sites	Cannot identify
DCFS	Refers children to providers	Cannot identify
TOTAL		\$ 14,432,162

¹ Federal Funds

² State General Revenue Funds

Note: An amount is listed only where agencies could identify specific expenditures for serving children from birth to 36 months of age.

Source: OAG summary of State agencies' information.

supplemental staff, equipment, and materials for direct service use. DMHDD does not keep information on the total number of children served each year with Chapter 1 funds.

Department of Mental Health and Developmental Disabilities Response:

DMHDD maintains statistics on the number of children eligible to receive Chapter 1 funds using the December 1 child count required by ISBE. Since ISBE is the fiscal agency in which Chapter 1 funds "flow-through" to the Department, they maintain information on the total number of children served with Chapter 1 funds, including those who have transitioned out of the early intervention program upon reaching age 3 and the names of those children who replace these children."

The Department of Rehabilitation Services (DORS) provides early intervention services through its Home Services Program. Services include: respite care, personal care assistants, and home care. Home Services Program expenditures were \$562,484 to furnish services for 191 children in Fiscal Year 1991 and \$1,037,031 for 260 children in Fiscal Year 1992.

DORS also funds Lekotek, a program which assists families with skills, materials, and knowledge to help their children at home through the use of adaptive toys. Lekotek expenditures from the General Revenue Fund were \$599,100 in Fiscal Year 1991. In Fiscal Year 1992, Lekotek expenditures were \$598,900 and 645 eligible children were served. These expenditures are for all children in the Lekotek program; DORS could not provide Lekotek's expenditures for infants and toddlers from birth to 36 months of age. Children enrolled in Lekotek may be simultaneously enrolled in another early intervention program.

The Illinois Planning Council on Developmental Disabilities provides advocacy, funds special projects, and conducts strategic planning within the disability field. The Planning Council provides grants to early intervention service providers; the Council does not provide direct services to recipients. Grants and staff costs for early intervention activities totalled \$82,599 in federal Fiscal Year 1991 and \$54,130 in federal Fiscal Year 1992. Also, in Fiscal Year 1991, the Planning Council received \$46,000 in Part H funds to administer a public awareness campaign (see Exhibit 4).

The State Board received its first State appropriation for early intervention in Fiscal Year 1993, when it received \$500,000 to pay for screenings and assessments, and to establish a central billing system. A State Board official stated that planning has begun for the central billing office for early intervention, but it is not expected to be implemented in the near future.

Exhibit 6 shows that most State agencies on the Council could not provide complete expenditure information on services for Illinois children from birth to 36 months. Service providers responding to our survey reported spending over \$19 million for early intervention

in Fiscal Year 1992. Most providers did not report the amount of early intervention services paid by the Medicaid program.

The State Board has hired a consultant to help develop a financial strategy for the early intervention system. The State Board is also planning to assess the financial structure of the system after the Children's Development Center in Rockford completes its federally-funded study of funding streams for early intervention services.

AVAILABILITY OF EARLY INTERVENTION SERVICES

There is not a complete, centralized source of information on the location or services of early intervention providers. Some early intervention service providers are local, community-based organizations that provide other services including mental health and public health services, counseling, and teen services. Some providers only serve the birth to 36 months population.

Part H lists 15 services as early intervention services. Federal rules currently in effect to implement the Act also list 15 services, noting others could be included. New rules for Part H were proposed in May 1992; they have not yet been implemented. However, states were given the option to follow these proposed rules when submitting their applications for funding. Illinois has operated under the new, proposed rules, which list 16 services as early intervention services. These 16 were included in our survey of providers.

Exhibit 7
THE 16 SERVICES AND PROVIDERS
IN ILLINOIS WHO FURNISH THE SERVICE

<u>Early Intervention Service</u>	<u>Number of Providers</u>
Assistive Technology Devices	30
Audiology	39
Family Training, Counseling, and Home Visits	78
Health Services	20
Medical Services	27
Nursing Services	46
Nutrition Services	31
Occupational Therapy	66
Physical Therapy	70
Psychological Services	29
Service Coordination Services	66
Social Work Services	60
Special Instruction	62
Speech-Language Pathology	74
Transportation	55
Vision Services	27

Notes: Provider numbers include referrals.
Most providers offer multiple services.

Source: OAG survey of early intervention providers.

We surveyed the 99 providers of early intervention services that we identified as either receiving funds from or providing services for State agencies. Five providers did not respond to our survey, one responded too late to be included in our analysis, and five respondents stated they did not provide early intervention services. Two providers were dropped from the list: one because it was listed twice and the other because it transferred its program to another provider. Three providers were added after they responded to the survey. Five of the remaining 89 providers reported they directly provided all of the 16 early intervention services listed or referred patients to providers of these services. State Board officials said it would not be necessary for every provider to supply all 16 services. Referring families to other providers is a common practice. Exhibit 7 shows the 16 services and the number of providers in the State who furnish the service. The data in the Exhibit includes services that are provided directly or through referrals.

Exhibit 8 summarizes how many of the 16 services are available in each county. Based on information from early intervention service providers responding to our survey, the Exhibit shows that none of the 16 early intervention services were available in four counties: Brown, Moultrie, Edgar, and Clark. A provider in Rock Island county responded to our survey too late to be included in our analysis. Appendix F shows the availability of services in each county.

State Board Response:

After receiving the report, staff of the lead agency contacted the mental health center in one of the four counties. The executive director of the center indicated that birth to three early intervention services had been provided by the agency for 20 years. (see Appendix G for full response and Auditor Comment number 2)

Department of Mental Health and Developmental Disabilities Response:

Through the Department's monitoring process it has been determined that these [four] counties are providing some early intervention services funded through DMHDD Program 16 (Child and Family Support), Title XX Donated Funds Initiative or local funding. (see Appendix G for full response and Auditor Comment number 2)

Our survey confirmed that not all developmentally delayed children are receiving services when needed. Fifty-two providers responding to our survey reported having a total of 1,048 children in need of early intervention services on waiting lists as of November 1, 1992. Providers reported that children spent from 2 weeks to 12 months on waiting lists before receiving services.

Pilot Sites

The State Act requires that the State Board and the Council establish 40 to 60 local service areas. For each area, the State Board and the Council must create a local council. Local councils assist in developing agreements between local agencies, resolving disputes, and conducting local needs assessments and identify and resolve local access issues. To test the proposed statewide early intervention system, the State Board funded three pilot implementation sites to serve as prototypes for future programs. The sites were paid a total of \$393,888 for Fiscal Year 1991 and \$496,946 for Fiscal Year 1992 in Part H funds. The sites, located in geographically diverse areas of the State, were: Illinois Masonic Medical Center - Chicago (metropolitan area), Children's Development Center - Rockford (suburban area), and Jonesboro Community Consolidated School District Number 43 (rural area). The pilot sites are testing definitions of eligibility, personnel standards, and other policies and procedures for possible implementation statewide. They are also establishing the role of core providers to perform assessments for eligibility and services.

Our visits to the three pilot sites found that each site has established a unique structure and approach to identifying eligible children, providing services, and establishing the parameters of parental involvement.

The local council at the Illinois Masonic Medical Center pilot site was established in March 1991 to serve the northern section of Chicago. There are four core providers within the local council's area. Children are initially screened at nine Child Find sites that include local health centers and a Women, Infants, and Children (WIC) Center. These sites conduct initial screenings and refer children to an area diagnostic clinic for further assessment as needed. Advocacy services are provided that focus on education for early childhood development and family support issues.

In Rockford, there was already a group in place that had been cooperating and coordinating services for several years. The group was expanded and now includes children from birth to five years old. The Rockford pilot site covers Boone, Ogle, and Winnebago counties. The local hospitals and other organizations work to refer children to services and the core provider refers children who need diagnostic services to the hospital. Case coordination is done by the core provider. Advocacy is provided by an organization which also provides staff for the local council. Eligible children are identified by screenings held at schools, day care centers, public health clinics, and other locations in the three counties. Most services are center-based, which means that the children go to an established center instead of being given therapy in the home.

The Jonesboro Community Consolidated School District Number 43 coordinates the activities of the area local council which serves nine southern Illinois counties: Jackson, Perry, Union, Alexander, Johnson, Pope, Hardin, Pulaski, and Massac. The local council was established in May 1991. In Fiscal Year 1992, one core provider and another provider received funds from DMHDD under Program 33. The core provider serves the southern seven counties and the other provider serves the remaining two counties. In the southern seven counties, screenings for children are administered by WIC (Women, Infants, and Children Program) nurses through the local public health department. Children in the remaining two counties can be screened by the provider for those counties. When screenings indicate a potential problem, the children are referred to the provider in their area. This health department is also the advocacy provider for the local council. Because of the largely rural nature of the area, the services are mostly provided in the home instead of at a center in the southern seven counties; the other two counties have both home-based and center-based services available for children.

Additionally, the local council at the Jonesboro pilot site has developed a diagnostic clinic program to provide evaluations of children when initial assessment tools are inconclusive. The clinic's team is comprised of various members from different community and medical organizations. A developmental pediatrician is paid to conduct the assessments, but all other organizations provide free services to the clinic.

An additional 17 local councils were established in June 1992. A map showing the locations of the local councils is shown as Exhibit 9. The State Board also plans to establish additional local councils.

Review of Cases Selected

We selected a total of 80 cases from four providers' files. We examined Individualized Family Service Plans to determine when they were prepared and if they were reviewed and updated.

Additionally, we asked three providers for a summary of each case including entry assessment, exit assessment, the services provided, and why the case was closed. One provider only had active files on-site for our review; thus, we did not use the 20 cases from that provider for the more detailed review. Of the 60 remaining cases, 34 were still active. Of the 26 closed cases, 17 children had turned three years old and were no longer eligible for early intervention, 5 children had moved, and 2 cases were closed for other reasons. Two cases were closed because the children no longer needed services.

Diagnostic Centers

Besides funding service providers, the State Board funded two diagnostic centers to identify, diagnose, and monitor infants and toddlers who need early intervention services; to assess their health, development and family needs; and to coordinate services with medical and developmental service providers. These centers were located at Lutheran General Hospital in Park Ridge and La Rabida Children's Hospital in Chicago. In Fiscal Year 1992, Lutheran General and La Rabida received \$256,112 and \$247,821 respectively in Part H funds. However, as of October 1992, these centers were no longer funded. A State Board official stated that these centers were not cost-effective.

State Board officials said eligible infants will be referred to either DMHDD-funded diagnostic centers or Public Health perinatal centers for diagnostic evaluations. A Request for Contracts is being developed to assure that diagnostic services are provided in the State.

CHAPTER THREE SYSTEM IMPLEMENTATION

The Council and State Board have not implemented all of the requirements of the Illinois Early Intervention Services System Act or all of the relevant provisions of the State's five-year implementation plan. Additionally, only 9 of the 14 components required by federal law have been fully implemented. The Council and State Board have addressed the remaining components, which include the development of uniform standards and policies for training early intervention personnel; they expect to fully implement all components by 1996.

IMPLEMENTATION OF FEDERAL REQUIREMENTS

The Individuals with Disabilities Education Act (20 U.S.C. 1400 *et seq*) requires that a state early intervention system contain 14 components. These components are the basis for all early intervention efforts and should be operational by the beginning of a state's fifth year of participation in the program. We reviewed Illinois' progress toward establishing the 14 components.

As shown in Exhibit 10, Illinois has successfully implemented 9 of the 14 components required: establishing a central directory of services, programs, and personnel; developing a public awareness program; designating the lead agency; establishing a comprehensive, multidisciplinary evaluation of each child; developing an individualized family service plan for each child; implementing a comprehensive Child Find system in the State; adopting procedures for arranging for early intervention services; developing procedural safeguards; and establishing a timetable for services by the beginning of the fifth year. The other five components have not been fully implemented. These are integral parts of the entire statewide system. Although these five components are not fully implemented, they have been addressed by the Illinois Interagency Council on Early Intervention (Council) and the State Board of Education (State Board).

Exhibit 10
SUMMARY OF ILLINOIS PROGRESS
TOWARD THE 14 COMPONENTS REQUIRED BY FEDERAL LAW

1.	Definition of developmentally delayed.	Partially Implemented
2.	Timetables for ensuring that services will be available to all infants and toddlers with disabilities before the beginning of the fifth year.	Implemented
3.	Timely, comprehensive, multidisciplinary evaluation of each infant and toddler with a disability.	Implemented
4.	Individualized family service plan for each infant and toddler with a disability.	Implemented
5.	Comprehensive Child Find system, including referrals to service providers.	Implemented
6.	Public awareness program focusing on early identification of infants and toddlers with disabilities	Implemented
7.	Central directory of services, resources, experts, and demonstration projects in the State.	Implemented
8.	Comprehensive system of personnel development, including training personnel for rural areas and for transition services.	Partially Implemented
9.	Single line of responsibility in a lead agency.	Implemented
10.	Policy for contracting or otherwise arranging for early intervention services.	Implemented
11.	Procedure for securing timely reimbursement of funds.	Not Implemented
12.	Procedural safeguards for programs.	Implemented
13.	Policies and procedures for standards for training and licensing early intervention personnel.	Partially Implemented
14.	System for compiling data on the numbers of infants and toddlers with disabilities in need of services, the number served, and the types of services provided.	Partially Implemented

Source: OAG analysis of State Board, Council, and U.S. Dept. of Education materials and the federal Individuals With Disabilities Education Act.

Illinois has not fully implemented the following early intervention system components required by federal law:

Component 1 - Definition of developmentally delayed

The Council has not formally approved and implemented a definition of children at risk of developmental delay. The federal law requires state early intervention programs to serve infants and toddlers with either an identified developmental delay or a condition suggesting a high probability of developmental delay. The federal law allows, but does not require, states to serve those at risk of developmental delay. Each state must define all groups eligible for services in that state.

Illinois law includes all three of these groups as eligible for early intervention services. The Council has only formally adopted definitions for children with identified delays and with high probability of delay. A list of at-risk conditions was developed in July 1991, but the Council has not formally approved it. The at-risk conditions include family history of developmental disability, mother less than 15 years of age, or growth deficiency and/or nutritional problems.

Components 8 & 13 - Comprehensive system of personnel development and procedure for maintaining standards on training and licensing early intervention personnel.

The State is required to establish a personnel development system to recruit and retain early intervention providers and to ensure that personnel are adequately prepared and trained. The personnel system may include training personnel to work in rural areas and to coordinate transition services.

Personnel standards are being tested at the three pilot sites: Rockford, Chicago - Illinois Masonic Medical Center, and Jonesboro. The Council established a committee in August 1992 to evaluate the standards and make recommendations for statewide implementation. However, the committee has not yet completed its review.

Component 11 - Procedure for timely reimbursement of funds

There is no procedure for securing timely reimbursement of funds used to provide services. The Council has not conducted a complete in-depth study of the financial aspects of the system. Additionally, a central billing office has yet to be established. Its purpose is to simplify the billing and payment for early intervention services.

Component 14 - System for collecting data on infants toddlers with disabilities

The system for compiling data on children in need of services and those receiving services is partially implemented. The State Board's computer system does not include all the information required; further, no agency compiles information on all infants and toddlers in the State in need of early intervention services. The State Board, DMHDD, and DORS collect detailed information from providers on individual children who receive early intervention services. DORS maintains information on the Home Services and Lekotek programs. DMHDD keeps information on Program 33. The State Board maintains information for Part H only.

Part H providers report to the State Board on data collection forms that contain demographic information, assessment scores, medical diagnosis, service location, and services provided. State Board staff enter the information into a computer system which provides annual reports on the number of children receiving Part H services.

The State Board's data collection system does not identify the number of children in need of services, the costs per service, or the amount spent per child. This information would help in analyzing the costs of early intervention services and would be useful in planning and estimating the potential costs of a comprehensive early intervention system. Also, there are few controls over the accuracy of the data in the computer system. The forms are visually checked and an edit program is run, but these controls only catch obvious errors. The data is self-reported by each provider and no on-site verifications are done of the numbers reported.

Timetables for the Availability of Services

Under Component 2, Illinois has developed timetables to ensure services are available to all eligible infants and toddlers before beginning the fifth year of participation in the system. However, services are not available to all eligible infants and toddlers in the State at this time.

The federal law states that "timetables for ensuring that appropriate early intervention services will be available to all infants and toddlers with disabilities in the State, ... before the beginning of the fifth year of a State's participation" (20 U.S.C. 1476). However, there were local councils in only 20 local service areas of the State as of June 1992. Seventeen of the local councils were created about one year ago; not all are fully functioning. State Board is in the process of developing a Request For Contracts to create at least 20 additional local councils. Further, until December 1992, only 27 providers received Part H funds. At that time, the State Board added 29 additional providers to the Part H program. Exhibit 9 shows the location of the existing local councils.

Council Chairperson

The federal law was reauthorized by Congress in 1991. During this process, a provision was added requiring the Governor to appoint up to 25 members to the State Interagency Coordinating Council.

The federal law also requires the Governor to appoint a Council chairperson who is not a representative of the lead agency. Illinois' Council is chaired by a representative of the State Board of Education, which is the lead agency.

IMPLEMENTATION OF STATE LAW

The Early Intervention Services System Act (325 ILCS 20/1 *et seq*; formerly Ill.Rev.Stat.1991, ch. 23 par. 4151 *et seq*), effective September 1991, is designed to provide for a comprehensive, coordinated, interagency, interdisciplinary early intervention system for eligible infants and toddlers. Specific provisions of the Act include: establishing rules and regulations for the system, receiving the Governor's approval of long-range plans, and completing individualized family service plans for children within the time specified.

The Act includes the required 14 system components listed in the federal law. In addition, the Act also requires a system of evaluation and compliance with program standards. Program standards are not currently in effect statewide. Preliminary standards are being tested at the three pilot sites. The Council will review these standards. Once the Council adopts standards for the entire State, it will be possible to evaluate the standards and progress toward meeting them.

State's Five-Year Plan

The Early Intervention Services System Act required the State Board to develop a five-year plan for implementing the statewide early intervention system. The plan sets the tasks to be accomplished every year through the fifth year (FY 1996), when the system is to be fully in place.

We reviewed the five-year plan and related documentation to determine if the items listed for Year 1 were completed within the time specified (September 1991 - June 1992). The plan lists 29 activities which were to be completed or initiated during the first year. The following items were completed or scheduled during the first year: appointed lead agency;

developed Part H budget; prepared applications for federal funds; issued a report to the U.S. Department of Education on the number of children receiving Part H services; designated local community areas; planned for preservice, inservice, and training programs; expanded the Early Intervention Clearinghouse, Central Directory, Public Awareness, Evaluation, and Inservice Development activities; developed strategies and procedures to resolve local disputes, and created plans to ensure family participation.

Of those 29 items, 9 were not completed and 5 were not initiated by the end of the first year (June 1992). Most of the items completed as scheduled related to general administrative and oversight activities. The following items were not completed by the end of the first year:

Appoint liaison from Governor's office to work with the Lead Agency and Council - The liaison's role is to work with the Council and State Board. According to a State Board official, a liaison has not been appointed by the Governor.

Prepare and submit a report on accomplishments and revisions to the five-year plan and have the Governor certify the completeness of the tasks - The list of accomplishments from the first year has not been submitted to the Governor.

Define and finalize eligibility for early intervention services - The Council developed definitions for children with identified delays and with high probability of delay. At-risk conditions, which were developed in July 1991, have not been formally adopted by the Council. The State Act provides that children will be provided services in Illinois to the extent that funds are appropriated (325 ILCS 20/14; formerly Ill.Rev.Stat.1991, ch. 23, par. 4164). A State Board official stated that at-risk children would be served by the system in the fourth or fifth year (1995 or 1996).

Conduct local needs assessment and submit report to Council and Lead Agency - A State Board official said a formal needs assessment was not conducted during the first year. The official said the State Board has hired a consultant to assist local councils in conducting needs assessments for their areas.

Develop statewide funding plan for local councils in all local community areas - The Council and State Board have not developed a funding plan for local councils.

Develop rules and regulations for early intervention services - Agencies are to develop consistent rules and regulations for the early intervention program. This process has just begun and a State Board official estimated that the rules could take up to two years to be fully implemented.

Finalize and approve a plan to ensure availability and accessibility of diagnostic services in all local community areas - The three pilot sites have diagnostic services

in their areas. The State Board recently developed a Request For Contracts to coordinate diagnostic services throughout the State.

Develop a comprehensive financing strategy and policy including funding and fiscal management - A formal financing strategy has not been developed. A consultant was hired to develop a strategic plan and address financial issues.

Develop specific State interagency agreements defining financial responsibility of each agency and all additional components - The Council developed an interagency agreement, but the agreement does not assign financial responsibility to each agency.

Department of Mental Health and Developmental Disabilities Response:

DMHDD would be open to discussion on changing the interagency agreement to include steps toward defining financial responsibility such as scope of populations served by state agencies.

Establish and develop responsibilities of Resource Review Committee on the use of public and private sector resources and prepare an annual report for the Council - The Resource Review Committee has not been developed. A State Board official said the agency hired a consultant to assist in the financial areas of the early intervention system. The consultant will address this issue during the financial review.

Develop and implement personnel development activities - The Council adopted standards only in the pilot sites. A State Board official said the standards are being tested at the pilot sites to ensure they can be implemented statewide.

Coordinate the administration, supervision and monitoring of funded programs by participating State agencies - State Board has not monitored the Part H providers on site since 1990.

Individualized Family Service Plans

Both the federal and State laws require children in the system to receive an Individualized Family Service Plan (IFSP) which describes their diagnosis and treatment plan. Additionally, the IFSP is designed to include the child's parents as a member of the care team.

In our site visits at the pilot sites, we identified problems with IFSP preparation. Public Act 87-680 (325 ILCS 20/11; formerly Ill.Rev.Stat.1991, ch. 23 par. 4161) requires that an initial evaluation, assessment, and plan meeting must be held within 45 days of the first contact with the early intervention system. State Board officials consider the 45 day

"countdown" to begin when the parents sign a consent form or there is a signed referral. With this definition, providers at all three pilot sites did not meet that requirement. Of 80 cases reviewed, 46 cases contained IFSPs that were not completed within the 45 day requirement and 8 cases had no IFSP in the file. The time taken to complete the IFSP ranged from 0 to 729 days.

An additional problem is that some providers have waiting lists of up to 12 months for some services. With these waiting lists, some providers are not in compliance with the State Act. A State Board official said that the lack of funding is prohibiting providers from meeting the 45 day requirement.

Interagency Agreement

Both the federal and State laws require that agencies involved in the Council cooperate through interagency agreements that define the responsibilities of each agency in paying for services and in resolving disputes. The Council developed one agreement for the State Board and the Departments of Alcoholism and Substance Abuse, Rehabilitation Services, Children and Family Services, Mental Health and Developmental Disabilities, Public Aid, and Public Health. There is a separate Memorandum of Understanding with the University of Illinois - Division of Specialized Care for Children and a separate, special agreement with the Illinois Planning Council on Developmental Disabilities. The Department of Insurance, which became part of the Interagency Council on July 1, 1992, will be asked to sign a Memorandum of Understanding.

The standard interagency agreement states that the agencies will continue to participate in the Council, coordinate budget requests, and take part in dispute resolutions. It does not specify the roles and responsibilities of each agency.

Additionally, the agreement does not "define the financial responsibility of each agency for paying for services" as required in State law (325 ILCS 20/5; formerly Ill.Rev.Stat.1991, ch. 23, par. 4155). The agreement's section on the financial responsibility does not assign specific financial responsibilities to each agency.

Rules and Regulations

The Early Intervention Services System Act, adopted on September 23, 1991, required the State Board to develop rules and regulations within one year of the Act (325 ILCS 20/8; formerly Ill.Rev.Stat.1991, ch. 23, par. 4158). The first meeting for developing rules was in the Summer of 1992. State Board officials said they want to develop a single set of rules for the system, rather than have each agency make its own rules. However, they did not develop rules within the first year. An official estimated that it could take up to two years before rules are implemented.

Another issue has emerged over proposed rules for early intervention. DMHDD has proposed a set of rules that will allow it to capture Medicaid rehabilitation dollars for early intervention services and to have early intervention providers become Medicaid certified. These rules are separate from those being developed by the Council. DMHDD's rules would allow the State to capture more Medicaid funds from the federal government.

Department of Mental Health and Developmental Disabilities Response:

P.L. 87-680 allows: state agencies which directly or indirectly provides or administers early intervention services shall adopt compatible rules for the provision of services to eligible infants and toddlers and their families within one year of the effective date of this Act.

Local representatives told us that they are concerned about the effect of the DMHDD rules on their services. Some providers currently charge families fees for services rendered. Medicaid will reimburse providers for specified amounts for services; these specified amounts may be less than the fees providers charge. Providers are prohibited from charging families the difference between Medicaid's specified amount and the provider fee charged.

Another issue concerns whether Medicaid reimbursement funds would be returned to the individual providers. A provider in one of the pilot sites stated that DMHDD has indicated that these Medicaid funds will be used to create and furnish early intervention services in Illinois counties that do not currently have any services. However, DMHDD officials stated that the funds will be returned to providers.

DMHDD's proposed rules could affect all providers of early intervention services. A State Board official stated that eventually all providers will be required to be Medicaid certified in order to receive Part H funding. The official explained that since Part H is the payor of last resort, providers need to be Medicaid certified to maximize reimbursements.

A State Board official said DMHDD proposed Rule 121 (general provisions for early intervention) would be compatible with the rules promulgated for the system. However, if two sets of incompatible rules are developed, it could affect the State Act on a broader level. One of the goals of Public Act 87-680 was to create a system that was efficient and responsive to children and family needs. Administrative issues and service coordination could be affected if duplicate or conflicting rules are developed for the system.

RECOMMENDATION NUMBERS 1 - 6

To fully implement the Illinois Early Intervention System, the Illinois State Board of Education, as lead agency of the Illinois Interagency Council on Early Intervention, should:

- 1. Ensure that compatible rules are adopted as required by the Illinois Early Intervention Services System Act.**

State Board Response:

We agree with this recommendation. The Council is currently developing such rules, which are expected to be finalized by the beginning of 1994. All agencies represented in the Council have agreed that these rules would be compatible with any other rules affecting early intervention services.

- 2. Ensure that all of the components required in the federal law are implemented in Illinois' Early Intervention System.**

State Board Response:

The State Board is now in compliance with items #1, #8, and #13, since the Council, on April 1, 1993, approved the necessary measures to bring Illinois in compliance with those requirements.

As to item #11, the Council has contracted a consultant to review the financial aspects of early intervention in Illinois. After the review is completed, the State Board will encourage the Council and others to consider any action necessary to meet this requirement. (see Appendix G for full response)

- 3. Encourage the Governor to appoint a Council chairperson who is not a representative of the State Board of Education, thereby complying with federal law.**

State Board Response:

The State Board has notified the Governor's Office repeatedly to appoint an independent Council chairperson, and will continue to do so.

4. **Ensure that the provisions of the State's five-year implementation plan are achieved and that it is submitted to the Governor for approval as required by Public Act 87-680.**

State Board Response:

We agree with this recommendation. However, the Council has submitted a report on its first-year accomplishments to the Governor's Office in February 1993, and is awaiting certification. Further, the Council is in the process of developing a plan to monitor Part H providers. On-Site monitoring visits are expected to begin in the fall of 1993.

5. **Ensure that early intervention service providers develop Individualized Family Service Plans within 45 days after contact with the Early Intervention System as required by Public Act 87-680.**

State Board Response:

We agree with this recommendation. The Council offers staff training, technical assistance and additional funding to providers to help them ensure that Individualized Family Service Plans are prepared within the required time period. Additionally, on-site monitoring visits (see the response to the previous recommendation) scheduled to start later this year will help to meet this requirement.

6. **Ensure that the interagency agreement delineates the financial obligations of each agency involved in the Council as required by federal and State laws.**

State Board Response:

We believe that the financial obligations are delineated in the interagency agreement. In this document each agency committed itself to "demonstrate its best effort to maintain current funding levels and staff...". The State Board as lead agency will review the need to make these commitments more specific and encourage the Council to refine them further outside the agreement.

CHAPTER FOUR EFFECTIVENESS

Neither the Council nor State agencies collect the information necessary to evaluate the early intervention services system in Illinois. Most agencies did not keep information on the number of children eligible for services or the number actually served. Using the Council's methodology, we estimated that about 35,000 children with actual developmental delays and an additional 24,000 at-risk children are currently eligible for early intervention services in Illinois. Providers reported serving 9,126 (26%) of the children with actual delays and 3,681 (15%) of the at-risk children.

The Council and State agencies do not collect adequate information on the cost of services. The Council estimated that the average cost of serving a developmentally delayed child is from \$4,300 to \$7,500, which would make the cost of serving developmentally delayed children in 1992 between \$39 million and \$68 million. If all of the estimated eligible 35,000 were served, the cost would range between \$150 million and \$260 million. Because some eligible children do not participate in the program for the entire three years, the Department of Public Health estimates that no more than 15,000 children would participate in the program at any one time. Thus, Public Health participation estimates would yield an annual program cost for developmentally delayed children of between \$63 million and \$109 million, which is a 60 percent increase in the cost estimated for 1992. The cost of serving at-risk children is not known, but it is assumed to be less than those with actual delays.

EFFECTIVENESS

The State agencies on the Council do not collect the information necessary to analyze the effectiveness of the system. Only the State Board of Education, the Department of Mental Health and Developmental Disabilities (DMHDD), and the Department of Rehabilitation Services (DORS) keep information on the number of children served by early intervention programs that are paid for by agency expenditures. Further, as discussed in Chapter Two, few State agencies record specific expenditures for early intervention. No State agency collects complete information on the number of children that might be eligible for early intervention services in Illinois.

Council Studies

The State Board and the Council have attempted to evaluate the early intervention services provided with Part H funds; however, the studies did not examine the effectiveness of the services. Two studies have been conducted for the Council, one on system development and the other on system costs.

An evaluation of the three pilot implementation sites was conducted by La Rabida Hospital and the University of Chicago Research and Policy Center. The study focused on the process of forming the local community areas and incorporating them into the State system. Its findings centered on encouraging family participation, examining the role of a coordinating advocacy provider, and giving local councils adequate time to develop. The study also found that the existing programs were at or near the saturation level.

The study contained several recommendations concerning statewide development issues, including developing common goals for future local community areas, developing common guidelines for the coordinating advocacy provider, and establishing a technical assistance network. It also recommended that the Council and the State Board establish a permanent committee on evaluation that would recommend internal and external evaluation guidelines, procedures, and processes at both the State and local levels.

In 1990 the State Board contracted with Deloitte & Touche to conduct an early intervention study. The Deloitte & Touche report was a financial analysis of the system, not an evaluation of the system's effectiveness. The report estimated that Illinois would spend between \$51 million and \$121.5 million by the fifth year (full implementation) of early intervention under Part H.

Need to Monitor Child Development

State agencies on the Council do not collect and maintain the information necessary to monitor the effects of early intervention services on infants and toddlers. As mentioned in Chapter Three, the State Board, DMHDD, and DORS collect some information on programs and recipients, but this data is neither uniform nor complete.

Department of Mental Health and Developmental Disabilities Response:

DMHDD early intervention service providers are monitored through audit requirements of Rule 103 (Grants), Chapter 1 Project Grant, and will begin to have certification audits by DMHDD Bureau of Certification and Licensure, once the Illinois Administrative Code Parts 121 and 122 are adopted by JCAR. DMHDD would be available to collaborate with ISBE on monitoring strategies to be used for Part H and other early intervention programs statewide.

State agencies look for different information within their information retrieval systems making the system appear to be neither uniform nor complete. DMHDD would be willing to participate with other state agencies to determine if a uniform system is possible in Illinois.

Information which would be useful in evaluating the effectiveness of services includes the age of children entering programs, exit assessment scores to determine levels of progress, and parental comments. The monitoring of long-term effectiveness could be enhanced by collecting information on assessment tests administered after a child completes early intervention services, and on the number of children entering transition programs for three to five year-olds or school special education programs.

There is some duplication in the information that is currently being collected. Providers expressed concern that a provider who receives funds from both the State Board and DMHDD must complete a substantially similar report for each agency. A coordinated recipient-tracking system could eliminate duplicate reporting.

Department of Mental Health and Developmental Disabilities Response:

DMHDD representatives are willing to collaborate with the lead agency in determining a consistent tracking system to eliminate duplicate reporting.

Of the 32 states we contacted, 7 reported that they evaluated their programs. The evaluations included surveying parents and guardians to determine satisfaction and reviewing individualized family service plans. One state completing an assessment report concluded that early intervention programs reduced the number of persons with delays being placed in State institutions.

RECOMMENDATION NUMBER 7

The State Board of Education, as lead agency of the State Interagency Council on Early Intervention, should identify and collect information necessary to evaluate the effectiveness of the early intervention system in Illinois. In order to obtain the necessary evaluative data, the lead agency should work with the State agencies on the Council to develop uniform reporting requirements. Additionally, the State Board and the Council should examine the feasibility of eliminating duplicate reporting of information by service providers to various agencies on the Council.

State Board Response:

We agree with this recommendation. The State Board will work towards implementation of these issues.

Estimating the Number of Eligible Children

We were unable to obtain definitive information about the incidence of birth defects, developmental disabilities, or delays as compared to the number of live births. None of the organizations we contacted had complete information on the population that might be eligible for early intervention services. We contacted organizations such as the Centers for Disease Control, the National Center for Health Statistics, and the National Office of the March of Dimes.

Two Council documents used a figure of six percent of live births to estimate the number of children with delays that would be eligible for early intervention services. In a report to the General Assembly in 1991, the Joint Committee on Early Intervention used figures based on 180,000 live births per year and estimated that there were approximately 10,800 infants each year who were eligible for early intervention services. This equals 32,400 children from birth to three years of age who meet the definition of developmentally delayed or who have a high probability of developmental delay. In October 1991, the Council Finance Committee used the same figures in its estimate of the number of eligible infants in the birth to 36 month population.

Both reports attributed their estimates to Department of Public Health information on incidence rates for certain birth defects and delays. The Finance Committee estimate was based on information from the Illinois Vital Statistics database and the Adverse Pregnancy Outcomes Reporting System, both maintained by Public Health. The estimate was adjusted for various factors, including the possibility that delays were not apparent at birth.

The six percent of live births, however, includes only those children with identified delays or those with a high probability of delay; it does not include those children at risk of developmental delay. Since Public Act 87-680 includes at-risk children as eligible for services in Illinois, they must be included in estimates of the State's total eligible population. Both reports use the same estimate of children at risk. The figure was 8,000 children per year, or 24,000 children for the three years.

The at-risk diagnosis is made based on clinical judgment and the presence of at least three of the following conditions: family history of developmental disability, victim of child abuse, mother less than 15 years of age, mother less than 11th grade education (unless that

level is appropriate to mother's age), inadequate parenting/caregiving practices, disruption in meeting the child's basic needs, absence of regular professional health maintenance, or growth deficiency and/or nutritional problems. The Council developed this list of at-risk conditions in July 1991, but it has not been formally adopted. The definition finally adopted by the Council could affect the number of at-risk children in the State. For example, if the at-risk designation is allowed with the presence of two or fewer conditions, the number of at-risk children could increase; if the required number of conditions increases, the number of at-risk children could decrease.

The methodology used in both reports for estimating the number of infants and toddlers eligible for services in Illinois is limited: it does not account for varying birth rates or averaging the figures over the three year period. Despite these limitations, there was little information available from State agencies to use in estimating the numbers of eligible infants and toddlers. Therefore, we used the same methodology in estimating the eligible children for 1990 and 1991.

Exhibit 11 shows the estimates contained in the two Council reports for 1988 as a base year. An official at the Centers for Disease Control said the incident rates of birth defects do not change significantly over time. Thus, we estimated the numbers of eligible children for 1990 and 1991, the two most recent years for which live birth figures were available. These figures are also shown in the exhibit.

Exhibit 11				
ESTIMATE OF THE NUMBER OF CHILDREN ELIGIBLE FOR SERVICES IN ILLINOIS				
Year	Number Live Births	Children w/delays	At-Risk Children	TOTAL
1988	180,000	32,400	+ 24,000 =	56,400
1990	196,000	35,280	+ 24,000 =	59,280
1991	194,000	34,920	+ 24,000 =	58,920

Note: 1988 figures are used as a base estimate for comparison.

Source: OAG analysis of information supplied by the State Board of Education and the National Center for Health Statistics

State Board officials suggested two methods to estimate the number of children at risk. The first method was to use a formula based on the number of 3 and 4 year-olds to estimate the number of children at risk of academic failure; however, this method would not provide an estimate of at-risk children in the birth to 36 month age group. The State Board also suggested using numbers developed by a children's advocacy organization called Voices for Illinois Children; however, their estimates were not based on children from birth to 36 months and much of their data were already available from the Illinois Department of Public

Health. For these reasons, we use the 8,000 per year figure the Council used in its two previous reports.

As shown in Exhibit 11, an estimated 34,920 children would be developmentally delayed or have a high probability of delay based on 1991 live birth data. Adding the 24,000 estimated at-risk children yields a total of 58,920 children eligible for early intervention services in Illinois in 1991.

A member of the Council Finance Committee and State Board program staff agreed with our estimate of children with actual identified delays. They stated, however, that the number needed to be adjusted to account for children who would not participate during the three year period of eligibility. Based on its work with other states, the National Early Childhood Technical Assistance System estimated the number of eligible children can be reduced by 25 percent; this adjustment accounts for children who are not identified as delayed by their third birthday and children whose families choose not to participate in the program.

Further, not all children will enter early intervention services right away. Based on a sample of cases submitted to the State Board from June 1990 to December 1991, children entered programs at an average age of 16 months; a child entering at that age would have a maximum of 20 months of participation in the program. Thus, the numbers could be further adjusted to obtain the number of children who might actually participate in services. Exhibit 12 shows the adjusted estimate of 14,666 that might receive services as opposed to the 34,920 that were eligible in 1991.

Number of Children Served

We could not determine the total number of children and families served in Fiscal Years 1991 or 1992 because all the agencies on the Council did not collect this information. Only three agencies (State Board, DMHDD, and DORS) kept figures specifically for the birth to 36 month population.

DMHDD, the largest single funding source for early intervention services, requires providers receiving early intervention (Program 33) grants to submit demographic data on each child served, units of service provided, and the cost of each unit of service. DMHDD

Year	Delayed Estimate	Adjusted TOTAL
1988	32,400	13,608
1990	35,280	14,818
1991	34,920	14,666

Note: 1988 data used as base-year estimate for comparison.

Source: OAG analysis of Public Health data

reported serving 7,669 children in Fiscal Year 1991 through its State-funded early intervention grant program and 6,347 children in Fiscal Year 1992.

Department of Mental Health and Developmental Disabilities Response:

The Department did not view this statement as a negative reflection to services delivery. However, I did want to state the differences in numbers between the fiscal years could be the result of inaccurate data processes or because of the lack of a "cost of living adjustment" (COLA) in the past three fiscal years, providers may have reduced the number of children served and/or the intensity of service(s).

The State Board also requires Part H grant recipients to submit information on each child. When a child enters a program that provides services, the provider must submit a form that describes the child's assessment score and demographic information on the child and family. When the child leaves early intervention services, the provider must submit another form that describes the types of services provided, the frequency of services, and when the services ended. Additionally, all providers must submit quarterly reports that contain the number of children served each quarter, the number of children who entered and exited the program each quarter, and the number of children receiving each type of service that quarter. No data or reports on Part H existed at the State Board prior to 1990 because no staff were assigned to the data collection tasks.

The State Board, in its annual data report to the U.S. Department of Education, reported in February 1991, 1,164 children received services, with 569 on waiting lists. In February 1992, State Board reported 1,394 children served, with 494 on waiting lists.

DORS also collects information on children receiving services under two of its programs. For the Home Services Program, DORS reported that it served 191 children in Fiscal Year 1991 and 260 for 1992. In the Lekotek sites, 645 children were served in Fiscal Year 1992; the 1991 figure was not available.

Exhibit 13 shows the number of children that each agency reported serving in Fiscal Years 1991 and 1992.

Exhibit 13 NUMBER OF CHILDREN SERVED BY STATE AGENCIES		
AGENCY	FY 1991	FY 1992
DMHDD Program 33	7,669	6,347
State Board Part H	1,164	1,394
DORS Home Services	191	260
Lekotek	N/A	645
N/A - Not available		
Source: Data from the State Board of Education, DMHDD, DORS		

However, the numbers cannot be totalled because children might be counted in more than one program. In its financial analysis of the early intervention system in 1990, Deloitte & Touche estimated that about 8,500 children were served in Fiscal Year 1989. Deloitte & Touche based this estimate on agency data and on their experience with programs in other states.

Our survey of providers in the State asked them to identify the numbers of children and families served during Fiscal Years 1991 and 1992. The providers reported that they served 11,756 children from 9,991 families in 1991 and 12,807 children from 11,077 families in 1992.

In our survey of other states, the responses ranged from Vermont, which reported serving 120 of an eligible 750 children, to Florida, which served 30,000 of an eligible population of 48,000.

Potential Costs

Our potential cost estimates are based on two previous studies funded or conducted by the Council. The Deloitte & Touche study used 1989 information and projected an average cost per child of \$4,287 for 1991 for children with delays. The Council's Finance Committee used 1991 Medicaid reimbursement rates and estimated an average cost per child of \$7,452. Because no other complete cost information was available, we used the two existing estimates to show a range of potential costs.

Exhibit 14		
FY 1992 ESTIMATED COSTS IN ILLINOIS		
Delayed Children Served	At \$4,287 Per Child	At \$7,452 Per Child
9,126	\$39,123,162	\$68,006,952

Source: OAG analysis of information from the State Board and a provider survey.

Providers reported serving 12,807 infants and toddlers in Fiscal Year 1992, including 3,681 (15% of the 24,000 estimate) infants and toddlers considered to be at risk of developmental delay. Assuming that no child received services from more than one provider, 9,126 children with actual developmental delays (26% of the 35,000 estimated) were served in Fiscal Year 1992. Using the cost estimates developed by Deloitte & Touche and the Council Finance Committee, serving children with developmental delays in Illinois would have cost between \$39 million and \$68 million in Fiscal Year 1992. Data were not available to estimate how much of the total cost would be paid by State or federal funds.

Exhibit 15 shows a range of potential total costs for 1991 from nearly \$150 million to over \$260 million. These estimates used the total number of children eligible (excluding at-

risk children), not the adjusted figures. Using the adjusted figures, we calculated costs of almost \$63 million to over \$109 million for 1991.

The potential costs of serving the children at risk of developmental delay is not known. There were figures for this population in the Finance Committee report from October 1991, but the State Board believed those figures were not reliable. They were based on results of 18 cases out of 221, which, in our judgment, is a sample too small to project to the universe. It is assumed, however, that the costs of serving an at-risk child would be less than serving a child with a diagnosed delay because the at-risk child would require fewer, less intensive services.

**Exhibit 15
POTENTIAL COSTS FOR CHILDREN WITH DELAYS
USING TOTAL AND ADJUSTED FIGURES**

TOTAL POTENTIAL ELIGIBLES

Year	Live Births	Eligible Children	Projected Costs	
			\$4,287 Per Child	\$7,452 Per Child
1988	180,000	32,400	\$138,898,800	\$241,444,800
1990	196,000	35,280	\$151,245,360	\$262,906,560
1991	194,000	34,920	\$149,702,040	\$260,223,840

ADJUSTED FIGURES

Year	Live Births	Eligible Children	Projected Costs	
			(at \$4,287)	(at \$7,452)
1988	180,000	13,608	\$58,337,496	\$101,406,816
1990	196,000	14,818	\$63,524,766	\$110,423,736
1991	194,000	14,666	\$62,873,142	\$109,291,032

Note: 1988 data used as base-year estimate for comparison.
Source: OAG summary of State Board and Public Health data.

Other States Survey

While several other states have estimated the costs of providing early intervention services, few have actually done evaluations or analyses to determine the effectiveness of the services in their states.

We contacted 32 states that are currently receiving Part H funds for early intervention systems. We asked for the number of eligible children in each state, the number receiving services, the amount of funds spent from both state and federal sources, if the state had estimated the cost per child or family, and if the state had ever conducted an evaluation of the early intervention services in the state. A summary of responses is contained in Appendix D.

The estimates of the eligible population ranged from 400 in Wyoming to almost 518,000 in Pennsylvania. The numbers of children receiving services were not as broad, ranging from 120 to 30,000. However, the numbers of children served are not comparable because states reported figures using different state fiscal years and the calendar year. Many reported the child count figure reported to the U.S. Department of Education as of December 1, 1991 or 1992.

Of the 32 states, 15 had estimated the cost per child of providing early intervention services. The estimates ranged from a low of \$2,000 per child in Michigan to a high of \$12,000 per child in North Carolina. Exhibit 16 shows the states and the estimated cost per child for each state.

Similarly, total dollars spent on state early intervention systems varied greatly. Ohio reported spending a total of \$216 million; however, Ohio could not identify the amount of state funds spent.

Florida was second with a reported total of \$132.5 million, of which \$129 million was state funded. Kansas reported the lowest amount of total spending (\$400,000 with no state spending); Vermont was nearly as low at \$411,000, with \$70,000 in state funding. California reported spending over \$97 million, of which \$21 million was Part H funds. Other states included Maryland, which reported spending \$52 million and Hawaii, which reported \$10 million.

We contacted ten states that were in fourth-year extended participation to determine if they would continue Part H participation by applying for fifth year funding. Six states planned to continue participation and three states (Alaska, New Hampshire, and Oregon) were undecided. Florida reported that it had decided not to apply for fifth year Part H funding because of fiscal concerns. However, because Florida had not used Part H funds for direct services, the loss of these funds would not reduce existing services. Oregon and Alaska anticipated a reduction in services if Part H funds were not used, but New Hampshire did not.

**Exhibit 16
STATE ESTIMATES OF
COST PER CHILD**

State	Estimated Cost
Alaska	\$ 3,000
Arizona	\$ 5,000
Connecticut	\$ 4,000 to \$ 5,500
Delaware	\$ 7,800
Florida	\$10,000
Illinois	\$ 4,287 to \$ 7,452
Kansas	\$ 3,500 to \$ 8,000
Maryland	\$ 5,000 to \$ 7,000
Massachusetts	\$ 2,500 to \$ 4,300
Michigan	\$ 2,000
North Carolina	\$ 3,300 to \$12,000
Ohio	\$ 6,000 to \$ 8,000
Oregon	\$ 4,100
Pennsylvania	\$ 2,760
Utah	\$ 3,000
Wisconsin	\$ 3,380

Source: OAG survey of other states

Entitlement Questions

Another issue when considering potential costs is the entitlement to services. The federal law states that services are to be available to all eligible infants and toddlers by the beginning of the fifth year of participation.

The program coordinator to the states at the U.S. Department of Education for Part H stated that no decision on the entitlement question would be made until the law is reauthorized in 1995. Other states are also concerned about this issue, since it could escalate the costs of providing services in the states.

In Illinois, Public Act 87-680 does not contain a specific statement entitling children to early intervention services. The Act states that the system will be implemented in Illinois "as appropriated funds become available." Thus, as long as there is no federal entitlement, there is no additional liability for the State of Illinois. However, should the services be declared an entitlement under federal law, the costs to Illinois could be more than the \$150 million to \$260 million previously estimated due to the eligibility of at-risk children in Illinois.

The federal official also stated that a state could choose not to continue participation in Part H at any time. The state would have to notify the U.S. Department of Education in writing; then the state would no longer receive Part H funds. Therefore, Illinois could continue receiving funds until the services are declared an entitlement and then discontinue participation in Part H.

The loss of Part H funds would not mean eliminating all early intervention services in Illinois. Part H funds are only 22 percent of the identifiable funds spent in Illinois on early intervention. State-funded programs administered by DMHDD and other agencies would still provide services to children and families. Additionally, the State must use all other available sources before spending Part H funds, so any State and other funds must be spent first anyway. Thus, while losing these funds may not be a desirable choice, the other programs and funding sources would continue.

Department of Mental Health and Developmental Disabilities Response:

Should Federal law require entitlement of all early intervention services for all eligible infants and toddlers and their families, DMHDD would require expanded financial support from the executive and legislative branches of government.

Should Part H funds be terminated many programs and families will be effected. To date, Department-supported early intervention programs have been able to enhance early intervention services through Part H. Program 33 has only provided for very modest increases at best in the past year. Within this fiscal year, DMHDD-supported early

intervention providers will also be able to enhance services through the Medicaid Rehabilitation Option.

MATTER FOR CONSIDERATION BY THE GENERAL ASSEMBLY

The General Assembly may wish to consider amending the Illinois Early Intervention Services System Act (325 ILCS 20/4; formerly Ill.Rev.Stat.1991, ch. 23 par. 4154 (b)) to require the Illinois Interagency Council on Early Intervention to include the following information in its annual report to the Governor and General Assembly:

- a. The estimated number of children in Illinois with developmental delays during the reporting year;
- b. The estimated number of children in Illinois who were considered "at risk" of having developmental delays during the reporting year;
- c. The total number of eligible children who received early intervention services in Illinois during the reporting year;
- d. The total amount of State, federal, and other funds spent to provide early intervention services during the reporting year; and
- e. The estimated amount of State, federal, and other funds required to provide early intervention services to all eligible children in Illinois.

This information will be of use in planning, funding, and evaluating Illinois' participation in the federal Part H Early Intervention Program.

State Board Response to "e":

Reporting these costs may be misleading, since the downstream effect of early intervention services is not taken into account, and may create the impression that the reported costs represent all new expenditures. It is reasonable to assume that cost of early intervention services would be at least partially offset by future savings in programs that serve children above age three.

APPENDICES

APPENDIX A

**Illinois' Early Intervention Services System Act
(Section 15)**

Appendix A

**Early Intervention Services System Act
Section 15
(Effective September 23, 1991)**

"§ 15. The Auditor General of the State shall conduct an evaluation of the system established under this Act, in order to evaluate the effectiveness of the system in providing services that enhance the capacities of families throughout Illinois to meet the special needs of their eligible infants and toddlers, and provide a report of the evaluation to the Governor and the General Assembly no later than April 30, 1993." (325 ILCS 20/15; formerly Ill.Rev.Stat.1991, ch. 23, par. 4165)

APPENDIX B

Methodology

APPENDIX B AUDIT METHODOLOGY

METHODOLOGY FOR ESTIMATING THE NUMBER OF ELIGIBLE CHILDREN

During the course of the audit we were able to obtain only limited information about the incident of birth defects, developmental disabilities, or delays compared to the number of live births. We contacted the National Center for Health Statistics, the Centers for Disease Control (CDC), the United States Department of Education, the National Foundation of the March of Dimes, the National Early Childhood Technical Assistance Service (NEC*TAS), and the Illinois Department of Public Health. None of these groups collected these statistics. The Illinois Department of Public Health collects birth defect information from hospitals through its Adverse Pregnancy Outcome Reporting System (APORS). APORS data, however, only contains information recorded at an infant's discharge. Problems or conditions that manifest after discharge are not registered. This leads to under-reporting of birth defects in the State. Further, the most recent published data available from APORS for birth defects is 1989. The CDC collects data on birth defects, but their data represents only 35 percent of births in the country. The CDC also does not collect nationwide data on developmental delays. We were, however, able to determine the incidence of some birth defects such as spina bifida, cleft palate, and others using the *Birth Defects Compendium*. According to a geneticist at Children's Memorial Hospital in Chicago, roughly 10 percent of live births have some kind of birth defect or developmental delay.

In a report to the General Assembly, the Joint Committee on Early Intervention (Joint Committee) used figures attributed to the Illinois Department of Public Health on the incidence in the population of certain birth defects and delays. Those figures were based on 180,000 live births per year and estimated that there were approximately 10,800 infants each year who were eligible for early intervention services. This equates to 32,400 children from birth to 3 years of age that meet the definition of developmentally delayed or with a high probability of developmental delay. They estimated that another 8,000 infants per year (and a total of 24,000 for the birth to 3 age classifications) are considered "at risk," making the total number of eligible children that could be served 56,400.

The Finance Committee of the State Interagency Council on Early Intervention (Council) developed a draft report in October 1991 (which was revised in February 1992) that contained estimates of the number of potentially eligible children, both developmentally delayed and at risk. Using the 180,000 live births in 1988, it estimated that 6 percent would

be eligible for services as developmentally delayed. This does not include the at-risk population of children. The 6 percent estimate was based on information from the Illinois Vital Statistics database and APORS, both at the Illinois Department of Public Health. These figures had been adjusted for HIV seroprevalence, controlled substance exposure, and the possibility that delays were not present at birth. Additionally, Vital Statistics figures were adjusted for infants not expected to experience developmental delays based on "best medical professional judgment." This report also presents an estimate for the number of at-risk children in the population. However, due to the small number of at-risk children in their sample (18 of 221) and the fact that programs currently in operation generally give priority to children with more serious disabilities and have little capacity to accept at-risk children, these estimates were limited. Therefore, the at-risk children are under-represented in the population of children sampled from the existing programs. State Board of Education officials have expressed concern that the at-risk estimates are flawed.

We were able to collect live birth figures from the National Center for Health Statistics for 1990 and 1991. Based on the methodology used by the Finance Committee report and opinion from the CDC that incident rates of birth defects do not change over time we used the 6 percent figure for the percentage of live births that would be developmentally delayed. This does not include the at-risk population. Since both the Joint Committee and Finance Committee reports used an at-risk figure of 8,000 children per year and State agencies do not collect data on this population, we included the figure in our estimate of the number of potentially eligible children. Our estimate for the number of potentially eligible infants and toddlers is given below.

EXHIBIT 1
ESTIMATE OF THE NUMBER OF ELIGIBLE CHILDREN

Year	Number of <u>Live Births</u>	Per <u>Year</u>	Children <u>w/Delays</u>	At Risk <u>Children</u>	<u>TOTAL</u>
1988	180,000 x 6% =	10,800 x 3 =	32,400 +	24,000 =	56,400
1990	196,000 x 6% =	11,760 x 3 =	35,280 +	24,000 =	59,280
1991	194,000 x 6% =	11,640 x 3 =	34,920 +	24,000 =	58,920

Number of live births for 1990 and 1991 are rounded.

Source: OAG analysis of information from Council studies and the National Center for Health Statistics

The Illinois Department of Public Health presented the OAG with an estimate of the number of children with delays who will participate in the early intervention program at some point in their first three years of life. A Public Health official agreed with the OAG methodology but indicated that an adjustment needs to be made for the number of children that will never participate in the program. Using information from NEC*TAS, the number of eligible children with delays can be reduced by 25 percent. This percentage is comprised of 15 percent that were not identified as developmentally disabled by their third birthday and an additional 10 percent for children whose families choose not to participate in the program. Public Health also takes the adjustment further under the assumption that a child will not receive services for the entire 36 months. Based on data collected by the Illinois State Board of Education, the Finance Committee estimated that a child enters the program at an average age of 16 months. A Public Health official said that the number eligible should be adjusted by a percentage equating to 20/36 because the annual costs per child figures are based on a full twelve month period. The Public Health estimate information made no mention of the at-risk population. The Illinois State Board of Education has concurred with the estimate submitted by Public Health. Whereas the OAG has attempted to estimate the potential number of eligible infants and toddlers, the Illinois Department of Public Health has attempted to estimate the potential participants. An illustration of the Public Health estimate is given below.

**EXHIBIT 2
ADJUSTED ESTIMATE
CHILDREN WHO MIGHT PARTICIPATE**

Estimate of Children w/Delays	Reduced <u>25%</u>		Duration <u>Rate (20/36)</u>		TOTAL <u>CHILDREN</u>
32,400 x (1988)	75% =	24,300 x	.56 =		13,608
35,280 x (1990)	75% =	26,460 x	.56 =		14,818
34,920 x (1991)	75% =	26,190 x	.56 =		14,666

Source: OAG analysis of Public Health data

METHODOLOGY FOR ESTIMATING POTENTIAL COSTS

To develop a potential cost for early intervention services we examined the prior studies done on the program. In 1990 Deloitte & Touche did a study for the State

Interagency Council that examined the potential costs of the program. Using 1989 information they projected an average cost per child of \$4,287 for 1991 for children with delays. The Council's Finance Committee report, dated October 1991, used then-current medicaid reimbursement rates to estimate an average cost per child of \$7,452. We could not estimate the potential cost of serving at-risk children since there was no reliable data available on services or costs. The range of potential costs for serving children with developmental delays (not including those considered at risk) is illustrated below.

**EXHIBIT 3
ESTIMATE OF POTENTIAL COSTS
FOR CHILDREN WITH DELAYS**

Using Deloitte-Touche Estimate

Year	Live Births	Per Year	Total Children	Cost/Child	Total Cost
1988	180,000	x 6% = 10,800	x 3 = 32,400	x \$4,287	= \$138,898,800
1990	196,000	x 6% = 11,760	x 3 = 35,280	x \$4,287	= \$151,245,360
1991	194,000	x 6% = 11,640	x 3 = 34,920	x \$4,287	= \$149,702,040

Using Finance Committee Estimate

Year	Live Births	Per Year	Total Children	Cost/Child	Total Cost
1988	180,000	x 6% = 10,800	x 3 = 32,400	x \$7,452	= \$241,444,800
1990	196,000	x 6% = 11,760	x 3 = 35,280	x \$7,452	= \$262,906,560
1991	194,000	x 6% = 11,640	x 3 = 34,920	x \$7,452	= \$260,223,840

Number of live births for 1990 and 1991 are rounded.

Source: OAG summary of data from the State Board and the National Center for Health Statistics.

PILOT SITE TESTING

For survey and fieldwork testing, we visited the three pilot implementation sites established by the State Board of Education in 1991. These sites were chosen because they had been operating for over a year and the 17 new local councils had just been created in June 1992.

We visited at least one provider at each pilot site. These providers were Children's Development Center in Rockford, the Developmental Diagnostic and Treatment Center at Illinois Masonic Medical Center in Chicago, Archway Inc. in Carbondale, and the Delta Center in Cairo. At each of these providers, we selected a sample of case files.

First we determined the number of case files available. Then we used a random number table to pick the starting point for selecting the sample, calculated the sampling interval based on the number of cases, and systematically selected the 20 cases at each provider. A total of 80 cases was selected for review.

We requested further information on each case from three providers: Archway, Delta Center, and Children's Development Center. We asked for information on whether the case was open or closed, the entry and exit assessment scores, diagnosis, and brief treatment description. The Developmental Diagnostic Center only had open cases in the sample we tested; therefore no additional information on those cases was requested. Of the 60 cases at the three remaining providers we found that:

- 57 percent (34 of 60) were active cases,
- 8 percent (5 of 60) of the cases were closed due to a family move,
- 28 percent (17 of 60) of the cases were closed due to the child aging out,
- 3 percent (2 of 60) of the cases were closed due to goals being met, and
- 3 percent (2 of 60) of the cases were classified as closed due to parent request or the child being placed in a foster home.

SURVEY OF STATE SERVICE PROVIDERS

During the fieldwork phase of the audit we identified and surveyed 99 providers of early intervention services throughout Illinois. We compiled a listing of service providers from master lists provided by three sources: the Illinois Department of Children and Family Services, Direction Services, Inc., and the Illinois Department of Mental Health and Developmental Disabilities. These lists were verified, combined, and survey questionnaires were distributed to the providers. For a complete listing of providers and results of the survey see Appendix C.

SURVEY OF OTHER STATES

As part of this audit we conducted a survey of 32 other states' early intervention programs. The survey was divided into three sections. The first section gathered data on midwestern states, regardless of what year of participation in the Part H program they were

currently implementing. These states were selected due to the geographic proximity to Illinois. The second section of the survey involved states that were in their fifth year of Part H implementation as identified by the United States Department of Education. These states were selected because they have a fully implemented early intervention services system and presented the potential for an evaluative review. The third section of the survey examined states that were in their second year of extended participation in the Part H program (again as identified by the U.S. Department of Education). These states were selected to determine if they were going to continue participation in Part H in the coming fiscal year, to identify problems encountered with the step towards full implementation, and to identify if any evaluations were conducted that would provide a means of comparison with the program in Illinois. A listing of the states contacted under the three scenarios is provided below.

**Midwestern
States**

Indiana
Iowa
Kentucky
Michigan
Minnesota
Missouri
Ohio
Wisconsin

**Fifth Year
States**

Arkansas
Colorado
Hawaii
Idaho
Kansas
Maryland
Massachusetts
North Carolina
Oklahoma
Pennsylvania
Tennessee
Utah
West Virginia
Wyoming

**Extended
Participation
States**

Alaska
Arizona
California
Connecticut
Delaware
Florida
Mississippi
New Hampshire
Oregon
Vermont

APPENDIX C

Provider Survey Summary

APPENDIX C
PROVIDER SURVEY RESULTS

Provider	Early Intervention Funding Spent		Family Charges for Services		Children and Families Receiving Services						Services Provided						
	Total FY91 Spent	Total FY92 Spent	FY91	FY92	Total	FY91		FY92		FY91		FY92		FY91		FY92	
						Children	Families	Children	Families	Children	Families	Children	Families				
Abilities Plus, Inc.	\$46,080	\$44,224	N/A	N/A	N/A	71	67	86	80	X	X	X	X	X	X	X	X
Abraham Lincoln Center	\$265,625	\$271,730	\$0	\$0	\$0	138	N/P	138	N/P	X	X	X	X	X	X	X	X
Ada McKinley Comm. Services	\$189,535	\$183,660	\$0	\$0	\$0	N/P	141	N/P	152	X	X	X	X	X	X	X	X
ARC Comm. Support Systems	\$102,134	\$108,515	\$980	\$832	\$1,812	60	60	62	62	X	X	X	X	X	X	X	X
ARC Springfield	\$123,524	\$128,613	\$0	\$0	\$0	60	60	61	61	X	X	X	X	X	X	X	X
Archway, Inc.	\$266,191	\$322,921	\$0	\$0	\$0	60	60	60	60	X	X	X	X	X	X	X	X
Asn. for Individual Dev.	\$379,524	\$402,407	N/A	N/A	N/A	256	N/P	244	N/P	X	X	X	X	X	X	X	X
Blue Cap Infant-Parent Center	\$244,458	\$258,133	\$2,739	\$4,887	\$7,626	67	64	64	62	X	X	X	X	X	X	X	X
Career Development Center	\$91,479	\$71,378	\$0	\$0	\$0	52	52	61	61	X	X	X	X	X	X	X	X
Case County Mental Health	\$42,509	\$45,728	\$0	\$0	\$0	12	10	13	6	X	X	X	X	X	X	X	X
Chicago ARC	\$865,404	\$863,897	\$0	\$0	\$0	143	143	172	172	X	X	X	X	X	X	X	X
Chicago Lighthouse for Blind	\$148,132	\$188,451	\$1,168	\$224	\$1,392	125	123	127	125	X	X	X	X	X	X	X	X
Chicago Public School-Dist 299	\$92,715	\$92,715	\$0	\$0	\$0	259	259	346	346	X	X	X	X	X	X	X	X
Chicago Urban Day School	\$753,157	\$766,620	N/A	N/A	N/A	11	11	9	9	X	X	X	X	X	X	X	X
Childrens Dev. Center	\$828,950	\$1,019,264	\$26,000	\$34,930	\$60,930	270	N/P	322	N/P	X	X	X	X	X	X	X	X
Childrens Home Asn. of IL	\$150,000	\$150,000	\$0	\$0	\$0	167	64	180	66	X	X	X	X	X	X	X	X
Cleabrook Center	\$224,005	\$254,314	\$36,773	\$37,670	\$73,443	75	75	74	74	X	X	X	X	X	X	X	X
Clinton Co. Rehab Center	\$112,135	\$112,998	N/A	N/A	N/A	61	61	70	66	X	X	X	X	X	X	X	X
Coleman Tri-County	\$264,893	\$268,377	\$0	\$0	\$0	104	104	108	108	X	X	X	X	X	X	X	X
Coles County ARC (CCAR)	\$276,142	\$300,820	N/A	N/A	N/A	139	139	141	141	X	X	X	X	X	X	X	X
Community Counseling Center	\$193,555	\$200,362	\$0	\$0	\$0	150	130	160	135	X	X	X	X	X	X	X	X
Cook County Hospital	\$421,745	\$424,815	N/A	N/A	N/A	2081	2040	2198	2160	X	X	X	X	X	X	X	X
Counseling Center of Pike Co.	\$23,648	\$23,846	\$0	\$0	\$0	45	41	36	33	X	X	X	X	X	X	X	X
Crosspoint Human Services	\$153,412	\$158,870	N/A	N/A	N/A	120	120	137	137	X	X	X	X	X	X	X	X
DeKalb Co. Spec. Ed. Asn.	\$35,176	\$33,097	N/A	N/A	N/A	30	28	21	20	X	X	X	X	X	X	X	X
Delta Center	N/P	N/P	\$0	\$0	\$0	52	50	73	70	X	X	X	X	X	X	X	X
Developmental Services Center	\$569,818	\$533,749	N/A	N/A	N/A	345	335	392	379	X	X	X	X	X	X	X	X
DeWitt Co. Human Res. Center	\$59,669	\$49,664	N/A	N/A	N/A	27	30	30	30	X	X	X	X	X	X	X	X
Easter Seal Society	Did Not Respond	Did Not Respond	Did Not Respond	Did Not Respond	Did Not Respond												
El Valor Corporation	Did Not Respond	Did Not Respond	Did Not Respond	Did Not Respond	Did Not Respond												
Esperanza Comm. Services	\$73,529	\$79,113	\$0	\$0	\$0	36	34	40	36	X	X	X	X	X	X	X	X
FAYCO Enterprises, Inc.	\$65,258	\$65,084	\$0	\$0	\$0	25	25	31	31	X	X	X	X	X	X	X	X
Franklin-Williamson Human Ser.	\$177,431	\$185,092	\$360	\$0	\$360	64	64	72	72	X	X	X	X	X	X	X	X
Fulton County Rehab Center	\$79,001	\$106,477	\$0	\$0	\$0	60	59	63	61	X	X	X	X	X	X	X	X
Gateway Services, Inc.	\$28,876	\$37,968	\$0	\$0	\$0	48	40	48	38	X	X	X	X	X	X	X	X
Glentrik ARC	\$56,373	\$54,058	\$4,286	\$2,234	\$6,520	62	62	66	66	X	X	X	X	X	X	X	X
Good Shepherd Center	\$308,835	\$304,511	\$0	\$0	\$0	50	50	54	54	X	X	X	X	X	X	X	X
Habilitative Systems, Inc.	\$210,187	\$191,114	N/P	N/P	N/P	80	N/P	109	N/P	X	X	X	X	X	X	X	X
Helping Hand Rehab Center	\$244,508	\$287,016	\$0	\$0	\$0	70	70	64	64	X	X	X	X	X	X	X	X
Hoopston Migrant-Headstart	\$223,640	\$242,495	N/A	N/A	N/A	86	68	102	75	X	X	X	X	X	X	X	X
IL Masonic Diag/Treat Center	\$91,000	\$148,000	N/P	N/P	N/P	40	40	45	45	X	X	X	X	X	X	X	X
Institute for study of DD	\$81,912	\$162,239	\$0	\$0	\$0	80	80	89	87	X	X	X	X	X	X	X	X
Iroquois ARC	\$87,463	\$86,806	\$275	\$251	\$526	43	37	62	58	X	X	X	X	X	X	X	X
Jacksonville ARC	\$73,994	\$93,020	N/A	N/A	N/A	65	63	58	56	X	X	X	X	X	X	X	X
Jayne Shover Easter Seals	\$278,167	\$329,216	\$9,034	\$5,944	\$14,978	450	446	513	510	X	X	X	X	X	X	X	X
Jefferson Co. Comp. Services	\$85,789	\$90,005	N/A	N/A	N/A	37	32	39	36	X	X	X	X	X	X	X	X
Jo Daviess Workshop, Inc.	\$23,943	\$29,713	\$0	\$0	\$0	11	11	10	10	X	X	X	X	X	X	X	X
Kastakia Workshop, Inc.	\$54,590	\$60,272	\$0	\$0	\$0	56	52	55	51	X	X	X	X	X	X	X	X
Kreider Services	\$73,961	\$87,480	N/A	N/A	N/A	39	37	44	41	X	X	X	X	X	X	X	X
La Rabida Children's Hospital	\$270,566	\$266,468	\$0	\$0	\$0	234	234	250	250	X	X	X	X	X	X	X	X
Lake-McHenry Reg Prog (SEDOJ)	\$890,116	\$991,556	\$0	\$0	\$0	929	916	1069	1040	X	X	X	X	X	X	X	X
LaSalle County Easter Seals	\$112,823	\$137,197	\$864	\$1,154	\$2,038	99	99	116	116	X	X	X	X	X	X	X	X
Little Friends, Inc.	\$143,110	\$160,686	\$23,161	\$24,372	\$47,533	58	58	73	73	X	X	X	X	X	X	X	X

APPENDIX C
PROVIDER SURVEY RESULTS

Provider	Early Intervention Funding Spent		Family Charges for Services		Children and Families Receiving Services			Services Provided																	
	FY91 Spent	Total FY92 Spent	FY91	FY92 Total	FY91 Children	FY91 Families	FY92 Children	FY92 Families	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	
Longview Day Care	\$503,736	\$512,880	\$11,901	\$5,360	120	101	108	90	N/A																
Lutheran General Hospital	\$273,091	\$310,694	N/P	\$2,770	253	237	192	189		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Lutheran Social Services of IL	\$187,666	\$197,601	\$0	\$0	62	62	68	68		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Macon Resources	\$461,756	\$467,155	\$902	\$844	246	232	291	280		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Macoupin County MHC	\$12,583	\$19,268	N/A	N/A	21	18	24	19		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Malcolm Eaton Enterprises	\$216,919	\$191,665	\$2,500	\$2,372	94	92	86	86		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
MARC Center	\$183,645	\$185,821	\$0	\$0	71	71	74	74		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Mason County Health Dept.	\$14,000	\$7,000	N/A	N/A	71	71	N/P	N/P																	
Mau Gio Day Care School	\$158,508	\$172,737	N/A	N/A	25	25	27	N/P		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
McDonough Co. Rehab Center	\$122,830	\$115,989	N/A	N/A	67	62	77	64		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Northwestern University	\$413,089	\$411,828	\$95,914	\$89,612	100	100	100	100		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Oak Leyden Dev. Services	\$176,306	\$162,481	\$20,296	\$2,789	49	49	72	72		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Opportunity Center SE IL, Inc.	\$117,740	\$132,470	\$0	\$0	116	N/P	109	N/P		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Pecola ARC	\$348,672	\$372,209	N/A	N/A	120	115	135	128		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Platt County MHC	\$32,710	\$33,970	\$0	\$0	194	162	177	150		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Pioneer Center	\$598,124	\$697,894	\$0	\$0	283	N/P	320	N/P		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
PrimeCare (Spec. Children)	\$331,139	\$336,723	\$0	\$0	114	109	98	87		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Promise Center	\$241,455	\$281,012	N/A	N/A	62	62	65	65		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Proviso ARC	\$327,249	\$372,536	\$2,429	\$3,101	105	105	130	128		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Ray Graham Association	\$180,028	\$198,008	\$22,244	\$19,989	57	57	70	68		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Rehab Center-Will/Grundy Co.	\$414,405	\$335,909	\$10,634	\$6,923	170	170	220	220		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Rehab Institute	\$105,000	\$95,385	\$0	\$0	42	42	48	48		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Rock Island ARC	Did Not Respond	Did Not Respond																							
Rock River Valley Self Help	\$66,564	\$96,244	\$0	\$0	68	67	72	70		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Salem Children's Home	Did Not Respond	Did Not Respond																							
Schuyler Counsel./Health Cnt.	\$8,827	\$15,284	\$0	\$0	19	15	12	11		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Shore Comm. Services Center	\$41,236	\$45,719	\$2,161	\$2,340	14	14	15	15		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
South Metro Association	\$685,052	\$621,076	\$3,653	\$1,840	364	223	315	193		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
South Suburban School	\$16,836	\$29,008	N/A	N/A	34	34	52	52		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
St. Francis Childrens Hospital	Did Not Respond	Did Not Respond																							
St. Mary's Hospital	N/P	N/P	N/P	N/P	N/P	N/P	41	4																	
SWCCCSE	\$166,029	\$172,804	\$0	\$0	99	90	93	89		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Tazewell Co. Resource Center	\$29,888	\$39,461	N/A	N/A	76	76	93	93		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
U. of Chi.-Woodlawn EIM/lers	N/P	N/P	\$0	\$0	N/P	N/P	N/P	N/P																	
UCP Land of Lincoln	\$150,563	\$247,518	\$0	\$938	483	470	728	700		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
United Cerebral Palsy	\$109,047	\$94,096	\$0	\$0	30	30	32	32		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
United Dev. Services	\$246,175	\$247,857	\$3,223	\$2,054	63	68	53	49		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Wabash Area Dev. (WADI)	Did Not Respond	Did Not Respond																							
Warren Achievement Center	\$181,360	\$199,857	\$0	\$0	205	N/P	204	197		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
William M. BeDell Center	\$254,904	\$282,113	\$0	\$0	119	117	118	118		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
WLU Speech-Lang-Hear Clinic	\$0	\$0	N/P	N/P	N/P	N/P	N/P	N/P																	
WVOVSED	\$144,145	\$145,305	\$0	\$0	28	28	25	25		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
TOTAL	\$18,053,314	\$19,277,422	\$293,015	\$263,227	11,756	9,991	12,807	11,077		30	39	78	20	27	46	31	66	70	29	66	60	62	74	55	27

N/A - Not Applicable
N/P - Not Provided
Services

ARC - Association for Retarded Citizens
MHC - Mental Health Center

SWCCCSE - Southwest Cook County Cooperative Association for Special Education
WVOVSED - Wabash & Ohio Valley Special Education District

1. Assistive technology devices
2. Audiology
3. Family training, counseling, and home visits
4. Necessary health services
5. Medical services (diagnosis/evaluation only)
6. Nursing services
7. Nutrition services
8. Occupational therapy
9. Physical therapy
10. Psychological services
11. Service coordination services
12. Social work services
13. Special Instruction
14. Speech/Language pathology
15. Transportation costs
16. Vision services

SOURCE: OAG survey of early intervention providers.
NOTE: Rock Island ARC responded too late to be included in our analysis. They reported serving 142 children in FY91 and 153 children in FY92 (with no at risk reported).

APPENDIX C
PROVIDER SURVEY RESULTS

Provider	Referral Services		Waiting List/Duration for Services		At Risk Service		Number of Screenings		Team	
	Yes	No	Yes	No	Yes	No	FY91	FY92	Yes	No
Abilities Plus, Inc.	X			X	N/A	N/A	86	69	X	
Abraham Lincoln Center	X			X	N/A	N/A	138	136	X	
Ada McKinley Comm. Services	X		X		10	6 months	N/P	N/P	X	
ARC Comm. Support Systems	N/A			X	N/A	N/A	221	247	X	
ARC Springfield	X			X	N/A	6 months	29	25	X	
Archway, Inc.	X			X	3	2-3 months	102	87	X	
Asn. for Individual Dev.	X			X	N/A	N/A	N/P	250	X	
Blue Cap Infant-Parent Center	X			X	4	5 weeks	25	30	X	
Career Development Center	X			X	N/A	N/A	7	7	X	
Cass County Mental Health	X			X	N/A	N/A	4	1	X	
Chicago ARC	X			X	110	6-9 months	0	0	X	
Chicago Lighthouse for Blind	X			X	10	6 wks.-3 mos.	125	127	X	
Chicago Public School-Dist 289	X			X	N/A	N/A	0	0	X	
Chicago Urban Day School	X			X	5	4-5 months	0	0	X	
Childrens Dev. Center	X			X	46	8-12 weeks	13	12	X	
Childrens Home Assn. of IL	X			X	18	4-6 months	1247	1276	X	
Clearbrook Center	X			X	N/A	N/A	54	66	X	
Clinton Co. Rehab Center	X			X	N/A	N/A	N/P	N/P	X	
Coleman Tri-County	X			X	N/A	N/A	174	263	X	
Coles County ARC (CCAR)	X			X	N/A	N/A	93	120	X	
Community Counseling Center	X			X	N/A	1-2 months	172	330	X	
Cook County Hospital	X			X	20	6-8 weeks	160	160	X	
Counseling Center of Pike Co.	X			X	N/P	4-6 weeks	1082	1082	X	
Crosspoint Human Services	X			X	6	6-8 weeks	17	28	X	
Crosspoint Human Services	X			X	10	3-4 months	35	28	X	
DeKalb Co. Spec. Ed. Assn.	X			X	N/A	N/A	100	100	X	
Della Center	X			X	22	30-60 days	3	3	X	
Developmental Services Center	X			X	6	5 weeks	135	152	X	
DeWitt Co. Human Res. Center	X			X	6	5 weeks	290	248	X	
Easter Seal Society	X			X	N/A	N/A	18	22	X	
El Valor Corporation										
Esperanza Comm. Services	X			X	10	3 months	N/P	N/P	X	
FAYCO Enterprises, Inc.	X			X	2	2-6 months	0	0	X	
Franklin-Williamson Human Ser.	X			X	N/P	6 months-1 year	391	439	X	
Fulton County Rehab Center	X			X	5	2-3 months	67	91	X	
Gateway Services, Inc.	X			X	N/A	N/A	50	71	X	
Glenkirk ARC	X			X	N/A	N/A	60	80	X	
Good Shepherd Center	X			X	N/A	N/A	100	N/P	X	
Habilitative Systems, Inc.	X			X	45	2-4 months	25	28	X	
Helping Hand Rehab Center	X			X	N/P	2 months	80	109	X	
Hoopston Migrant-Headstart	X			X	N/A	N/A	20	78	X	
IL Masonic Diag/Treat Center	X			X	N/A	3-6 months	N/P	510	X	
Institute for study of DD	N/P			X	N/A	6 months	80	100	X	
Iroquois ARC	X			X	N/A	N/A	30%	182	X	
Jacksonville ARC	X			X	N/A	N/A	28	37	X	
Jayne Shover Easter Seals	X			X	40	3 months	100	100	X	
Jefferson Co. Comp. Services	X			X	N/A	N/A	215	268	X	
Jo Daviess Workshop, Inc.	X			X	N/A	N/A	31	37	X	
Kaskaskia Workshop, Inc.	X			X	25	4 months	5	15	X	
Kreider Services	X			X	N/A	N/A	102	216	X	
La Rabida Childrens Hospital	X			X	74	3-4 months	1	0	X	
LaSalle County Easter Seals	X			X	N/P	4 months	445	420	X	
LaSalle County Easter Seals	X			X	N/A	N/A	399	323	X	
Little Friends, Inc.	X			X	0	N/P	210	163	X	

APPENDIX C
PROVIDER SURVEY RESULTS

Provider	Referral Services		Waiting List/Duration for Services		Length of wait on list		At Risk Service		Number of Screenings		Team	
	Yes	No	Yes	No	Number on list (11/1/92)	Length of wait on list	Yes	No	FY91	FY92	Yes	No
Longview Day Care	X				51	11 months	X		N/P	N/P		X
Lutheran General Hospital	X				20	2 months	X		0	0	X	
Lutheran Social Services of IL	X				41	N/P	X		62	66		X
Macon Resources	X				46	11 months	X		214	197		X
Maccoupin County MHC		X			N/A	N/A			15	27		X
Malcolm Eaton Enterprises	X				N/A	N/A	X		157	140		X
MARPC Center	X				N/A	N/A			14	26		X
Mason County Health Dept.	X				N/A	N/A			10	20		X
Mau Gio Day Care School	X				18	3-12 months	X		21	18		X
McDonough Co. Rehab Center	X				N/A	N/A			46	42		X
Northwestern University	X				6	2 months	X		N/P	N/P		X
Oak Leyden Dev. Services	X				23	1-6 months	X		27	45		X
Opportunity Center SE IL, Inc.	X				10	3 months	X		70	76		X
Peoria ARC	X				10	4 months	X		N/P	N/P		X
Platt County MHC	X				4	1-2 months	X		N/P	N/P		X
Pioneer Center	X				0	1-8 months	X		180	170		X
Prime/Care (Spec. Children)	X				20	3-6 months	X		126	139		X
Promise Center	X				24	14-30 days	X		N/P	115		X
Proviso ARC	X				18	2-3 months	X		N/P	16		X
Ray Graham Association	X				N/A	N/A			65	68		X
Rehab Center-Mill/Grundy Co.	X				73	4-6 months	X		35	47		X
Rehab Institute	X				12	3-6 months	X		77	77		X
Rock Island ARC	X				22	2-4 weeks	X		14	16		X
Rock River Valley Self Help	X				22	2-4 weeks	X		51	41		X
Salem Children's Home	X				N/A	N/A			2	1		X
Schuyler Counsel./Health Cnt.	X				2	3 months	X		N/P	32		X
Shore Comm. Services Center	X				37	2-3 months	X		243	274		X
South Metro Association	X				15	N/P	X		N/P	N/P		X
South Suburban School	X											X
St. Francis Childrens Hospital	X				N/A	N/A			0	0		X
St. Mary's Hospital	X				0	1 month	X		64	67		X
SWCCCASE	X				7	6 months	X		6	6		X
Tazewell Co. Resource Center	X				56	2-3 months	X		212	332		X
U. of Chi.-Woodlawn E/Mylers	X				N/A	N/A			211	339		X
UCP Land of Lincoln	X				0	1-3 months	X		30	32		X
United Cerebral Palsy	X				9	3-6 months	X		145	165		X
United Dev. Services	X				80-100							X
Wabash Area Dev. (WADI)	X				11				6	6		X
Warren Achievement Center	X				63	4-6 months	X		157	150		X
William M. BeDell Center	X				N/P	3 months	X		N/P	N/P		X
WU Speech-Lang-Hear Clinic	X				N/P	3-6 months	X		77	192		X
WOVSED	X				25				0	0		X
TOTAL	83	3	52	37	1068		73	14	9,679	11,067	70	18

ARC - Association for Retarded Citizens
MHC - Mental Health Center
SWCCCASE - Southwest Cook County Cooperative Association for Special Education
WOVSED - Wabash & Ohio Valley Special Education District

Figures are rounded.
SOURCE: OAG survey of early intervention providers.
NOTE: Rock Island ARC responded too late to be included in our analysis. They reported serving 142 children in FY91 and 153 children in FY92 (with 130 at risk reported).

APPENDIX D

Other States Survey

APPENDIX D
Results From Survey of Other States
Midwestern States

#	QUESTION	Indiana	Iowa	Kentucky	Michigan
1	Year of Participation	4th Extended	4th Extended	4th Extended	4th Extended
2	State Law on Early Intervention	Yes	Yes	No	No
	"At Risk" Eligibility	Yes	No	N/A	N/A
	Serve "At Risk" in Future	N/A	No (funding)	N/A	N/A
3	# of Services from Federal Law Available	All	All	All	All
4	Eligible Population	10,000	1,000	4,000	300,000
	# Children Receiving Services	2,500	986	1,000	3,000
		Dec. 1991 Count	Special Ed. Figures	State FY92 Data	Dec. 1991 Count
5	Dollars Spent				
	Total	\$ 11,097,000	\$ 1,000,000	\$ 3,545,000	\$ 11,820,000
	Part H State	\$ 1,500,000 (all on adm.) \$ 97,000	\$ 1,000,000 Unknown	\$ 1,045,000 \$ 2,500,000	\$ 2,820,000 \$ 9,000,000
6	Cost Estimate Per Child	No	No	No	Yes \$2,000/yr
7	Family Services	Family Training	Respite Care	Family Coordination	Respite Care
8	Cost Estimate Per Family	No	No	No	No
9	Overall Effectiveness Study	No	No	No	No
10	Lead Agency	Div. of Family & Children	Dept. of Education	Cabinet for Human Resources	Dept. of Education

APPENDIX D
Results From Survey of Other States
Midwestern States

#	QUESTION	Minnesota	Missouri	Ohio	Wisconsin
1	Year of Participation	4th Extended	4th Extended	5th	5th
2	State Law on Early Intervention	Yes	No	Executive Order	Yes
	"At Risk" Eligibility	No	N/A	Yes	No
	Serve "At Risk" in Future	Yes	N/A	N/A	Unknown (funding)
3	# of Services from Federal Law Available	All	All	All	All
4	Eligible Population	200,000	5,000	29,220	5,140
	# Children Receiving Services	2,200	1,323	14,000	4,800
		Dec. 1991 Count	Dec. 1991 Count	Dec. 1991 Count	Calendar Year 1991
5	Dollars Spent				
	Total	\$ 660,000	\$ 4,047,987	\$ 216,000,000	\$ 8,250,000
	Part H	\$ 660,000	\$ 544,000	\$ 3,000,000	\$ 1,500,000
	State	Unknown	\$ 1,103,707	Unknown	\$ 6,000,000
6	Cost Estimate Per Child	No	No	Yes \$6,000 to \$8,000/yr	Yes \$3,380/yr
7	Family Services	Respite Care	Parents as Teachers	Family Info Network	Support Groups
8	Cost Estimate Per Family	No	No	Yes \$6,000 to \$8,000/yr	No
9	Overall Effectiveness Study	No	No	No	No
10	Lead Agency	Dept. of Education	Dept. of Education	Dept. of Health	Dept. of Health & Social Serv.

APPENDIX D
Results From Survey of Other States
Second Year of Extended Participation States

#	QUESTION	Alaska	Arizona	California	Connecticut	Delaware
1	Second Year Of Extended Participation	Yes	Yes	Yes	Yes	Yes
2	State Law on Early Intervention	Yes	Yes	Yes	No	No
	"At Risk" Eligibility	Yes	No	Yes	N/A	N/A
	Serve At Risk in Future	N/A	Yes	N/A	N/A	N/A
3	# of Services from Federal Law Available	All	All	All	All	All
4	Eligible Population	1,940	4,000	18,000	2,100	930
	# Children Receiving Services	1,460	1,300	17,500	1,300	785
		State FY92 Data	Dec. 1991 Count	1992-93 Data	State FY92 Data	Dec. 1991 Count
5	Dollars Spent					
	Total	\$ 1,460,000	\$ 6,000,000	\$ 97,200,000	\$ 2,255,000	\$ 1,210,121
	Part H	\$ 84,000	\$ 1,000,000	\$ 21,000,000	\$ 790,000	\$ 341,396
6	State	\$ 956,000	\$ 5,000,000	\$ 73,900,000	\$ 1,465,000	\$ 868,725
	Cost Estimate Per Child	Yes \$3,000/yr	Yes \$5,000/yr	No	Yes \$4,000 (DOE) to \$5,500/yr (DMH)	Yes \$7,800/yr
	7 Family Services	Respite Care	Parent Groups	Financial Assistance	Respite Care	Parent Info. Center
8	Cost Estimate Per Family	No	No	No	Yes \$4,000 (DOE) to \$5,500/yr (DMH)	Yes \$7,800/yr
9	Overall Effectiveness Study	No	No	Yes Highly Satisfied	No	Yes Contractor Inv. Serv.
10	Apply for Part H Next Fiscal Year	Unknown	Yes	Yes	Yes	Yes
11	Implementation Problems	Fiscal Resources & State Size	Fiscal Resources	Policy Development	System Development	Coord. Services
	Analysis of Costs or Program Data	No	N/A	N/A	N/A	Yes
12	Impact from Loss of Part H	Spread Less Money Over Same Number	N/A	N/A	N/A	N/A
13	Lead Agency	Dept. of Health & Soc. Serv.	Dept. of Economic Security	Education/Develop. Services	Education/Mental Retardation	Dept. of Health & Soc. Serv.

APPENDIX D
Results From Survey of Other States
Second Year of Extended Participation States

#	QUESTION	Florida	Mississippi	New Hampshire	Oregon	Vermont
1	Second Year Of Extended Participation	Yes	Yes	Yes	Yes	Yes
2	State Law on Early Intervention	Yes	Yes	No	Yes	No
	"At Risk" Eligibility	Yes	Yes	N/A	No	N/A
	Serve At Risk in Future	N/A	N/A	N/A	No (funding)	N/A
3	# of Services from Federal Law Available	All	All	All	All	All
4	Eligible Population	48,000	6,100	50,000	1,200	750
	# Children Receiving Services	30,000	400	1,300	1,000	120
		June 1991 Count	Dec. 1991 Count	State FY92 Data	March 1992 Count	Dec. 1991 Count
5	Dollars Spent					
	Total	\$ 132,500,000	\$ 1,030,000	\$ 4,000,000	\$ 6,230,000	\$ 411,000
	Part H	\$ 3,500,000	\$ 30,000	\$ 500,000	\$ 630,000	\$ 341,000
	State	\$ 129,000,000	\$ 1,000,000	\$ 3,500,000	\$ 4,100,000	\$ 70,000
6	Cost Estimate Per Child	Yes \$10,000/yr	No	No	Yes \$4,100/yr	No
7	Family Services	Respite Care	None	Respite Care	None	Service Coordinator
8	Cost Estimate Per Family	Yes \$15,000/yr	No	No	No	No
9	Overall Effectiveness Study	No	No	Yes Good State Program	No	No
10	Apply for Part H Next Fiscal Year	No (budget deficit)	Yes	Unknown	Unknown	Yes
11	Implementation Problems	Consensus on Receivers	Cooperation Among Agencies	Fiscal Problems	Potential Legal Problems	Reluctant Towards Entitlement
	Analysis of Costs or Program Data	No	No	No	No	No
12	Impact from Loss of Part H	Part H Money Not Used For Services	N/A	Little Impact Few Federal Dollars	Reduction in Services	N/A
13	Lead Agency	Dept. of Education	Dept. of Health	Div. Mental Health & Dev. Serv.	Dept. of Education	Dept. of Education

APPENDIX D
Results From Survey of Other States
Fifth Year States

#	QUESTION	Arkansas	Colorado	Hawaii	Idaho	Kansas
1	Fifth Year of Participation	Yes	Yes	Yes	Yes	Yes
2	State Law on Early Intervention	Yes	Yes	Yes	Yes	Yes
	"At Risk" Eligibility	Yes	Yes	Yes	No	No
	Serve "At Risk" in Future	N/A	N/A	N/A	No (funding)	Yes
3	# of Services from Federal Law Available	All	All	All	All	All
4	Eligible Population	6,000	2,900	3,000	1,920	35,000 to 40,000
	# Children Receiving Services	1,500	1,780	3,000	638	1,262
		State FY92 Data	Dec. 1991 Count	Dec. 1991 Count	Dec. 1992 Count	Dec. 1991 Count
5	Dollars Spent					
	Total	\$ 2,007,087	\$ 4,900,000	\$ 10,000,000	\$ 2,872,000	\$ 400,000
	Part H	\$ 459,251	\$ 2,100,000	\$ 572,000	\$ 572,000	\$ 400,000
	State	\$ 1,547,836	\$ 2,800,000	\$ 8,500,000	\$ 2,300,000	\$ 0
6	Cost Estimate Per Child	No	No	No	No	Yes \$3,500 to \$8,000/yr
7	Family Services	Respite Care	Fam. Support Dollars	From Federal List	Respite Care	Respite Care
8	Cost Estimate Per Family	No	No	No	No	Yes \$3,500 to \$8,000/yr
9	Overall Effectiveness Study	Yes Summary of all IFSP's	No	No	No	No
10	Lead Agency	Dept. of Human Services	Dept. of Education	Dept. of Health	Dept. of Health & Welfare	Dept. of Health & Environment

APPENDIX D
Results From Survey of Other States
Fifth Year States

#	QUESTION	Maryland	Massachusetts	North Carolina	Oklahoma	Pennsylvania
1	Fifth Year of Participation	Yes	Yes	Yes	Yes	Yes
2	State Law on Early Intervention	Yes	Yes	Yes	Yes	Yes
	"At Risk" Eligibility	Yes	Yes	Yes	No	No
	Serve "At Risk" in Future	N/A	N/A	N/A	No (funding)	No (funding)
3	# of Services from Federal Law Available	All	All	All	All	All
4	Eligible Population	70,000	14,000	8,000	73,333	517,734
	# Children Receiving Services	4,500	9,500	5,000	2,200	11,000
		Dec. 1991 Count	State FY92 Data	State FY92 Data	State FY92 Data	1992-93 Projection
5	Dollars Spent					
	Total	\$ 52,000,000	\$ 23,400,000	\$ 8,700,000	\$ 10,973,626	\$ 28,000,000
	Part H	\$ 2,000,000	\$ 2,600,000	\$ 2,700,000	\$ 2,992,642	\$ 3,000,000
	State	\$ 50,000,000	\$ 14,500,000	\$ 6,000,000	\$ 7,980,984	\$ 25,000,000
6	Cost Estimate Per Child	Yes \$5,000 to \$7,000/yr	Yes \$2,500 to \$4,300/yr	Yes \$3,300 to \$12,000/yr	No	Yes \$2,760/yr
7	Family Services	Specialized Child Care	Service Coordination	Respite Care	Substance Abuse Asst.	Respite Care
8	Cost Estimate Per Family	Yes \$5,000 to \$7,000/yr	No	Yes \$3,300 to \$12,000/yr	No	No
9	Overall Effectiveness Study	Yes Evaluation of Jurisdictions	No	Yes Less Placement in Institutes	No	Yes No Results Reported Yet
10	Lead Agency	Gov. Office for Children Youth & Family	Dept. of Health	DMHDD	Dept. of Education	Public Welfare

APPENDIX D
Results From Survey of Other States
Fifth Year States

#	QUESTION	Tennessee	Utah	West Virginia	Wyoming
1	Fifth Year of Participation	Yes	Yes	Yes	Yes
2	State Law on Early Intervention	No	No	Yes	No
	"At Risk" Eligibility	N/A	N/A	No	N/A
	Serve "At Risk" in Future	N/A	N/A	No (funding)	N/A
3	# of Services from Federal Law Available	All	All	All	All
4	Eligible Population	6,700	3,300	2,800	400
	# Children Receiving Services	6,200	1,400	1,405	400
		Dec. 1991 Count	Dec. 1991 Count	Dec. 1991 Count	Dec. 1992 Count
5	Dollars Spent				
	Total	\$ 1,926,000	\$ 4,300,000	\$ 2,207,780	\$ 1,934,230
	Part H	\$ 1,900,000	\$ 1,700,000	\$ 58,440	\$ 388,764
	State	\$ 26,000	\$ 2,600,000	\$ 881,827	\$ 1,323,540
6	Cost Estimate Per Child	No	Yes \$3,000/yr	No	No
7	Family Services	Respite Care	Counseling	In-Home Care	Family Counseling
8	Cost Estimate Per Family	No	Yes \$3,000/yr	No	No
9	Overall Effectiveness Study	No	No	No	No
10	Lead Agency	Dept. of Education	Dept. of Health	Dept. of Health & Soc. Serv.	Dept. of Health

APPENDIX E

**Providers Receiving State
or Federal Funds**

PROVIDERS RECEIVING STATE OR FEDERAL FUNDS (Part H, Program 33, Chapter 1) - Fiscal Years 1991 & 1992

Provider	Location	Part H (SBE)		Program 33 (DMHDD)		Chapter 1 (DMHDD)		FY91 Total	FY92 Total	TOTAL
		FY91	FY92	FY91	FY92	FY91	FY92			
Abilities Plus, Inc.	Kewanee			\$25,106		\$25,321	\$1,568	\$1,884	\$27,205	\$53,879
Abraham Lincoln Center	Chicago			\$249,061		\$251,208	\$16,464	\$24,492	\$275,700	\$541,225
Ada S. McKinley Community Services	Chicago			\$185,263		\$186,862	\$6,272	\$7,536	\$194,398	\$385,933
ARC Community Support Systems	Teutopolis			\$88,781		\$90,784	\$7,448	\$9,891	\$100,675	\$196,904
ARC Springfield	Springfield			\$68,571		\$121,171	\$6,664	\$8,949	\$130,120	\$205,355
Archway, Inc.	Carbondale			\$161,971		\$163,367	\$8,624	\$10,833	\$174,200	\$344,795
Association for Individual Development	Aurora			\$305,362		\$360,427	\$21,168	\$25,434	\$385,861	\$712,391
Blue Cap Infant-Parent Center	Blue Island		\$58,186	\$80,773		\$81,468	\$9,800	\$11,775	\$151,429	\$306,052
Career Development Center	Fairfield			\$46,395		\$48,945	\$2,744	\$7,536	\$54,481	\$103,620
Chicago ARC	Chicago			\$456,699		\$463,553	\$42,728	\$56,049	\$735,017	\$1,476,584
Chicago Lighthouse for the Blind	Chicago			\$108,444		\$109,377	\$33,712	\$40,506	\$149,883	\$292,039
Chicago Public Schools - District 299	Chicago			\$129,156		\$130,269	\$5,096	\$7,065	\$85,844	\$177,515
Chicago Urban Day School	Chicago			\$274,296		\$276,522	\$43,120	\$51,810	\$137,334	\$271,586
Children's Development Center	Chicago			\$57,247		\$57,741	\$19,208	\$23,079	\$628,803	\$1,240,693
Clearbrook Center	Ri Meadows			\$76,437		\$77,053	\$4,704	\$5,652	\$80,820	\$157,275
Clinton County Rehabilitation Center	Breese			\$156,881		\$158,159	\$9,408	\$11,304	\$82,705	\$163,846
Coleman Tri-County Services	Harrisburg			\$172,395		\$176,263	\$17,640	\$25,905	\$263,104	\$528,004
Coles County ARC (CCAR)	Charleston			\$71,169		\$71,169			\$275,337	\$545,039
Community Counseling Center	Quincy			\$99,696		\$77,166			\$47,269	\$99,301
Cook County Hospital	Chicago			\$130,473		\$131,599	\$9,408	\$14,130	\$222,895	\$482,472
Crosspoint Human Services	Danville			\$83,986		\$85,919	\$4,704	\$5,652	\$91,571	\$180,281
DeKalb County Special Education Association	Cortland			\$9,196		\$9,275	\$4,704	\$5,652	\$13,900	\$28,827
Delta Center	Cairo			\$134,511		\$135,671	\$3,920	\$4,710	\$14,927	\$28,827
Developmental Services Center	Champaign			\$212,147		\$213,976	\$19,600	\$26,376	\$193,432	\$396,014
East Seal Society of Metro Chicago	Chicago			\$51,639		\$52,142	\$10,976	\$17,898	\$372,994	\$759,014
El Valor Corporation	Chicago			\$199,774		\$201,946	\$37,632	\$48,984	\$132,695	\$281,913
Esperanza Community Services	Chicago			\$43,238		\$46,660	\$5,096	\$7,536	\$296,992	\$602,006
FAYCO Enterprises, Inc.	Vandalia			\$53,685		\$54,921	\$7,056	\$8,478	\$76,034	\$148,448
Franklin-Williamson Human Services, Inc.	W Frankfort			\$87,796		\$88,553	\$11,760	\$14,130	\$63,399	\$124,140
Fulton County Rehabilitation Center	Canton			\$42,837		\$43,204	\$8,624	\$10,362	\$102,683	\$202,239
Gateway Center	Princeton			\$26,324		\$26,550	\$5,880	\$7,536	\$69,784	\$139,095
Glenkirk ARC	Northbrook			\$29,580		\$29,834	\$3,528	\$4,239	\$34,086	\$66,290
Good Shepherd Center	Flossmoor			\$180,136		\$181,691	\$15,288	\$21,866	\$34,073	\$67,181
Habitative Systems, Inc.	Chicago			\$189,313		\$190,947	\$15,288	\$23,079	\$228,732	\$452,086
Helping Hand Rehabilitation Center	Countryside			\$72,867		\$73,496	\$10,976	\$13,188	\$214,026	\$418,627
Humana/Developmental Institute (Michael Reese)	Chicago			\$387,694		\$309,367	\$12,152	\$14,601	\$86,684	\$170,527
IL Masonic Medical Center/Diagnostic & Treatment Center	Chicago *			\$132,510		\$166,255			\$323,968	\$723,814
Institute for Study of Developmental Disabilities	Chicago *						\$28,616	\$34,383	\$166,255	\$298,765
Iroquois ARC	Waukega			\$20,366		\$20,547	\$3,920	\$6,123	\$34,383	\$62,999
									\$26,670	\$50,956

PROVIDERS RECEIVING STATE OR FEDERAL FUNDS (Part H, Program 33, Chapter 1) - Fiscal Years 1991 & 1992

Provider	Location	Part H (SBE)		Program 33 (DMHDD)		Chapter 1 (DMHDD)		FY91 Total	FY92 Total	TOTAL
		FY91	FY92	FY91	FY92	FY91	FY92			
Jacksonville Area ARC	Jacksonville			\$67,487	\$94,515	\$6,272	\$7,536	\$73,759	\$102,051	\$175,810
Jayne Shover Easter Seals	Elgin			\$273,936	\$325,593	\$19,992	\$47,100	\$293,928	\$372,693	\$666,621
Jefferson County Comprehensive Services	Mt. Vernon	\$26,702	\$24,259	\$52,938	\$54,158	\$5,488	\$6,594	\$85,128	\$85,011	\$170,139
Jo Daviess Workshop, Inc.	Galena			\$13,661	\$13,793	\$1,960	\$2,355	\$15,621	\$16,148	\$31,769
Jonesboro Community Consolidated School District #43	Jonesboro *	\$126,862	\$163,433					\$126,862	\$163,433	\$290,295
Kaaskakia Workshop	Centralla			\$43,035	\$44,027	\$6,272	\$7,536	\$49,307	\$51,563	\$100,870
Kreider Services, Inc.	Dixon			\$53,793	\$54,254	\$9,408	\$11,304	\$63,201	\$65,558	\$128,759
La Rabida Children's Hospital	Chicago	\$270,586	\$247,821					\$270,586	\$247,821	\$518,407
Lake Parent Infant Center (SEDOL)	Libertyville	\$74,301	\$69,362					\$105,963	\$99,231	\$205,194
LaSalle County Easter Seals	Ottawa			\$31,662	\$29,869	\$6,664	\$8,949	\$45,279	\$47,896	\$93,175
Little Friends, Inc.	Naperville			\$38,615	\$38,947	\$6,664	\$8,949	\$81,331	\$85,135	\$166,466
Lutheran General Hospital	Park Ridge	\$279,853	\$258,112	\$66,827	\$66,766	\$14,504	\$18,369	\$279,853	\$258,112	\$535,965
Lutheran Social Services of Illinois	Chicago			\$177,089	\$178,616	\$19,600	\$23,550	\$196,689	\$202,166	\$398,855
Macon Resources	Chicago			\$120,874	\$121,714	\$25,872	\$35,796	\$146,546	\$157,510	\$304,056
Macoupin County MHC	Decatur			\$11,722	\$13,831	\$3,136	\$3,768	\$14,858	\$17,589	\$32,457
Malcolm Eaton Enterprises	Carlinville			\$45,887	\$48,282	\$16,856	\$23,079	\$104,505	\$107,289	\$211,804
McLean ARC (MARC Center)	Freeport	\$41,782	\$37,958					\$105,245	\$110,381	\$215,626
Mau Glo Day Care School	Bloomington			\$93,093	\$93,898	\$12,152	\$16,485	\$121,578	\$128,018	\$249,596
McDonough County Rehabilitation Center	Chicago			\$118,050	\$119,069	\$3,528	\$8,949	\$121,578	\$128,018	\$249,596
Mental Health Authority of West Central Illinois	Macomb	\$38,750	\$33,387	\$55,432	\$55,908	\$3,920	\$4,710	\$96,102	\$94,005	\$190,107
Northwestern University	Quincy			\$3,234	\$3,281	\$14,504	\$32,499	\$17,738	\$35,760	\$53,498
Oak Leyden Developmental Services	Evanson			\$149,259	\$150,546	\$11,760	\$18,369	\$161,019	\$168,915	\$329,934
Opportunity Center of Southeastern Illinois, Inc.	Oak Park			\$89,211	\$91,267	\$9,016	\$14,130	\$98,227	\$105,397	\$203,624
Peoria ARC	Olney			\$89,253	\$100,562	\$6,664	\$9,891	\$95,917	\$110,453	\$206,370
Pioneer Center	Peoria			\$246,832	\$248,961	\$19,600	\$28,260	\$266,432	\$277,221	\$543,653
Prime/Care	McHenry	\$71,410	\$84,872	\$159,400	\$159,399	\$31,360	\$43,332	\$262,170	\$267,603	\$529,773
Promise Center	Belleville	\$80,644	\$73,674	\$139,459	\$140,610	\$23,520	\$30,144	\$243,623	\$244,428	\$488,051
Proviso ARC	E St. Louis			\$225,475	\$227,419	\$12,544	\$16,485	\$238,019	\$243,904	\$481,923
Ray Graham Association	Bellwood	\$41,957	\$38,117	\$102,140	\$103,020	\$10,976	\$13,659	\$155,073	\$154,798	\$309,869
Rehabilitation Center of Will/Grundy Counties, Inc.	Elmhurst			\$124,365	\$125,439	\$16,856	\$20,724	\$141,221	\$146,163	\$287,384
Rehabilitation Institute of Chicago	Joliet			\$159,744	\$172,990	\$28,224	\$35,796	\$187,968	\$208,786	\$396,754
Rock Island County ARC	Chicago	\$105,000	\$95,385					\$105,000	\$95,385	\$200,385
Rock River Valley Self Help	Rock Island			\$81,179	\$82,588	\$13,328	\$17,427	\$74,507	\$80,015	\$154,522
Salem Children's Home	Sterling			\$57,860	\$58,358	\$12,936	\$16,014	\$70,796	\$74,372	\$145,168
Shore Community Service Center	Flanagan			\$15,265	\$15,394	\$3,920	\$5,181	\$19,185	\$20,575	\$39,760
South Metropolitan Association	Evanson			\$38,789	\$39,122	\$2,744	\$3,768	\$41,533	\$42,890	\$84,423
South Suburban School	Floresmoor	\$238,184	\$121,968					\$238,184	\$121,968	\$360,152
SWCCCASE	Harvey			\$349,659	\$352,675	\$25,088	\$34,854	\$374,747	\$387,529	\$762,276
Tazewell County Resource Center	Oak Forest	\$58,000	\$53,307					\$58,000	\$53,307	\$111,307
	Tremont			\$29,215	\$29,888	\$10,584	\$12,717	\$39,799	\$42,605	\$82,404

PROVIDERS RECEIVING STATE OR FEDERAL FUNDS (Part H, Program 33, Chapter 1) - Fiscal Years 1991 & 1992

Provider	Location	Part H (SBE)		Program 33 (DMHDD)		Chapter 1 (DMHDD)		FY92 Total	FY91 Total	TOTAL
		FY91	FY92	FY91	FY92	FY91	FY92			
United Cerebral Palsy/Land of Lincoln	Springfield			\$77,985	\$78,657	\$31,360	\$42,390	\$109,345	\$121,047	\$230,392
United Cerebral Palsy	Chicago					\$6,272	\$7,536	\$6,272	\$7,536	\$13,808
United Developmental Services	Bourbonnais			\$227,263	\$229,223	\$7,448	\$8,949	\$234,711	\$238,172	\$472,883
Univ. of Chicago-Woodlawn Early Intervention	Chicago			\$175,682	\$177,198	\$22,736	\$27,318	\$198,418	\$204,516	\$402,934
Warren Achievement Center	Monmouth		\$39,007	\$131,886	\$132,320	\$10,976	\$16,956	\$185,471	\$188,283	\$373,754
William M. BeDell Center	Wood River			\$111,796	\$112,759	\$11,760	\$16,956	\$123,556	\$129,715	\$253,271
Wabash & Ohio Valley Special Education District	Norris City	\$159,995	\$149,539					\$159,995	\$149,539	\$309,534
Subtotal		\$3,231,981	\$2,941,458	\$8,627,232	\$8,837,662	\$975,296	\$1,317,858	\$12,834,509	\$13,096,978	\$25,931,487
DEPARTMENT OF REHABILITATION SERVICES **										
Home Services Program										
TOTAL		\$3,231,981	\$2,941,458	\$8,627,232	\$8,837,662	\$975,296	\$1,317,858	\$13,396,983	\$14,134,009	\$27,531,002

Total providers - 85

- * Pilot implementation site.
- ** DORS Early Intervention consist of home care services (personal attendants, respite care, home healthcare).
- ARC - Association for Retarded Citizens
- MHC - Mental Health Center
- SEDOL - Special Education District of Lake County
- SWCCCSE - Southwest Cook County Cooperative Association for Special Education

SOURCE: Summary data from State Board of Education and Department of Mental Health and Developmental Disabilities.

APPENDIX F

**Number of Services Provided
By County**

APPENDIX F
Number of Services
Provided in Each County
Reported from Provider Survey

<u># of Services</u>	<u>Counties</u>
16	Boone, Cook, Crawford, Hamilton, Jasper, Lake, Lawrence, Ogle, Richland, Saline, Wabash, Winnebago
15	Coles, Cumberland, Douglas, DuPage, Macon, Monroe, Randolph, St. Clair, Shelby
14	Kane, Will
13	Alexander, Champaign, Hardin, Johnson, Marshall, Massac, Pope, Pulaski, Union, Vermilion
12	Adams, Bond, Bureau, Fayette, Gallatin, Kendall, Madison, McHenry, Putnam, Stephenson, Tazewell, White
11	DeKalb, Henderson, Iroquois, Jo Daviess, Knox, McDonough, Warren
10	Ford, Henry, Mercer, Peoria, Stark, Woodford
9	Cass, Edwards, Fulton, Grundy, LaSalle, Menard, Sangamon, Wayne
8	Clinton, Effingham, Macoupin, Washington
7	Christian, Jefferson, Kankakee, Logan, Mason, McLean, Montgomery
6	DeWitt, Jackson, Perry, Pike
5	Calhoun, Carroll, Franklin, Greene, Jersey, Lee, Livingston, Morgan, Scott, Whiteside, Williamson
4	Clay, Marion, Piatt
3	Schuyler
2	Hancock
1	NONE
0	Brown, Clark, Edgar, Moultrie, Rock Island

NOTE: One provider in Rock Island County responded too late to be included in our analysis.

APPENDIX F
Number/Percentage of Services
Available in Illinois Counties
Reported from Provider Survey

	<u>Service</u>	<u># of Counties</u>	<u>Percentage</u>
1.	Assistive Technology Devices	51	50
2.	Audiology	62	61
3.	Family Training/Home Visits	93	91
4.	Necessary Health Services	37	36
5.	Medical Services: Diagnosis and Evaluation	39	38
6.	Nursing Services	60	59
7.	Nutrition Services	56	55
8.	Occupational Therapy	75	74
9.	Physical Therapy	87	85
10.	Psychological Services	30	29
11.	Service Coordination	79	77
12.	Social Work Services	72	71
13.	Special Instruction	69	68
14.	Speech-Language Pathology	90	88
15.	Transportation	73	72
16.	Vision Services	42	41

NOTE: One provider in Rock Island County responded too late to be included in our analysis.

APPENDIX G

Agency Responses

Note: Following the agencies' responses is a series of sequentially numbered auditor comments. The number of each auditor comment corresponds to a number in the margin of the agency response.



AUDITOR GENERAL
SPRINGFIELD
93 APR 12 PM 1 40

ILLINOIS STATE BOARD OF EDUCATION

100 North First Street • Springfield, Illinois 62777-0001

Louis Mervis
Chairman

Robert Leininger
State Superintendent

April 12, 1993

Honorable William G. Holland
Auditor General
Springfield, Illinois 62701

Dear Mr. Holland:

Attached are the Illinois State Board of Education's responses to the recommendations included in the report on the Early Intervention System (Attachment A). In addition to the responses we would like to make the following comments to some of the other parts of the report.

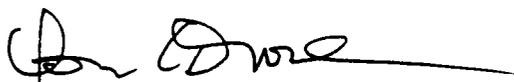
1. We have a general concern that the report does not directly address the criteria by which the effectiveness of the Early Intervention System might be evaluated. Since the objective of the audit is to determine effectiveness, and since effectiveness is an elusive concept, some consideration of criteria would have been helpful in placing the array of information in the report in a conceptual framework which focused on elements by which effectiveness might be measured. We are also concerned that given the expectation of "enhancing the capacity of families", that there was not greater emphasis on this in the conduct of the audit. (1)
2. Exhibit C in Chapter Two indicates that no services are available in four Illinois counties. After receiving the report, staff of the lead agency contacted the mental health center in one of the four counties. The executive director of the center indicated that birth to three early intervention services had been provided by the agency for over 20 years. Based on this follow-up we are concerned that the information obtained from the survey on which Exhibit C is based may be flawed. (2)
3. Chapter One includes as Exhibit A a listing of significant events in the development of early intervention in Illinois. However, none of the important developments that occurred after July 1992 are mentioned. Since this report is to address events through April, 1993, we have prepared a listing of events that reflects the significant progress (3)

made since July 1992 (see Attachment B).

4. In Chapter Four under "Matter for Consideration by the General Assembly", it is recommended that the Council be required to provide in its annual report to the Governor and General Assembly the estimated amount of state, federal and other funds required to provide early intervention services to all eligible children in Illinois. Reporting these costs may be misleading, since the downstream effect of early intervention services is not taken into account, and may create the impression that the reported costs represent all new expenditures. It is reasonable to assume that cost of early intervention services would be at least partially offset by future savings in programs that serve children above age three.

We realize the difficulty assessing the effectiveness of this program, and the necessity for the auditors to explore many avenues and to gather vast amounts of information. One of the most significant findings in the report seems to be that there is a great need in Illinois to provide services to children in the birth to three age group. We hope that the needs of these children are not lost in the large amount of data in this report.

Sincerely,



Don A. Drone, CPA
Internal Auditor

RESPONSES TO THE RECOMMENDATIONS IN THE AUDIT REPORT ON THE EARLY INTERVENTION SERVICES SYSTEM.

Recommendation #1

We agree with this recommendation. The Council is currently developing such rules, which are expected to be finalized by the beginning of 1994. All agencies represented in the Council have agreed that these rules would be compatible with any other rules affecting early intervention services.

Recommendation #2

We do not agree with all aspects of this recommendation. The recommendation relates to the 14 items covered on Table 6 of the audit report. The State Board is now in compliance with items #1, #8, and #13, since the Council, on April 1, 1993, approved the necessary measures to bring Illinois in compliance with these requirements.

As to item #11, the Council has contracted a consultant to review the financial aspects of early intervention in Illinois. After the review is completed, the State Board will encourage the Council and others to consider any action necessary to meet this requirement.

The system for compiling data described under item #14 is not required by federal law, but by state law. Since the table, according to its heading, covers components of federal law, item #14 should not appear on it. However, the State Board has such a system in place, which is currently under revision to meet the state requirement as well. (4)

Recommendation #3

The State Board has notified the Governor's Office repeatedly to appoint an independent Council chairperson, and will continue to do so.

Recommendation #4

We agree with this recommendation. However, the Council has submitted a report on its first-year accomplishments to the Governor's Office in February 1993, and is awaiting certification. Further, the Council is in the process of developing a plan to monitor Part H providers. On-site monitoring visits are expected to begin in the fall of 1993.

Recommendation #5

We agree with this recommendation. The Council offers staff training, technical assistance and additional funding to providers to help them ensure that Individualized Family Service Plans are prepared within the required time period. Additionally, on-site monitoring visits (see the response to the previous recommendation) scheduled to start later this year will help to meet this requirement.

Recommendation #6

We believe that the financial obligations are delineated in the interagency agreement. In this document each agency committed itself to "demonstrate its best effort to maintain current funding levels and staff...". The State Board as lead agency will review the need to make these commitments more specific and encourage the Council to refine them further outside the agreement.

Recommendation #7

We agree with this recommendation. The State Board will work towards implementation of these issues.

Exhibit A Continuation
DEVELOPMENT OF THE EARLY INTERVENTION SYSTEM IN ILLINOIS

July 1992

The process of developing early intervention rules was begun with a meeting with parents to gain their input.

August 1992

Organizational Resources Associates was contracted to provide technical assistance to the current local councils. The contract was later amended to include technical assistance to all the local councils when they are finalized.

September 1992

The Illinois Interagency Council on Early Intervention held a Planning Day in addition to its regular monthly Council Meeting. The areas receiving concentrated effort included the system, personnel development and program standards.

October 1992

Illinois Part H was informed that they had received \$1,442,184 in federal reallocation funds, in addition to the Part H grant, because they had worked to stay within the time frames granted by the federal guidelines.

29 additional providers were provided grants to improve and expand existing early intervention services.

November 1992

A contract was let with a financial consultant to work with the Finance Committee.

December 1992

Appointments were made by the Governor's Office so that the Illinois Interagency Council membership totaled 24 including 6 parents and 6 providers.

A State Technical Assistance Plan was accepted at the December meeting to provide for coordination of efforts.

The lead agency received word on December 2 that the Federal FY 1992 Application had been approved and \$7,626,080 would be forthcoming to assist in meeting Fifth Year Requirements.

The Illinois Interagency Council on Early Intervention learned about work in progress to issue contracts to coordinate diagnostic services and to provide for the remaining areas of the state to become part of local interagency councils.



Illinois Department of
Mental Health and
Developmental Disabilities

Central Office

March 30, 1993

Mr. Jim Kincaid
Audit Manager
Office of the Auditor General
509 South Sixth Street, Room 151
Springfield, IL 62701-1878

Dear Mr. Kincaid:

The Department of Mental Health and Developmental Disabilities has received the updated draft report, dated March 24, 1993, on the Early Intervention Services system in Illinois prepared by the Office of the Auditor General as specified in P.A. 87-680.

I have reviewed the updates from the exit conference held March 24, 1993 and found most of the Department's recommendations were incorporated. I would like the following recommendations and comments to also be included in this report. Specific sections, page numbers, and paragraphs have been identified to assist you.

Glossary:

"At-Risk of Developmental Delay": The definition only lists environmental risk factors; biological and high probability is not included.

Recommendation: This definition be changed to reflect that in P.A. 87-680, e.g. "at-risk of having a substantial developmental delay" means the presence of at least three at risk conditions, plus consensus based on clinical judgement, that the presence of these conditions warrants a risk of having a substantial developmental delay if early intervention services are not provided....."

"Developmental Delay": This definition is brief and would allow any child with slight delays to be eligible for early intervention services. The definition should also include definite criteria.

Recommendation: P.A. 87-680's definition of developmental delay be used, "means a delay in one or more of the following areas of childhood development as measured by appropriate diagnostic instruments and standard procedures: cognitive, physical including vision and hearing; language, speech and communication; psycho-social; and self-help skills.

Add: Physical or mental condition which has a high probability of resulting in a developmental delay means: 1) diagnosed medical disorder bearing a relatively well known expectancy for developmental outcomes within varying ranges of developmental disabilities; or 2) a history of prenatal, perinatal, neonatal or early developmental events suggestive of biological insults to the developing central nervous system and which either singly or collectively increase the probability of developing a disability or delay based on a medical history". (Source: P.A. 87-680)

Other Programs Serving the Eligible Population: Page 9. DMHDD would agree there is confusion on the part of service providers and among state officials on the various "initiatives" for children in Illinois.

Comment: Because P.L. 102-119 gives the lead agency responsibility to oversee all early intervention efforts, any initiatives or projects which affect children in Illinois should be presented to the lead agency and the Illinois Interagency Council on Early Intervention (IICEI) to determine if and how the initiative/project(s) is part of the collaborative, coordinated system for early intervention.

Additional Funding Sources and Services: Page 16. "... DMHDD does not keep information on the number of children served with Chapter 1 funds.

Comment: DMHDD maintains statistics on the number of children eligible to receive Chapter 1 funds using the December 1 child count required by ISBE. Since ISBE is the fiscal agency in which Chapter 1 funds "flow-through" to the Department, they maintain information on the total number of children served with Chapter 1 funds, including those who have transitioned out of the early intervention program upon reaching age 3 and the names of those children who replace these children."

Availability of Early Intervention Services: Page 18, first full paragraph. "Exhibit Cthe exhibit shows that none of the 16 early intervention services were available in four counties: Brown, Moultrie, Edgar, and Clark...."

(2) Comment: It may appear these four counties are not provided early intervention services through Part H, Program 33 or P.L. 89-313, however, through the Department's monitoring process it has been determined these counties are providing some early intervention services funded through DMHDD Program 16 (Child and Family Support), Title XX Donated Funds Initiative or local funding.

State's Five-Year Plan: Page 29, "Develop specific state interagency agreements defining financial responsibility..."

Comment: DMHDD would be open to discussion on changing the interagency agreement to include steps toward defining financial responsibility such as scope of populations served by state agencies.

Rules and Regulations: Page 31. "...These rules (DMHDD) are separate and distinct from those being developed by the Council."

Comment: P.L. 87-680 allows: state agencies which directly or indirectly provides or administers early intervention services shall adopt compatible rules for the provision of services to eligible infants and toddlers and their families within one year of the effective date of this Act.

Effectiveness: Page 33. "No state agency collects information on the number of children that might be eligible for early intervention services in Illinois."

Comment: DMHDD has a mechanism (prevalence which includes tables) in place to estimate numbers of children who may need early intervention services funded by DMHDD. (5)

Need to Monitor Child Development: Page 34. "State agencies on the Council do not collect and maintain the information necessary to monitor the effects of early intervention services on infants and toddlers...."

Comment: DMHDD early intervention service providers are monitored through audit requirements of Rule 103 (Grants), Chapter 1 Project Grant, and will begin to have certification audits by DMHDD Bureau of Certification and Licensure, once the Illinois Administrative Code Parts 121 and 122 are adopted by JCAR. DMHDD would be available to collaborate with ISBE on monitoring strategies to be used for Part H and other early intervention programs statewide.

State agencies look for different information within their information retrieval systems making the system appear to be neither uniform nor complete. DMHDD would be willing to participate with other state agencies to determine if a uniform system is possible in Illinois.

Page 35. "and DMHDD must complete a substantially similar report for each agency. A coordinated recipient-tracking system could eliminate duplicate reporting."

Comment: DMHDD representatives are willing to collaborate with the lead agency in determining a consistent tracking system to eliminate duplicate reporting.

Number of Children Served: Page 38, third paragraph. Indicates that DMHDD service reporting has gone from 7,669 in FY91 to 6,347 in FY92.

Comment: The Department did not view this statement as a negative reflection to services delivery. However, I did want to state the differences in numbers between the fiscal years could be the result of inaccurate data processes or because of the lack of a "cost of living adjustment" (COLA) in the past three fiscal years, providers may have reduced the number of children served and/or the intensity of service(s).

Entitlement Questions: Page 42.

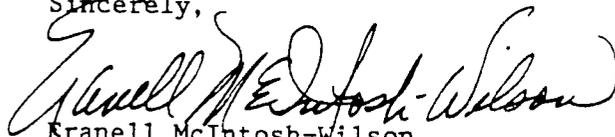
Comment: Should Federal law require entitlement of all early intervention services for all eligible infants and toddlers and their families, DMHDD would require expanded financial support from the executive and legislative branches of government.

Should Part H funds be terminated many programs and families will be effected. To date, Department-supported early intervention programs have been able to enhance early intervention services through Part H. Program 33 has only provided for very modest increases at best in the past year. Within this fiscal year, DMHDD-supported early intervention providers will also be able to enhance services through the Medicaid Rehabilitation Option.

The Department has a major commitment to funding and continued availability of early intervention services throughout the State and working as a collaborative member of the Illinois Interagency Council on Early Intervention.

Thank you for allowing the Department to provided recommendations and comments into this report.

Sincerely,


Eranell McIntosh-Wilson
Associate Director

EMW:JAJ