Program Evaluation

KENTUCKY EARLY INTERVENTION SYSTEM FIRST STEPS
Adopted by Program Review and Investigations

PROGRAM REVIEW & INVESTIGATIONS

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FOREWORD

On April 8, 1999, the Legislative Program Review and Investigations Committee authorized a study of the Kentucky Early Intervention System (KEIS). Staff was instructed to estimate the percentage of eligible children who are actually receiving services, examine the efficacy of the early intervention services provided by the program, and evaluate the fiscal accountability of the program, with a particular focus on the Centralized Billing and Information System (CBIS).

The Program Review and Investigations Committee adopted the staff report and recommendations on December 9, 1999.

Staff would like to acknowledge the considerable cooperation and assistance of First Steps Director Jim Henson, the Director of the Division of Adult and Child Health, Zaida Belendez, CBIS managers Bruce Gale, Brenda Curry-White and other First Steps participants in the completion of this study. Their commitment to the goals of the program was obvious and they have labored under difficult conditions. Throughout this project, staff observed much evidence of great dedication and professionalism on the part of those throughout the state who are working to improve the lives of infants and toddlers with developmental delays.

This report is the result of dedicated time and effort by Program Review staff Alice Hobson and Ginny Wilson, Ph.D., and LRC staff Barry Boardman, Deborah Crocker, Miriam Fordham, Erica Warren, and DeeAnn Wenk, Ph.D..

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February 23, 2000

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MEMORANDUM

TO: **The Hon. Paul E. Patton, Governor**
The Legislative Research Commission, and
Interested Individuals

FROM: **Representative H. "Gippy" Graham, Co-Chair**
Senator Marshall Long, Co-Chair
Program Review and Investigations Committee

SUBJECT: **Adopted Committee Staff Report: Kentucky Early Intervention System-First Steps**

DATE: **December 9, 1999**

On April 8, 1999, the Legislative Program Review and Investigations Committee authorized a study of the Kentucky Early Intervention System (KEIS), also known as First Steps. The Committee had requested that staff estimate the percentage of eligible children who are actually receiving services, examine the efficacy of the early intervention services provided by the program, and evaluate the fiscal accountability of the program, with a particular focus on the Centralized Billing and Information System (CBIS).

The staff review concluded that the managers and professionals associated with First Steps exhibited a strong commitment to the goal of improving the developmental progress of infants and toddlers who have developmental delays. Because of the complicated nature of the task and the fact that about twice as many children as expected received services during the current budget period, these professionals have been successful in only some parts of program administration. It does appear that children are receiving services that improve their developmental progress. However, there are serious questions regarding the efficiency and fiscal accountability of the processes used to reimburse providers for those services.

Based on its review of the program, staff developed Priority Recommendations and Secondary Recommendations. The following recommendations are considered to have the highest priority. Most of these concern improvements in the efficiency and accountability

in the use of program resources. These are considered the highest priority because of the large opportunity cost of expending resources in an inefficient manner. Every dollar spent for an unnecessary or inappropriate service is lost for use in prevention and recruitment activities shown to yield impressive returns.

Priority Recommendations:

1. **The Commissioner of the Department for Mental Health and Mental Retardation Services should provide immediate assistance to First Steps for a complete review of fiscal procedures and the development of a plan for improvements in fiscal accountability.** The Financial Management Branch of the Division of Administration and Financial Management should be assigned to work with the program to review all current fiscal and financial procedures, such as estimation of the number of enrollees in the upcoming budget period, provider billing compliance, external validation of CBIS payments, and cost saving measures. The result should be a written plan for improvement.

    1.1.1. **A fiscal officer should be assigned to work with the program on a permanent basis to implement and update the plan on an ongoing basis.**

    1.1.2. **Vacant positions in the First Steps central office should be filled as soon as possible. An additional program consultant for monitoring supervision and a fiscal analyst should be added to the staff roster.**

    1.1.3. **The Program Review and Investigations Committee should recommend to the Budget Review Subcommittee on Human Resources that it request submission of the written fiscal operations improvement plan when it considers the First Steps budget during the 2000 Session of the General Assembly.**

2. **The Commissioner of the Department for Mental Health and Mental Retardation Services and the Commissioner of Medicaid Services should establish a team to identify all feasible means for First Steps to maximize its access to federal Medicaid and KCHIP matching funds.** This team should consider whether it is advisable to require the completion of an application for Medicaid and KCHIP as a criterion for participation in First Steps. It should also include consideration of a waiver that would allow Medicaid to reimburse some of the administrative costs of the program.

3. **The Commissioner of the Department for Mental Health and Mental Retardation Services should dedicate the necessary resources and expertise to explore the identification of other sources of federal funds for program services.**

4. **Immediate attention should be given to the development of a workable organization of the primary service coordination function.** The assignment of a primary service coordinator (PSC) to each child is required under federal law. How that function is organized is left to the states. As a reaction to the inclusion of unnecessary services in the IFSP, First Steps regulations now prevent PSCs from providing other intervention services. There is some logic in that. The problem is fewer professionals are now willing to provide service coordination. It is not clear how the program will successfully address this problem.

5. **The number of full-time equivalent monitoring specialists should be increased.** These are the professionals most qualified to assess the reasonableness of the services authorized in the IFSP. There are currently four full-time equivalent monitoring positions, which is judged too few to adequately perform the monitoring function. It is recommended that an additional two to four full-time equivalent positions be established, at least on a temporary basis. While this may seem expensive, it has the potential to result in significant program savings.

6. **The Program Review and Investigations Committee should request that the State Auditor of Public Accounts perform an external audit of the Centralized Billing and Information System.** In an internal review of the database, staff did not identify any obvious accountability problems with the payment of invoices. However, there appears to be a lack of external control procedures, a situation that could compromise the integrity of the system. This audit should specifically address whether the billing system should continue to be maintained outside the state accounting system.

Questions or requests for additional information should be directed to Dr. Ginny Wilson, Committee Staff Administrator for the Program Review and Investigations Committee.

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Glossary

ADD	Area Development District
CBIS	Centralized Billing and Information System
CFS	Cabinet for Family Services
CHAMPUS	Civilian Health And Medical Program of the Uniform Services
CHS	Cabinet for Health Services
Consanguinity	Consanguinity means descent from a common ancestor or birth from blood-related parents.
DEIC	District Early Intervention Committee One of 15 local Committees formed along the area development districts boundaries that provide local assistance for First Steps
DPH	Department for Public Health of the Cabinet for Health Services
EPSDT	Medicaid Early and Periodic Screening, Diagnosis and Treatment
FTE	Full Time Equivalent
ICC	Interagency Coordinating Council Federal mandated advisory council for the state agency in charge of the program
IDEA	Individuals with Disabilities Education Act Enabling Federal Legislation
IDEA, Part C	Individuals with Disabilities Education Act, Enabling Federal Legislation for First Steps (Infants and Toddlers with Disabilities)
IDEA, Part D	Individuals with Disabilities Education Act, National Activities to Improve Education of Children with Disabilities
IDEA, Part H	Individuals with Disabilities Education Act, now Part C, IDEA reauthorization in 1997
IEP	Individualized Education Plan: Plan for the child in the school system
IFSP	Individualized Family Service Plan
KCHIP	Kentucky Children's Health Insurance Program
KEIS	Kentucky Early Intervention System
MH/MRS	Department of Mental Health/ Mental Retardation Services
NECTAS	National Early Childhood Technical Assistance System
POE	Point of entry Contact point which handles the initial intake, family contact, evaluations, eligibility determinations and the initial individualized family service plan.
PSC	Primary Service Coordinator
RTC	Early Childhood Regional Training Center
Section 619	Individuals with Disabilities Education Act, Part B (preschool program)
TANF	Transitional Assistance for Needy Families Federal welfare reform program
Teratogen	A teratogen is any substance, agent, or process that interferes with normal prenatal development which can cause developmental abnormalities in the fetus.
WIC	Special Supplemental Food Program for women, Infants and Children

Program Review: First Steps – Kentucky's Early Intervention System

INTRODUCTION

On April 8, 1999, the Legislative Program Review and Investigations Committee authorized a study of the Kentucky Early Intervention System (KEIS). KEIS, which operates under the auspices of the Cabinet for Health Services, is a state system that reimburses private providers, such as speech therapists and physical therapists, for early intervention services delivered to infants and toddlers, from birth through two years, who are determined to have significant developmental delays. The federal government provides grants to states that have identified a single lead agency to establish coordinated family-centered early intervention programs that meet minimum requirements specified in the Individuals with Disabilities Education Act. First Steps is the coordinating agency for the Kentucky Early Intervention System. Throughout this report, KEIS and First Steps are used interchangeably to denote the early intervention program under review.

In FY 1999, just over 7,000 infants and toddlers had screening or intervention services reimbursed under First Steps. Total program expenditures for that year were $23.3 million. Nearly $10 million, or 41 percent of the total, was from state General Funds. By accepting the federal program grant of $4.3 million in that year, the Commonwealth agreed to establish First Steps as an entitlement program and to mount an aggressive effort to find all infants and toddlers eligible for intervention services. Growth in the program has far exceeded original expectations and the program has suffered significant budget deficits for the past three years. In FY 1999, a mid-year appropriation increase of $8.4 million was required to address the deficit.

In requesting this study of KEIS, the Committee specifically asked staff to:

1. estimate the percentage of eligible children who are actually receiving services;
2. examine the efficacy of the early intervention services provided by the program; and
3. evaluate the fiscal accountability of the program, particularly the Centralized Billing and Information System (CBIS).

Staff would like to acknowledge the considerable cooperation and assistance of First Steps Director Jim Henson, Zaida Belendez, CBIS managers Bruce Gale, Brenda Curry-White, and and other First Steps participants in the completion of this study. Their commitment to the goals of the program was obvious and they have labored under difficult conditions. Throughout this project, staff observed much evidence of great dedication and professionalism on the part of those throughout the state who are working to improve the lives of infants and toddlers with developmental delays.

The report is presented in five sections. The first section provides a description of the program and its operations. The second section discusses the available information regarding the number of Kentucky infants and toddlers with developmental delays. The

third section presents national and state-specific evaluations of the efficacy of early intervention services. The fourth section addresses the fiscal aspects of the program, and the final section offers conclusions and recommendations.

METHODOLOGY

The general methods used for this study included statute and regulation reviews, a review of relevant research literature, review of official documents and contracts, and review of relevant budget documents. Interviews were conducted with the First Steps central office staff, points of entry, program consultants, evaluation specialists, parent consultants, primary service coordinators, Centralized Billing and Information System officials, Medicaid officials, Department of Education officials, preschool coordinators, the Early Childhood Regional Training Centers, and others. Additionally, staff conducted a survey of other states to determine how they projected their original populations and how program quality is assured. Finally, staff obtained a complete copy of the Centralized Billing and Information System database to independently assess its past operations.

SECTION 1: KENTUCKY EARLY INTERVENTION SYSTEM

First Steps is a joint state/federal program designed to identify and serve infants and toddlers with developmental delays. The federal enabling statute is the Individuals with Disabilities Education Act (IDEA), which was reauthorized in 1997. This federal law made grants available to states that develop intervention programs offering families a single contact person to coordinate a range of family-centered services tailored to the individualized needs of each child. IDEA establishes minimum components for an eligible state program. (Table 1.1)

TABLE 1.1

Minimum State Components Required under IDEA

Eligibility and Intake	Definition of Developmental Delay; State policy that appropriate early intervention services are available to all infants and toddlers; Timely, comprehensive, multidisciplinary evaluation and a family-directed identification of the needs of the family
Service Plan	Individualized family service plan including service coordination
Outreach and Referral	Public awareness campaign; Central directory of services, resources, research and demonstration projects.
Program Administration	A single line of responsibility in a lead agency established by the Governor: General administration and supervision; Identification and coordination of all resources; Assignment of financial responsibility; Procedures to ensure timely services pending dispute resolution; Resolution of intra-agency and interagency disputes; Formal interagency agreements; Policies and procedures that promote natural environments
Personnel	Comprehensive system of personnel development; Policies and procedures relating to training and preparation of personnel.
Data Systems	System for compiling data;
Advisory Council	State Interagency Coordinating Council

Source: Individuals with Disabilities Education Act, 20 USC 1435 as reauthorized in 1997

Under the federal requirements, state programs must be entitlement programs – they must offer services to all eligible children and they must engage in significant efforts to identify and recruit eligible children. States are given flexibility in defining the criteria for eligibility and the range of services to be offered.

Note that federal requirements generally pertain to the organization and features of service delivery. A review of the minimum components required by the federal government makes it clear that the federal goal was to offer a financial incentive to states to provide families one-stop coordination of the myriad government services available for eligible infants and toddlers, and to provide those services in the individualized family-centered manner preferred by Congress.

Except for the requirement that the federal grants not replace existing state or local service dollars, IDEA imposes no requirements on the management of resources. States are encouraged to maximize their use of federal dollars, particularly Medicaid dollars, to fund services. However, responsibility for fiscal management, and a significant share of the fiscal risk associated with an entitlement program, fall to the states.

Kentucky Establishes an Eligible Early Intervention System

In 1994, the General Assembly established the Kentucky Early Intervention System and appropriated federal and state funds to support the program. As noted in KRS 200.650, the General Assembly's intent in creating the program was:

- to enhance the development of infants with disabilities;
- to minimize developmental delay;
- to maximize the potential for future adult independence;
- to reduce the costs of special education and health costs; and
- to reduce future social service costs and to minimize the likelihood of institutionalization of individuals with disabilities.

Kentucky First Steps is a collaborative program with a statewide system of community-based, family-centered services for infants and toddlers with a developmental disability or an established risk condition, such as cerebral palsy. Kentucky choose to have its program for infants and toddlers through age two under the Cabinet for Health Services, while the Department of Education administers the preschool program, which serves children three to five years old.

Other than designation of the lead agency, the first task in implementation of the program was to define eligibility criteria. General developmental skills for infants and toddlers are shown in Table 1.2. Children are eligible for First Steps if they have fallen significantly behind developmental norms in the following skill areas:

- Cognitive Development
- Communication through speech and language development
- Physical development including vision and hearing
- Social and emotional development
- Adaptive skills development

Table 1.2
Average Skills Exhibited by Infants and Toddlers

Months	Average Skills
0 – 3	Smiles back at parent, makes cooing sounds, lifts head and chest when lying on tummy, watches movement
3 – 6	Laughs and babbles, rolls from back to tummy, turns head to sounds, reaches for and holds objects, touches hands together
6 – 9	Sits up without falling, imitates peek-a-boo or bye-bye
9 – 12	Associates simple words with correct object (bottle, ball), pulls to standing, associates names to correct people (Mama or Dada), picks up small things using thumb and one finger
12 – 15	Asks for particular things, feeds self with fingers, walks
15 – 18	Drinks from a cup, points to correct body parts when named (nose, foot), puts things in and out of containers, asks for things by name, looks at books and turns pages
18 – 24	Puts two words together (Mama's shoe), points to correct pictures when names given, runs, removes sweater, hat, or socks alone
24 – 30	Walks up stairs, can draw straight line, asks to go to the bathroom, can follow simple 2-step direction (go to your room and get your ball), puts 3 words together
30 – 36	Knows own name, unbuttons buttons, asks questions, understands concepts like in & out, and the number one

Source: First Steps.

Evaluators use diagnostic instruments and procedures, which are norm-referenced and age-appropriate, to determine if the child has fallen significantly behind developmental norms. Children are eligible for the program if they are found to be two standard deviations below the norm in one skill area, or 1.5 standard deviations below the norm in two skill areas.

Also, children with one of 179 established risk conditions automatically qualify for the program. Examples of the established risk conditions are spina bifida, autism and cerebral palsy.

The federal government also allows states to include children who are at-risk for developing developmental delays, such as those with environmental risks including poverty and those at biological or medical risk. Kentucky did not choose to include such children in the program until delays meeting the above criteria are actually diagnosed.

In FY 1999, speech, occupational, and physical therapy accounted for 50 percent of the cost of services delivered to the 7,050 children who received screening or intervention services. In that year, the 5,098 children who met the First Steps eligibility criteria after screening received an average of 188 units of service (a unit is usually one quarter of an hour of therapy) at an average unit cost of $15.87 per unit. The average total payment per child was $2,990.

KEIS Incorporates Five Major Features

Features of the Program are summarized in Table 1.3. The five major features are referral, evaluation, development of the individualized plan, service delivery, and transition. Initially, a family member, physician, nurse, or community member realizes that there is a developmental delay. Then, the child is referred to the Point of Entry (POE) in the community. The POE is an organization which handles the initial intake and evaluation of the child. This includes determination of eligibility and, if the child is eligible, the POE participates through the development of the first Individualized Family Service Plan (IFSP). The POE is the initial contact point for the family. One of their primary responsibilities is to consult and educate the family by explaining the program features, family rights, family choice of providers, and other resources. The POE arranges for the evaluations and assessments of the child. Finally, a POE representative is a key player at the initial IFSP meeting. The IFSP is a pivotal document in the process. It describes all the services that the child will receive, the providers selected by the family, and the outcome targets for the child. After this initial meeting, the primary service coordinator takes over the service coordination for the child and the family.

Many Organizations have Roles in First Steps

Under IDEA Part C, the Cabinet for Health Services serves as the lead agency and is primarily responsible for the administration and supervision of the program. The Cabinet delegates much of the responsibility for administration to the Division of Mental Retardation. The Division for Adult and Child Services in the Department of Public Health (DPH) serves as a partner for some activities related to intake, evaluation, and assessment of the children. Figure A gives a brief overview of the program structure. The lead agency has overall responsibility for planning, development, implementation, and monitoring of First Steps. Other agency responsibilities include training, financial matters, interagency matters and dispute resolution, and resource coordination. Full-time staff are assigned to First Steps in the Division of Mental Retardation, while one is assigned in DPH.

The Kentucky Early Intervention Interagency Coordinating Council (ICC) advises and assists the lead agency. This Council is statutorily created and administratively attached to the Cabinet for Health Services. Table 1.4 shows the composition of the council as well as its primary responsibilities.

Table 1.3
How First Steps Works

Community Referral

Family, Social Worker, Doctor, Child Care, Nurse, Teachers, Others

?

Point of Entry

Tasks
1. Intake
2. Initial Service Coordination
3. Information Gathering
4. Evaluation
5. Verification of Eligibility
6. Pre-Service Planning

?

Individualized Family Service Plan
Developed by a Multidisciplinary Team

1. Identify Multidisciplinary Team members
2. Conduct Assessment
3. Identify Primary Service Coordinator
4. Refer to Community Services

?

Eligible Intervention Services in the IFSP

Screening services	Nutrition services
Evaluation services	Occupational Therapy services[1]
Assessment services	Communication development services
Service coordination	Sensory development services
Transportation and related costs	Developmental intervention services
Family services including counseling, psychological, and social work services	Assisted technology services
Health services including medical services for diagnostic and evaluation purposes only;	Respite services

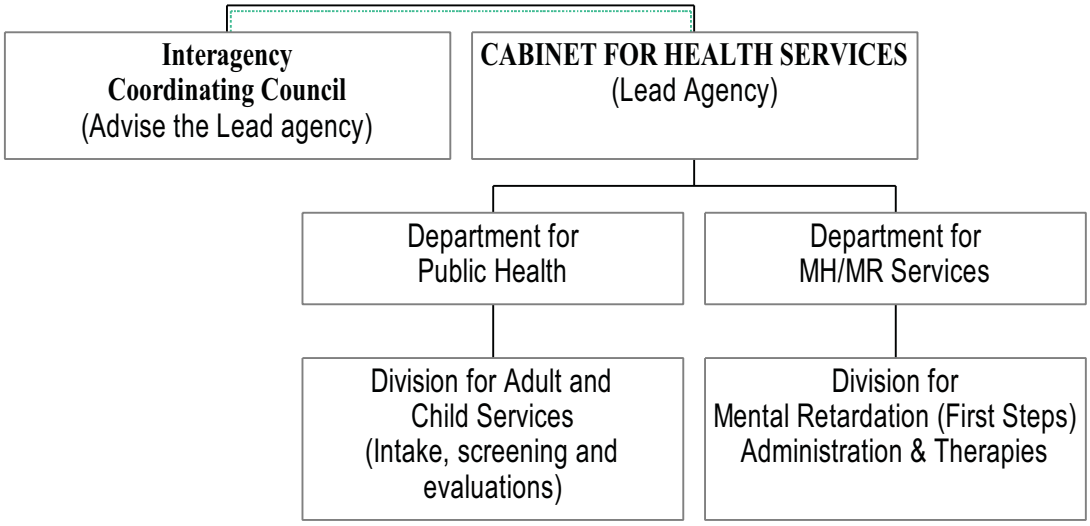
?

Transition

To Education
To Age Norms
To Other Services

[1] Occupational Therapy addresses the fine motor needs of the child, such as gripping and eye-hand coordination. These therapies generally concern the upper body .
Source: First Steps

Figure 1.A
Organization of Kentucky Early Intervention System



Source: First Steps

Table 1.4
Interagency Coordinating Council

Membership	5 members are parents (includes minorities) of disabled children who is 12 years old or less; At least one parent must have a child who is 6 or younger. All parents must have knowledge of or experience with programs for infants with disabilities
	5 public or private providers of early intervention services
	1 or more members of the General Assembly
	1 or more members of an entity responsible for personnel preparation. These members may be on the staff of an institution of higher education or preservice training organization.
	At least 1 member is the Commissioner or his designee or a person serving in an equivalent position of the following Departments: Public Health Medicaid Services Mental Health and Mental Retardation Services Social Services Education Insurance
	1 representative of the Commission for Handicapped Children (now Commission for Children with Special Health Care Needs)
Duties to advise and assist CHS	Advise and assist the cabinet in at least the following: Developing and implementing of the statewide system and the administrative regulations Achieving the full participation, coordination and cooperation of all individuals, departments, agencies and other entities through the promotion of interagency agreements Establishing a process to seek information from service providers, service coordinators, parents, and others concerning the identification of service delivery problems and their resolution Resolving disputes to the extent the Cabinet deems appropriate Providing appropriate services for children from birth to age 5 Identifying sources of fiscal and other support services Transitioning of the infants and their families.
Duty to Report	Report with recommendations to the Governor, LRC, and the federal Department of Education no later than December 30 of each year

Source: KRS 200.658

On the local level, there are fifteen District Early Intervention Committees to advise and assist in providing services at the community level. The General Assembly created these broad-based councils that correspond to the Area Development Districts boundaries (Table 1.5).

Table 1.5
District Early Intervention Committee

Membership	15 to 25 members including at least 5 parents 5 early intervention providers one representative of: local health dept. local office of the DSS local community MH/ MR center local Commission for Handicapped Children
	Representatives from one of the following: child day-care facility public school medical provider therapy provider home health agency operated separately from a local health department university or college family resource center local business local charity Others deemed appropriate
Duties on behalf of Infants and their Families	Advise and assist the CFS and the Council in the development, implementation and monitoring of the system Identify local resources available Assist in identifying unmet needs Assist in establishing and maintaining a point of entry Facilitate interagency coordination Assist in the establishment of local interagency agreements and provide a forum for coordinating district early intervention services

Source: KRS 200.672

The major partner of the Cabinet for Health Services, Division of Mental Retardation, is the Department of Public Health, which shares responsibilities for intake and evaluations. In FY 99, the Department of Public Health had a $458,000 contract to manage points of entry in the initial screening of referrals to First Steps. As noted above, these services include initial intake, eligibility determination, and initial service planning and coordination. First Steps uses the Area Development Districts as its geographic division for the points of entry. Generally, the POE services are provided by a registered nurse with the local health department and a developmental interventionist, or similar professional, from the Comprehensive Care Center. The POE also has primary responsibility for public relations and outreach to inform the public about First Steps. Additionally, the Department of Public Health informs, educates and trains health professionals about First Steps, early identification and management of developmental delays.

First Steps Contracts for Technical Assistance through the Regional Universities

First Steps has program administration contracts with the regional universities to supply all provider training, to conduct compliance monitoring of the providers and to

consult with the families. Table 1.6 shows the contract employees at the regional universities.

TABLE 1.6
First Steps Program
University Full-Time Equivalent Contract Employees

Regional Universities	ADD Districts Served	Program Consultants	Monitoring Specialists	Parent Consultants
Western Kentucky	Barren River Green River	1 (Vacant)	1	.5
Murray State	Purchase, Pennyrile	1 (Vacant)	Never Existed	.5 (Vacant)
Eastern Kentucky	Ky River, Cumberland Valley	1	.5	.5
University of Kentucky	Bluegrass	1	1	.5
University of Louisville	Kentuckiana, Lincoln Trail	1	.5	.5
Northern Kentucky	Northern KY, Buffalo Trace	1	.5	.5
Morehead State	Fivco, Big Sandy, Gateway	1	.5	.5 (Vacant)
Total Full-Time Equivalent		**7**	**4**	**3.5**

Please note that there is a Project Director at each regional university, but these positions do not have any funding through First Steps, except at Murray where a small fraction of the position is funded.
Source: First Steps Program.

Each regional university has a technical assistance team, including a program consultant and parent consultant. Basically, each technical assistance team trains the service providers. (Table 1.7) The program consultants and parent consultants provide training for all the service providers. The program consultant serves as staff for the local District Early Intervention Committee. According to one program consultant, consultants serve as a "regional training agency" whose primary job is to ensure regulatory compliance. The providers in the field drive most of their work.

Parent consultants are parents of developmentally delayed children who work on a part-time basis to explain the family's perspective to providers and give them advice on how best to meet the family's needs. They are involved in every training session. Parent consultants also represent First Steps on committees and assist in the development of policies and procedures, including personnel issues.

Table 1.7
Duties of Technical Assistance Teams

Job Title	Duties
Program Consultant	Provide training and answers questions for the Points of Entry, Primary Service Coordinators, local service providers, and families. Serve as staff to the District Early Intervention Committee (DEIC) Develop and facilitate linkages between the Interagency Coordinating Council, state staff, and the local DEIC. Provide inservice training to personnel, families, and potential contract personnel Assist in the development of inservice training Act as liaison between families, regional service systems, the DMH/MR Services, and the Dept. of Public Health Participate in professional development training and activities
Parent Consultant	Assist families whose names come from the POE through personal contact, mentoring, dissemination of information, and referrals to appropriate community resources. Provide inservice training for personnel, contract personnel, family members, and others Assist in developing training materials Assure family centered perspective by reviewing and developing documents Participate in district/ regional meetings, state technical assistance team meetings, and other meetings

Source: First Steps Program.

University Contract Employees Focus on Compliance Monitoring

Monitoring specialists work under contract on a part-time basis to ensure that First Steps services are consistent with statutes and regulations. The monitoring specialists originally were to focus on both compliance monitoring and program evaluation but have only been able to conduct compliance monitoring at this point. The federal law (IDEA) requires monitoring to comply with all the funding and legal requirements under the federal statute and regulations. Monitoring also includes taking corrective action, if necessary. On the other hand, program evaluation examines the overall performance of the program. The program is evaluated by using criteria and performance indicators that are derived from the missions and goals of the program. What the program is actually doing is judged against performance standards.

The original intent was for the monitoring specialists to have an evaluative role by incorporating quality assurance into the system. Because of the need to focus on compliance issues after the state provider review, quality assessment has not yet been implemented, although First Steps management realizes its importance. These specialists conduct site visits to the providers to collect required data on compliance, write reports, oversee action plans and conduct follow-up visits. The monitoring specialists work independently of the technical assistance teams but communicate their concerns to the technical assistance teams to assist in provider training. Currently, four full-time equivalent monitors have the task of reviewing the 3,400 IFSPs presently in force.

SECTION II: NUMBER OF CHILDREN ELIGIBLE FOR EARLY INTERVENTION SERVICES

One of the primary questions raised by the Committee is whether a large percentage of eligible children are actually being served in First Steps. This is important for two reasons. First, the federal grant requires that the program do an effective job of identifying and serving as many eligible children as possible. The General Assembly has stated that, because it expects early intervention to reduce later social support costs, it also places a high priority on extensive program coverage of the eligible population. Thus, a measure of the percentage of eligible children actually served is an important indicator of program effectiveness.

Second, the program has experienced a rapid growth in the number of children served. This figure is more than double the original estimate and has resulted in significant and growing budget deficits. In planning for the upcoming budget, it would be beneficial to have some assessment of whether that recent rate of program growth is expected to continue.

This section first reviews the methods used to make the original estimates of the number of children eligible for early intervention services in Kentucky, then considers information that could improve these estimates. Based on this information, factors which could determine the future growth in the number of children served are assessed.

The Original Estimate of the Number of Eligible Children Was Significantly Low

The eligible population under P.L. 99-457 is defined as those infants and toddlers who (1) have an *established risk,* a diagnosed physical or medical condition that has a high probability of resulting in developmental delay, or (2) are experiencing *developmental delay*s. The federal law allows states to determine the eligibility criteria for established risk and the degree of delay required for service eligibility. States can control the number of children served through broadening or narrowing the eligibility definitions.

The national estimates of those eligible for early intervention services under P.L. 99-457 have ranged from two to three percent of the population aged birth to three years. The 1998 National Health Interview Survey (NHIS) estimates that 2.35% of the population aged birth to three years have limitations in some daily activity. The federal law does not require states to document the method they use to estimate the eligible population, but it is assumed that states will attempt to serve all children meeting the state criteria.

When P.L. 99-457 was first implemented, only a few states had existing high-risk infant tracking programs that could provide quality data on the number of infants and

toddlers with developmental delays. Among states that had tracking systems, California, Iowa, and Washington had estimated rates of 2.9%, 1.0%, and 3.2% of the birth to three population eligible for services, respectively. Other states used a variety of data and methodologies to estimate the size of the population to be served. Some states relied on the national estimate of 2% of the population age birth to three years. Other states, like South Carolina and Pennsylvania, used the national figure as a base but varied their estimates by county depending upon environmental risk factors such as poverty levels and the proportion of minorities. Texas had a special census in 1989 that suggested about 3.4% of children under age three had one or more disabilities or other chronic health problems that could cause developmental delays. North Carolina, which uses a broad definition of developmental delay, estimates that within ten years they will serve six to seven percent of their population age birth to three years. The diversity in state estimates depends upon the state definitions of established risk and developmental delay, the accuracy of available data, the method of estimation, and, one presumes, actual differences in prevalence rates.[2]

Kentucky does not have a fully operating infant tracking system so another method had to be used to derive an estimate of the birth to three year old population eligible for early intervention services in Kentucky. Researchers from the University of Louisville used a formula developed by the state of Washington. This formula was derived from data collected in the Washington Infant Tracking Program and Birth Defects Monitoring Program. The Washington formula could easily be used with the birth and population data available for Kentucky. Methods used by Iowa and California, for instance, required much more detailed information from state infant tracking programs. The estimate of the birth to three year old population eligible for early intervention services in Kentucky using the Washington formula was 2.5%.[3]

The Washington formula makes the following assumptions:

1. The percent of children age one year with developmental delays is twice the established risk rate at birth.

2. The estimated percentage of children with developmental delays by age five is 10% of live births.

3. Of the developmental delays by age five, 40% have health impairments and 20% show signs of developmental delays by age three years.

4. The percent of children age two years with developmental delays is the mean between the percent age one year and the percent age three years with developmental delays.

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[2] Information obtained through interviews with state offices.

[3] Millicent H. Abel, Darlene A. Burke, and Brenda Curry-White,*Kentucky Statewide Estimate of Developmental Delays in Infants under Three Years of Age*, Louisville: University of Louisville, June 1991, 22-23.

Notice that two major determinants in this formula are the established risk rate at birth and the percent of births with developmental delays by age five years. Variations in these figures have large effects on the estimate of the eligible population. Also, this method inherently assumes that the proportion of children eligible for services gradually increases between ages zero and five. The following sections discuss these determinants in greater detail.

Established Risk. Kentucky included ten categories of established risk in its definition (Table 2.1). Many of these conditions are difficult to diagnose at birth, and only seven of these conditions are recorded on Kentucky birth certificates. Data from birth certificates showed only 377 births in established risk categories in 1989, 0.7% of all births (377 of 54,198). The University of Louisville researchers considered this proportion as too low to be valid.[4] Information obtained from other states' birth defect registries has suggested ascertainment rates of developmental delays from birth certificates of only 30 - 50%.[5]

TABLE 2
Total Estimate of Established Risk, State of

Established Risk Category	Rate Per Million	Expected Cases
Chromosome abnormalities	2,714.20	126.84
Recognizable syndromes	279.6	15.16
Central nervous system development	2,213.00	119.92
Neurological/neuromuscular disorder	2,467.50	133.71
Infection	2,093.20	113.71
Sensory impairments	189.8	10.29
Metabolic disease	125.7	6.81
Maternal teratogen exposure	N/A	17.88
Behavioral/emotional disorder	440	23.84
Central nervous system malignancy	73	3.96
Total Estimated Established Risk	**10,596.00**	**572.12**

Source:

The information included on Kentucky birth certificates in 1997 showed a total of 9.36% of all births with abnormal conditions (4,947 of 52,843) and 3% of all births with congenital anomalies (1,567 of 52,843). However, not all of these conditions place a child at risk of developmental delay, and some of the births have multiple congenital anomalies or abnormal conditions, or both. Additionally, nearly one-half of the abnormal conditions and the congenital anomalies are unspecified[6]. Finally, the Kentucky Birth

[4] Abel, Burke and Curry-White, 4.
[5] *The KBSR Reporter:* The newsletter of the Kentucky Birth Surveillance Registry, 1:1, Spring (1999), 2.
[6] Kentucky Vital Statistics Birth File, 1997; Kentucky Department for Public Health, Cabinet for Health Services.

Surveillance Registry currently only receives reports from 65 percent of Kentucky hospitals, primarily those in urban areas. Since there is an anticipated difference in the incidence of birth defects in urban and rural areas, it is not possible to generalize these figures to the entire state.[7] Thus, data from birth certificates is not adequate for estimating the number of infants with established risk conditions.

Since data from a birth defect registry were not available for Kentucky, the researchers from the University of Louisville applied nationally known prevalence rates of established risk conditions to Kentucky births. The estimated established risk rate for Kentucky using this procedure was 1.1% of births.[8] In comparison, Washington's established risk rate, that was based on infant tracking data, was 1.8% of births and Connecticut's rate, based on hospital discharge data, was 2.4% of births.[9]

Several Kentucky Factors Lead to Increased Estimates

There are several reasons why using national rates yielded estimates of established risk that were low for Kentucky. As indicated in the University of Louisville report, there is not an exhaustive list of known prevalence rates for conditions leading to developmental delay. For instance, national prevalence rates for behavioral or emotional disorders are not available. The only national prevalence rate for behavioral or emotional disorders used in the University of Louisville estimate was for autism, and this estimate was considered low. Also, many conditions are difficult to diagnose at birth so even the national estimates are likely to be low.[10]

One major set of conditions for which national prevalence rates are not available is teratogen exposure. **A teratogen is any substance, agent, or process that interferes with normal prenatal development which can cause developmental abnormalities in the fetus.** Two of the most common teratogens are maternal alcohol consumption and maternal smoking. The University of Louisville researchers used an estimate of exposure to alcohol derived from self reports of alcohol use on Kentucky birth certificates. As indicated by the researchers, it is likely that the estimate produced for Kentucky, about 18 cases of alcohol exposure, is much lower than would be expected in reality.[11] Additionally, maternal smoking is thought to expose the fetus to teratogens, but national prevalence rates of resulting abnormalities are not available. Maternal smoking is much higher in Kentucky that in the nation. Nearly twice as many teen mothers smoked during pregnancy in Kentucky than in the United States, 31% in Kentucky compared to 17% in the United States in 1996.[12] The rate of smoking in Kentucky is 30.8 percent compared

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[7] Information provided in interview with representatives from the Kentucky Birth Surveillance Registry, Kentucky Department for Public Health, September 30, 1999.
[8] Abel, Burke, and Curry-White, 22.
[9] *Cost Estimate: Early Intervention Program for Infants and Toddlers with Handicaps* (Hartford, CT: Office of Policy and Management, 1989), 5.
[10] Abel, Burke, and Curry-White, 12.
[11] Abel, Burke, and Curry-White, 10-12.
[12] *Kids Count Data Book: State Profiles of Child Well-Being (*Baltimore: Annie E. Casey Foundation, 1999), 28 and 76.

to 22.9 percent in the United States in 1998.[13] However, the risk of teratogen exposure from maternal smoking is not included in the Kentucky estimate of the established risk rate.[14]

In addition to maternal smoking, there is one major risk factor that is higher in Kentucky, compared to other states. The estimated consanguinity rate is 7% of births in Kentucky, compared to 0.5% of births in the United States. **Consanguinity means descent from a common ancestor or birth from blood-related parents.** The estimated consanguinity rate is 10% among those seen in genetics clinics in eastern Kentucky. The high proportion of births from blood-related parents leads to a higher incidence of recessive disorders, multifactorial abnormalities, and pregnancy loss.[15] Specifically, the neural tube defect rate in eastern Kentucky is 1 in 500 compared to the national rate of 1 in 1,500 births. In part, this is related to the predominance of Scotch, English, Irish and Welsh heritage in eastern Kentucky. According to Dr. Cadle, geneticists consider families of up to fourth cousins to be consanguineous. The risk of congenital abnormalities are highest for births between first cousins, about eight percent. The risk of abnormality declines with the degree of relationship. In the general population, the risk is about four percent. For fourth cousins, the risk is about five percent. The risk of an abnormal birth is higher when there is a known family history of abnormality and blood related birth parents. Dr. Cadle indicated that estimates of consanguinity are based on the experience of geneticists in different states. Kentucky, eastern Kentucky in particular, continues to have a higher rate of consanguineous births than other states, but in his experience, this rate has been declining in the past few years.[16](KRS 402.010 prohibits marriage "between persons who are nearer of kin to each other by consanguinity, whether of the whole or half-blood, than second cousins.")

Kentucky's higher incidence of key risk factors has resulted in a higher incidence of conditions associated with developmental delays. Kentucky has the highest incidence of spina bifida of all 50 states and the second highest birth defects mortality rate in the nation. (Table 2.2). Given the underestimates of categories and unknown prevalence rates for conditions, the figure of 1.1% for established risk derived by the University of Louisville researchers is judged seriously low. This is a major consideration because the formula used to estimate the percent of the population age birth to three years at risk of developmental delay is highly dependent upon the established risk estimate. If, for instance, Kentucky had used 1.8% as its estimate of established risk, as did Washington, the projection of the eligible population age birth to three years in 1995 would have been 5,453 compared to 3,894.

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[13]Centers for Disease Control and Prevention 1999.
[14]Abel, Burke, and Curry-White, 11.
[15]Dr. Ron Cadle and Barbara B. Biesecker, "Genetic Counseling in Eastern Kentucky,'*Birth Defects Original Article Series* 23:6 (1987), 258. (Article available through the National Library of Medicine: IGM, IDS PMIS: 345771 UI: 88135014).
[16] Information provided by Dr. Ron Cadle, University of Kentucky Medical Center, Lexington, Kentucky, November 8, 1999.

Developmental Delay. Federal law permits each state to define the criteria for developmental delay as long as eligibility is based on comprehensive evaluation in five skill areas:

(1) cognitive development,
(2) speech and language development,
(3) Psychosocial development,
(4) Self-help skills, and
(5) Physical development.

Table 2.2
Birth Defects Infant Mortality Rates
By State, Four Year averages, U.S., 1988-1991

State	Rate	Percent of U.S. Rate	Rank
Alabama	242.4	122%	49
Alaska	189.3	95%	15
Arizona	227.1	114%	45
Arkansas	211.4	107%	38
California	190.4	96%	17
Colorado	199.1	100%	23
Connecticut	160.0	81%	4
Delaware	232.5	117%	47
District of Columbia	180.6	91%	9
Florida	194.4	98%	21
Georgia	209.0	106%	35
Hawaii	153.5	77%	1
Idaho	218.9	110%	39
Illinois	208.6	105%	33
Indiana	209.8	106%	36
Iowa	221.8	112%	40
Kansas	200.1	101%	26
Kentucky	242.5	122%	50
Louisiana	226.1	114%	43
Maine	186.2	93%	11
Maryland	171.0	86%	6
Massachusetts	153.9	78%	2
Michigan	190.8	96%	18
Minnesota	200.1	101%	25
Mississippi	222.8	112%	41
Missouri	208.1	105%	32
Montana	225.8	114%	42
Nebraska	207.2	104%	29
Nevada	169.9	86%	5
New Hampshire	189.6	96%	16
New Jersey	179.6	91%	7
New Mexico	240.9	121%	48
New York	183.9	93%	10
North Carolina	207.8	105%	31
North Dakota	251.3	127%	51
Ohio	199.2	100%	24
Oklahoma	192.4	97%	19
Oregon	179.9	91%	8
Pennsylvania	195.8	99%	22
Rhode Island	188.4	81%	13
South Carolina	227.0	114%	44
South Dakota	205.8	104%	28
Tennessee	194.3	98%	20
Texas	208.8	105%	34
Utah	211.2	106%	37
Vermont	158.3	80%	3
Virginia	188.8	95%	14
Washington	188.1	95%	12
West Virginia	229.0	115%	46
Wisconsin	207.4	105%	30
Wyoming	205.4	104%	27
United States	198.4		

Source: Teratology: The Journal of Abnormal Development
Vol. 56, Nos. 1/2, July/August 1997

In Kentucky, the developmental delay category includes criteria which identify infants and toddlers who are significantly behind developmental norms. Developmental delays may be the result of birth into an established risk category but also may arise from environmental influences in early childhood. Socioeconomic conditions, such as the mother's age, educational level, income status, and the baby's birthweight shape the environment influencing early child development. These conditions are somewhat more severe in Kentucky relative to the United States.

The teenage birth rate is relatively high in Kentucky. In 1996 there were 37 births per 1,000 women aged 15 to 17 years in Kentucky compared to 34 births per 1,000 women aged 15 to 17 in the United States.[17] The infant tracking program in Washington found that enrollment rates in the early intervention program were 40 times higher for children of teenage mothers than for children of older mothers.[18]

Educational attainment is also lower in Kentucky compared to the national average. In 1996, 14% of Kentucky teenagers 16 to 19 years old were high school dropouts compared to 10% of teenagers in the United States.[19] The Washington infant tracking program found that enrollment rates in the early intervention program were twice as high for the 8 to 11 years of education group compared to the college graduate parent group.[20]

The Washington study also found that children of mothers qualifying for Medicaid in the lowest income categories had enrollment rates in the early intervention program twice as high compared to children of non-Medicaid mothers.[21] The percent of births covered by Medicaid was 42% in Kentucky in 1996 and 38% in the United States. The percent of children covered by Medicaid in Kentucky in 1996 was 31% compared to 25% in the United States.[22]

Birthweight is a primary indicator of the health of the newborn infant. Low birthweight is associated with increased risk for a variety of learning disorders and behavior problems. Kentucky has a slightly higher proportion of low birthweight babies compared to the United States, 7.9% compared to 7.4% of births.[23] The Washington infant tracking study found enrollment rates of up to 15 times higher for infants born with low birth weights compared to normal birthweight babies.[24]

While the environmental conditions increasing the risk of developmental delay are known, there are not accurate counts of the number of children who experience

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[17] *Kids Count Data Book*, 77.
[18] Washington State Department of Social and Health Services, Washington's Infant Toddler Early Intervention Program Study, December 1, 1998 (Olympia: Department of Social and Health Services, 1999), 25 and 27.
[19] *Kids Count Data Book*, 77.
[20] Washington State Department of Social and Health Services, 25 and 27.
[21] Washington State Department of Social and Health Services, 26-27.
[22] *Kids Count Data Book*, 76.
[23] *Kids Count Data Book*, 77.
[24] Washington State Department of Social and Health Services, 21.

developmental delay. Federal estimates of children with disabling conditions by age five range from 8.5% to 12% of births using the standards of P.L. 94-142. Connecticut used a conservative estimate of 8.5%[25]. Illinois estimated that 6% of births would have developmental delay and would be eligible for early intervention services based on figures in Appendix B of the Illinois Auditor;s report, attributed to the Illinois Department of Public Health.[26] Washington used a mid-range estimate of 10% of births. The University of Louisville researchers also used the estimate that 10% of births would have developmental delay by age five in order to estimate the eligible population age birth to three years with developmental delay in Kentucky.[27]

This estimate of the proportion of children with developmental delays by age five appears to be reasonable, but possibly somewhat low. The Kentucky Child Count report provides a one-day count of the number of handicapped children in Kentucky from ages three to 21 years who are receiving special education and related services under IDEA-Part B of the federal act. In 1997, Kentucky Child Count data indicated that 14,997 children age 3 to 5 years, 9.3% (14,997 of 160,599) of the population this age received services. Of the children age 5, 11.5% (6,273 of 54,423) received services.[28] If Kentucky had used 11.5% as its estimate of the proportion of children with developmental delay by age five and 1.8% as its estimate of established risk, the projection for the eligible population age birth to three years in 1995 would have been 5,633, compared to 3,894.

Number of Children in First Steps has Increased Rapidly

The number of infants and toddlers in First Steps has been reported in various ways. It is important to understand the differing definitions when assessing program growth rate. Starting in 1994, the number of children in the program was defined by a child count of those enrolled on a single day of the year. That was the only data available on the number of children in the program until the advent of CBIS in FY 1998. There were 1,078 active in the program on the child count date in FY 1994, and 3,402 active on the child count date in FY 1999.(Table 2.3)

With CBIS it is now possible to track the total number of children for whom payments are made throughout the year. These can be broken into two groups. The first includes those who are eligible and receive services. There were 5,098 of these children in FY 1999, a 27 percent increase over FY 1998. The second group who has payments made include those for whom screening is provided but who are determined to be ineligible for services. There were 1,952 of these children in FY 1999, up 34 percent

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[25] Connecticut. Office of Policy and Management, 5.

[26] *Evaluation of the Early Intervention Services System* (*as required by P.A. 87-680*) (Springfield, IL.: Office of the Auditor General, 1993), 59.

[27] Abel, Burke, and Curry-White, 18-19.

[28] Kentucky Department of Education, Division of Exceptional Children Services, faxed tables dated 3/28/98. Population figures from *1990-1998 Population Estimates for Kentucky by Single Year of Age-Totals*. Kentucky State Data Center, Kentucky Population Research, Urban Studies Institute, University of Louisville .

from the previous year. Thus, together, there were a total of 7,050 children for whom payments were made in FY 1999 under the First Steps program. This was 29 percent greater than FY 1998.

Table 2.3
First Steps Program Statistics

	A		B		C		D			
Fiscal Year	Child Count	Percent Increase	Eligible Children	Percent Increase	Ineligible Children	Percent Increase	Total Children	Percent Increase	Total Budget $M	Percent Increase
1994	1,078								$2.0	
1995	1,336	24%							$3.4	70%
1996	1,933	45%							$7.8	129%
1997	2,614	35%							$13.7	76%
1998	2,944	13%	4,007		1,456		5,463		$19.0	39%
1999	3,402	16%	5,098	27%	1,952	34%	7,050	29%	$23.4	23%

Definitions	
A	Number of children with active IFSPs on a particular day.
B	Number of children with active IFSPs any point during the year.
C	Number of children screened but found ineligible.
D	Number of children for whom payments were made during the year. (B+C)

Source: CBIS Database

In the United States, the number of children served increased from about 150,000 on December 1, 1993, to over 185,000 on December 1, 1998, an increase of 23%. Nationally, there was a slight decline in percent of the population served from December 1, 1996, to December 1, 1998, from 1.64% to 1.59% whereas in Kentucky the increase in the proportion of the birth to three population served was from 1.36% to 2.12%.[29]

State Variation. According to federal data, 35 states had increases in the percent of the total population served from 1996 to 1998. Most were small increases of less than 0.5 percent. Kentucky, Mississippi, and New York experienced the largest increases. Kentucky increased from 1.36% to 2.12%, Mississippi increased from .05% to 1.68%, and New York increased from 1.96% to 2.75%. Overall, 14 states experienced declines in the percent of the population served. Ohio experienced the largest decline from 3.88% to 1.13 %. December 1, 1998, Hawaii served 6.35% and Massachusetts served 4.06% of the birth to three population. In comparison, Iowa served only 0.86% and Louisiana served 0.89%.[30]

The only apparent explanations for the variation in rates among states are that actual need is lower in some states than others, identification is higher in some states than others, or eligibility criteria are broader in some states than others. It is not known which of these explanations accounts for more of the variation than another. Factors known to increase the risk of actual need do not seem to correlate perfectly with the percent of the

[29] 20th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act: Section II, 1998; U.S. Department of Education, Correspondence, 1999.
[30] 20th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act: Section II, 1998; U.S. Department of Education, Correspondence, 1999.

population served. For instance, the teenage birth rate in Massachusetts is 20 per 1,000 women age 15 to 17 years, the state high school dropout rate is 7%, the proportion of births covered by Medicaid 21%, and the percent of low birth-weight babies is 6.4%. The teenage birth rate in Louisiana is 43 per 1,000 women age 15 to 17 years, the state high school drop out rate is 12%, the proportion of births covered by Medicaid is 50% and the percent of low birth-weight babies is 9.9%. Massachusetts does have a higher maternal smoking rate among teenagers than Louisiana, 23% compared to 10%. Yet, Massachusetts serves four times more of its children birth to three years old population as Louisiana, 4% compared to 0.89%.[31] Thus, it is likely that the explanation of variation among states involves a complex combination of actual need, identification, and, to a very great extent, eligibility criteria – particularly the decision regarding whether to extend eligibility to the at-risk group.

Within Kentucky, there is a great deal of variation by county in the percent of the birth to three population receiving services. The range is from 0 in Green County and 0.3% in Trimble County to 6% in Muhlenberg County. The next highest proportions are for Menifee (5.4%), Rowan (4.9%), Hart (4.8%), and Caldwell (4.6%). All other counties have proportions below 4%. Most counties, 75 of them, report 2.0% or fewer children age birth to three years receiving services (Table 2.4). There is also variation in the number of children age birth to three years served by Area Development District (ADD). Barren River, Gateway, and Purchase districts are serving more children than estimated in the original University of Louisville estimate (Table 2.5).

The apparent explanations for the variation among counties and ADDs are that actual need is lower in some counties than in others or identification is higher in some counties than in others. Eligibility criteria are the same across the state. It is not known which of these explanations accounts for more variation than another. Factors known to increase the risk of actual need appear to account for some variation in the percent of the population served. For instance, in 1996 in Hart County, which serves 4.8% of children birth to three years old, the teen birth rate is 20.8 births per 1,000 women age 12 to 17 years, the dropout rate for 1996-97 is 2.4%, 29.4% of the children under 19 receive Medicaid, and 9.4% of the babies had low birthweight. In 1996 in Boone County, which serves only 1.6% of the population birth to three years old, the teen birth rate is 12.9 births per 1,000 women age 12 to 17 years, the dropout rate for 1996-97 is 2.3%, 7.7% of the children under 19 receive Medicaid, and 5.4% of the babies had low birthweight.[32] Since the criteria for eligibility are uniform across the counties since they are defined at the state level. Thus, it is likely that actual need and identification explain the county variation within Kentucky.

[31] *Kids Count Data Book*, 78-79 and 84-85.
[32] *1998 Kids Count County Data Book* (Baltimore: Annie E. Casey Foundation, 1998), Boone County.

TABLE 2.4
Number of Children Who Had Payments Made on Their Behalf, FY99

County	KEIS Children	Total Population Age 0-2	KEIS as % of Total	County	KEIS Children	Total Population Age 0-2	KEIS as % of Total	County	KEIS Children	Total Population Age 0-2	KEIS as % of Total
(Not Identified)	207			Greenup	52	1216	4.3%	Nelson	67	1471	4.6%
Adair	17	536	3.2%	Hancock	5	359	1.4%	Nicholas	7	223	3.1%
Allen	21	651	3.2%	Hardin	141	4351	3.2%	Ohio	33	809	4.1%
Anderson	13	745	1.7%	Harlan	58	1365	4.2%	Oldham	69	1592	4.3%
Ballard	18	249	7.2%	Harrison	18	645	2.8%	Owen	7	363	1.9%
Barren	53	1315	4.0%	Hart	37	607	6.1%	Owsley	7	184	3.8%
Bath	29	387	7.5%	Henderson	44	1741	2.5%	Pendleton	10	651	1.5%
Bell	59	1127	5.2%	Henry	21	556	3.8%	Perry	77	1132	6.8%
Boone	138	3653	3.8%	Hickman	9	181	5.0%	Pike	106	2653	4.0%
Bourbon	47	778	6.0%	Hopkins	62	1729	3.6%	Powell	9	542	1.7%
Boyd	111	1660	6.7%	Jackson	21	503	4.2%	Pulaski	84	1970	4.3%
Boyle	34	921	3.7%	Jefferson	1421	25937	5.5%	Robertson	0	75	0.0%
Bracken	21	306	6.9%	Jessamine	58	1536	3.8%	Rockcastle	27	600	4.5%
Breathitt	31	624	5.0%	Johnson	33	848	3.9%	Rowan	64	754	8.5%
Breckinridge	37	607	6.1%	Kenton	278	6948	4.0%	Russell	13	568	2.3%
Bullitt	94	2391	3.9%	Knott	32	676	4.7%	Scott	38	1159	3.3%
Butler	7	444	1.6%	Knox	61	1291	4.7%	Shelby	60	1047	5.7%
Caldwell	23	455	5.1%	Larue	16	459	3.5%	Simpson	25	692	3.6%
Calloway	37	1004	3.7%	Laurel	111	1915	5.8%	Spencer	21	344	6.1%
Campbell	137	4009	3.4%	Lawrence	24	597	4.0%	Taylor	28	813	3.4%
Carlisle	8	174	4.6%	Lee	11	288	3.8%	Todd	18	429	4.2%
Carroll	29	397	7.3%	Leslie	18	608	3.0%	Trigg	13	373	3.5%
Carter	45	986	4.6%	Letcher	28	943	3.0%	Trimble	14	302	4.6%
Casey	20	528	3.8%	Lewis	21	477	4.4%	Union	19	542	3.5%
Christian	145	3819	3.8%	Lincoln	18	849	2.1%	Warren	175	3155	5.5%
Clark	41	1232	3.3%	Livingston	15	300	5.0%	Washingtc	9	407	2.2%
Clay	64	958	6.7%	Logan	38	885	4.3%	Wayne	45	700	6.4%
Clinton	12	324	3.7%	Lyon	9	179	5.0%	Webster	17	481	3.5%
Crittenden	14	353	4.0%	Madison	113	2258	5.0%	Whitley	80	1430	5.6%
Cumberlan	4	257	1.6%	Magoffin	22	548	4.0%	Wolfe	16	262	6.1%
Daviess	181	3811	4.7%	Marion	25	619	4.0%	Woodford	39	936	4.2%
Edmonson	13	410	3.2%	Marshall	40	992	4.0%	**Total**	**7,050**	**152,890**	**4.6%**
Elliott	11	269	4.1%	Martin	37	519	7.1%				
Estill	12	563	2.1%	Mason	47	664	7.1%				
Fayette	401	9545	4.2%	McCracker	153	2258	6.8%				
Fleming	16	478	3.3%	McCreary	35	703	5.0%				
Floyd	81	1771	4.6%	McLean	11	321	3.4%				
Franklin	68	1626	4.2%	Meade	28	1648	1.7%				
Fulton	17	268	6.3%	Menifee	16	223	7.2%				
Gallatin	15	304	4.9%	Mercer	24	743	3.2%				
Garrard	14	478	2.9%	Metcalfe	16	330	4.8%				

Sources: Ky. State Data Center; Ky. Licensed Physicians By Speciality, Aug. 1999, CHR and CBIS Database

Table 2.5 University of Louisville Estimates of Eligible Population And 1997/1998 Actual Counts					
ADD	Estimate	1997 Count	1998 Count	+/- Estimate 1997	+/- Estimate 1998
Barren River	160	193	203	33	43
Big Sandy	199	144	161	-55	-38
Bluegrass	591	384	460	-207	-131
Buffalo Trace	58	51	60	-7	2
Cumberland Valley	283	220	246	-63	-37
Fivco	122	95	110	-27	-12
Gateway	63	106	93	43	30
Green River	218	109	142	-109	-76
Kentucky River	166	92	113	-74	-53
KIPDA	766	691	844	-75	78
Lake Cumberland	177	107	128	-70	-49
Lincoln Trail	281	156	165	-125	-116
Northern Kentucky	368	287	318	-81	-50
Pennyrile	220	150	160	-70	-60
Purchase	160	234	221	74	61
Total	**3832**	**3019**	**3424**	**1184**	**1590**

The Eligible Population and the Population Served

The number of children from birth to three years of age that are served in the First Steps program is higher and has increased faster than originally estimated. The projected number of eligible children is shown in Table 2.6.[33] In the budget for KEIS, the projected number to be served was about 75% of the projected eligible population. It was thought that not all of the eligible population would be served. Some children may not be identified and others may refuse services. Thus, the projected number of children on which the budget was based was 2,800. Until 1997, the actual child counts of the number of children in the program on particular days were lower than 2,800 (Table 2.3). By 1999, the actual child counts of the number of children in the program on particular days was 3,402 children. This number is still lower than the 3,738 eligible children projected in the University of Louisville report (Table 2.6). However, the number of children with active IFSPs at any point during the year was 4,098 in 1999 (Table 2.3). This indicates a higher number of children than estimated in the University of Louisville report. What accounts for the difference in the size of the eligible population as estimated by the University of Louisville and the actual child counts of eligible children served as reported by First Steps?

[33] Abel, Burke, and Curry-White, 24.

TABLE 2
Projected Number of Children inTh
Groups with Developmental De
1990, 1995, and 2000 for Ke

Age	Incidence Rate	1990	1995	2000
Birth to < 1 year	1.1	585	559	537
1 to < 2 years	2.2	1,171	1,122	1,077
2 to < 3 years	4.3	2,148	2,213	2,124
TOTAL	7.6	3,904	3,894	3,738

Source: Abel, Burke, and Curry-White, 1991; Table 19, page 24.

The evaluation of the methodology used to estimate the eligible population indicates that the original projections were significantly low. The University of Louisville researchers acknowledged this in their report. The method used did not accurately account for the relatively high-risk population in Kentucky. Specifically, the established risk rate was low because it did not incorporate the effects of Kentucky's relatively high risk rates including maternal smoking, consanguinity, and lower than average environmental conditions. As indicated in the University of Louisville report, other national prevalence rates for established risk conditions are likely to be low. While it is difficult to determine precisely how low the University of Louisville estimate is, small changes in the figures used result in significant differences in the projected numbers of eligible children. For example, changing the established risk rate to 1.8% of births from 1.1% of births increases the projected population in 1995 to 5,453, compared to 3,894. If the estimate of the proportion of children developmentally delayed by age five was increased to 11.5% from 10% the projected population increases to 5,633. These figures are much closer to the actual number of children served.

There are other indications that suggest that the original estimate was too low. Vital Statistics data show that in 1996 there were about 4,148 low birth weight babies in Kentucky.[34] Low birth weight is a major predictor of developmental delays. If the number of low birth weight babies remained constant and only one in fifteen of these babies had some developmental delay over the following three years, nearly 2,000 of these children would be eligible for services. This does not include children with established risk and developmental delays due to other causes.

Another consideration is the disconnect between the number of children served under First Steps and the number served in the pre-school program for three to five year olds. In Kentucky, the total number of three year olds with disabilities served in Head Start and in State Funded Preschool was 4,570 in FY 1999. Department of Education officials estimated that about 1,600 of those three year olds, or about one third, came from First Steps.[35] Kentucky served the highest percentage (9.5 percent) of the children ages three through five years compared to all other states under the IDEA Preschool

[34] Kentucky State Center for Health Statistics, Annual Vital Statistics Report, 1996.
[35] Lancaster Correspondence, 1999.

Grants Program.[36] There are more children diagnosed with learning disabilities in the three to five year age group than in the birth to three year age group. One reason for this is that many developmental disabilities go undiagnosed or do not appear before the age of three. As children enter preschool and pre-kindergarten programs the developmental delays become more apparent. Still, the fact that there is a much higher percentage of three to five year olds eligible for pre-school programs than have been identified for First Steps indicates that there may be a significant number of infants and toddlers, likely with less obvious delays, who have not been identified.

Most data on participation in programs for children with developmental delays show gradual increases in the proportion of children served between birth to five years. Estimating the population eligible for early intervention services, such as the Washington formula used by the University of Louisville researchers, also assumes this steady increase in the proportion with developmental delay (Table 2.7).[37] Increased infant and toddler screening is likely to result in diagnosis at earlier ages. This may increase the proportion of birth to three year old children served, but possibly lower the proportion of children needing services in later years.

TABLE 2
Kentucky and Washington Rates (in P
for Children Birth through 3 Years of A
Developmental Del

Age	Kentucky	Washington
Birth to < 1 year	1.1	1.8
1 to < 2 years	2.2	3.6
2 to > 3 years	4.3	5.2
3 to < 4 years	6.4	6.7

Source: Abel, Burke, and Curry-White, 1991

A couple of factors are likely to influence the future number of eligible children in Kentucky. One, increased use of prenatal care, a decline in maternal smoking, and increase use of maternal folic acid, could result in a significant decrease in the number of children at risk of developmental delays. On the other hand, the increased ability to sustain life among premature infants and an increased ability to diagnose developmental delays earlier could lead to an increase in the number of children eligible for services.

To summarize, the number of the birth to three children served nationally has increased since the initiation of the Part C program. Individual states have seen declines, but many have had increases. Thus, it is not extraordinary that Kentucky has experienced an increase in the proportion of the population served. It also seems that Kentucky initially underestimated the eligible population to be served. It is possible that the initial

[36] NEC*TAS, Chapel Hill, North Carolina, "Helping Our Nation's Infants and Toddlers with Disabilities and their Families," 1996, http//www.nectas.unc.edu/part_h/parthpap.htm.
[37] Abel, Burke, and Curry-White, 22.

estimates were low because the estimation formula used did not accurately determine the high risk populations in Kentucky. However, Kentucky is currently serving a higher percentage of the birth to three year old population than the majority of states.

Child Find Efforts Should be Improved

Child find is an outreach requirement under the federal law used as a means of identifying all eligible children. Basically, outreach is public relations and community education. Outreach activities include health fairs, visits to local health departments, information in doctor's offices, school resource centers, senior citizens centers, and any place the POEs can put brochures. First Steps personnel, POEs and other professionals interviewed by staff stated that there are many areas of the state where more children are eligible, but not referred to the system. It was stated that, in remote areas of rural Kentucky, there are children and families who need services, but do not know about the First Steps program.

Likewise, according to First Steps officials, there is underreporting of children with particular conditions, such as fetal alcohol syndrome and drug reactions, that may be more frequent in urban areas. Almost all the point of entries, program consultants, and others interviewed agreed that the program is not finding all the children who need services.

According to the First Steps personnel and providers, there are several reasons that an eligible child might not be identified. Some of the most common reasons are:

- In some areas, there are not as many pediatricians, who are more familiar with age norms
- Physicians take a wait-and-see approach so as not to alarm parents
- Physicians and parents are not familiar with the program
- Parents do not know the developmental milestones

Many POEs expressed the need for more resources to reach the children that are eligible, but are not referred to them. Due to tight fiscal constraints, the First Steps central office cannot even supply POEs with adequate numbers of brochures. Many POEs expressed the need for a statewide media campaign, including television, radio, and local newspaper coverage. Referrals could rise if this type of advertising campaign is taken by the Cabinet for Health Services on a statewide basis.

Points of Entry Have to Balance Child Find With New Referrals

In some instances, some POEs must balance their screening and development of the initial IFSP for children already referred and their child find activities to identify new referrals. By administrative regulation, each POE is supposed to contact two potential referring sources each month. Due to the demands of the increasing referrals, all POEs have not been able to meet this requirement. For example, one POE said that she has to

do a balancing act among the enrollment, evaluation, the intake for the referral, and the child find duties. Time constraints were mentioned as a major issue by several POEs.

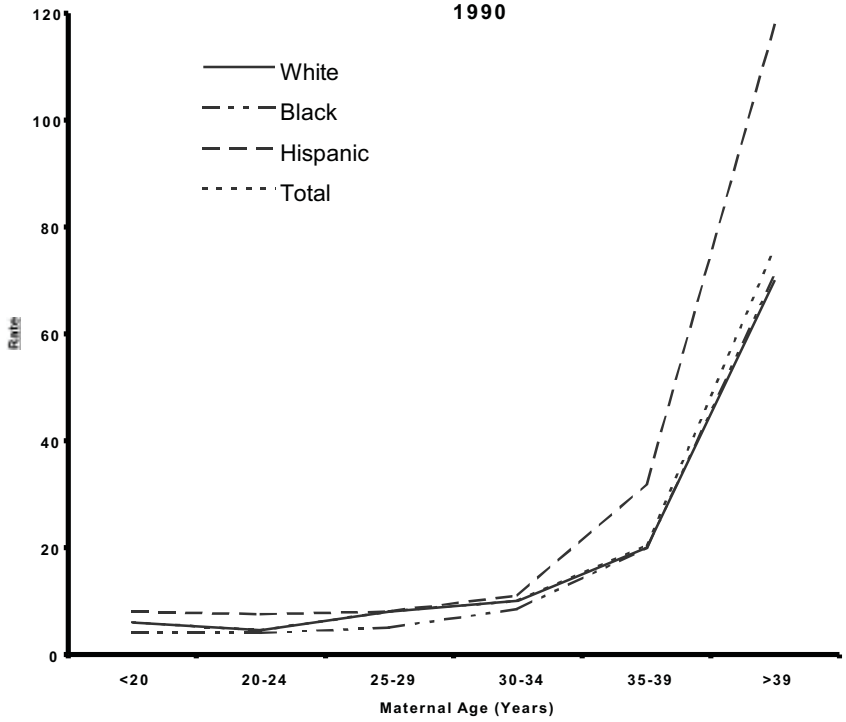
Another factor is that the number of referrals and children being served is rising constantly while there has been no increase in the number of POE staff to cover an entire area development district. Particularly in rural areas, there is often a need to drive long distances into isolated areas since some of the families do not have telephones and may not even be available, making the work of the point of entry much more difficult. The point of entry would be greatly assisted if there were local contact people in some of these remote areas. Although the District Early Intervention Councils work on the local level, it would be beneficial to have more local involvement, especially in these isolated areas.

State Policies Could Significantly Affect the Number of Eligible Children and the Percentage Served

Many of the infants and toddlers currently being served in First Steps have established risk conditions that arise from known, preventable causes. In the last two years, 59 children with spina bifida received the 7th largest total First Steps expenditure for services, at half a million dollars. Recent research has shown that consumption of adequate amounts of folic acid both prior to and during pregnancy can prevent most occurrences of spina bifida. It is also known that low birthweight babies have a much higher incidence of developmental delays. Delivery of low birthweight babies is known to be more common among teenaged mothers, poor mothers, smokers, and those who consume alcohol or drugs during pregnancy. Having parents who are related by blood to even the fourth degree is known to significantly increase the prevalence of mental retardation. Figure 2.A demonstrates that the risk of Down's Syndrome increases dramatically when the mother is aged 35 or more.

FIGURE 2.A

Rate of Down's Syndrome at birth, by race/ethnicity of mother and ı group - 17 state-based birth defects surveillance programs, United States, 1983-1990



If the state were to mount an aggressive and effective education and prevention campaign regarding some of these known risk factors, it could significantly change the number of infants and toddlers eligible for First Steps. If the campaign were successfully targeted to women who are currently pregnant, there could be an effect on the First Steps program within one or two years. For example, the Department of Medicaid Services recently announced that Medicaid will now cover substance abuse prevention and treatment for pregnant women and new mothers who are enrolled in the program.

As an entitlement program, First Steps is required to offer services to all children who meet the eligibility criteria. State policies could significantly increase the identification of such children. For example, the November 1999 report from the Governor's Early Childhood Task Force recommended audiological screenings for all newborn infants. If adopted, this recommendation could substantially increase the number of infants receiving services from First Steps. Similarly, state policies to improve identification of currently underreported conditions such as fetal alcohol syndrome, and to expand child find efforts in counties that appear to be relatively underserved, would increase the number of children in First Steps. If it increases the frequency and level of medical evaluations of infants and toddlers, KCHIP could both reduce the number with developmental delays and increase the percentage referred to First Steps.

Number of Eligible Children Remains Unknown
And Program Growth Rate Remains Uncertain

No reliable prevalence data on developmental delays among infants and toddlers has been collected, either in Kentucky or nationally. At this time, accurate estimation of the number with developmental delays is not possible. Therefore, it is also not possible to assess the percentage of eligible children who receive First Steps services. It is known that Kentucky serves a higher proportion of infants and toddlers that most other states. However, it is also known that Kentucky has a greater incidence of several risk factors than most other states.

In the absence of significant changes in state policies, it would be expected that the number of children served in the program in the last two years could be a reasonable basis for projecting the expected number for the next two years. The possibility of significant changes in policies affecting prevention and identification, however, reduces the reliability of the assumption that the future growth rate will be similar to that of the recent past.

SECTION III: PROGRAM EFFICACY AND QUALITY

The second question asked by the Committee was whether the developmental services received by infants and toddlers improve their developmental progress. As will be discussed, sufficient data has not been collected to allow the longitudinal tracking of developmental progress that is necessary to answer that question specifically for First Steps. In the absence of that data, staff did the following:

- Reviewed the outcomes research literature on other early intervention programs to develop general conclusions about efficacy of services;
- Reviewed the literature on recommended features of successful early intervention programs and compared the features of First Steps to those recommended in the literature;
- Interviewed 17 points of entry and 13 primary service coordinators to obtain their perspective as providers;
- Interviewed 6 pre-school coordinators and four of five regional training center coordinators to elicit their experiences with children who had received services in First Steps.

Other program quality indicators, such as monitoring, parent satisfaction, and provider satisfaction are addressed as well.

Measurement of Developmental Outcomes has Proven Difficult

Staff interviewers received overwhelmingly positive responses to their queries about the efficacy of services delivered by First Steps. However, from a research perspective, it has proven difficult to objectively measure early intervention outcomes, and a brief survey of literature in the field consistently confirmed this observation. The reasons for this difficulty are threefold.

First, early intervention studies have been hampered by an inability to conform to accepted research models. An objective study ideally uses a control group (a group that is not exposed to the programs or methods being tested) to gauge the resulting effects on the study sample who **do** receive the treatments. Researchers, however, have been reluctant to use control groups in the context of early intervention studies. Although early intervention lacks a large body of research literature to support its efficacy, preliminary studies and anecdotal information strongly suggest that it offers benefits. Given this positive perception, researchers have balked at utilizing control groups, citing the unethical implications of denying infants and toddlers access to programs that could provide them with an improved quality of life.

Second, many of the outcomes of early intervention, while certainly positive in nature, are difficult to express in statistical terms. Factors such as increased self esteem and decreased stress in the family environment can make all the difference in the world to a child's level of functioning but are difficult, if not impossible, for a researcher to

quantify. Researchers in the field of early intervention constantly confront the difficulty of quantifying intangibles.

Third, some members of the early intervention community have resisted subjecting children to the testing methods that would yield the statistical data sought by policy makers. In recent years, there have been many highly publicized studies of standardized testing instruments that point to economic, cultural, racial, and gender biases inherent in these supposedly objective tests. Some early intervention providers point to these doubts about standardized testing and voice concerns that such tests might not provide accurate assessments of a child's true abilities, especially a child who may be economically disadvantaged. Also, there is the additional consideration that a relatively low score may leave parents disappointed and demoralized and, thereby, slow the child's future progress. Given these doubts about testing accuracy and fairness, many children are not being tested for discernible outcomes because their providers believe they are better served by deferring testing activities in favor of additional intervention treatment.

Credible Research Shows Intervention Improves Development
Questions Remain about Increasing Service Intensity

Despite these three barriers to obtaining strict empirical evaluations, several credible researchers have attempted to evaluate the general efficacy of early intervention programs. For the sake of brevity, major findings have been condensed into Table 3.1

Clearly, the bulk of the research literature supports the conclusion that early intervention has a positive effect on the developmental process. Recent studies have shown, however, that this knowledge cannot be used to extrapolate an argument that the more often children receive early intervention services, the better off they will be. In 1985, Dr. Mark Innocenti and researchers at the Early Intervention Research Institute began conducting a series of long-term studies that measured several aspects of early intervention programs. One of the findings of these studies was that high intensity intervention (intensity being equated with the frequency of services per week) did not produce significant effects on measures of child and family functioning, compared to low intensity intervention.

Nine separate well-controlled studies indicated that increasing the number of service hours per child did not lead to detectable positive effects on the child's skill development. In fact, the only positive effect that researchers could point to was a perception by families that they were receiving "better" support because they received more service hours. While the importance of positive family perceptions should not be discounted, they may not be sufficient alone to justify the marked increase in spending necessitated by expanded service offerings. These public funds may be better used to offer additional children basic early intervention services.[38]

[38] *Longitudinal Studies of the Effects of Alternative Types of Early Intervention for Children with Disabilities* (Washington D.C.: Department of Education, Early Intervention Research Institute Report No. ED 378 756, 1994).

According to lead researcher Dr. Mark Innocenti, these study results should not be used to question the value of providing early intervention services, because an overwhelming body of evidence supports the contention that early intervention benefits target groups. Instead, he suggested that these studies should serve as an impetus for better management of services. Budgets should be adjusted to maximize efficiency and economy, and, in some cases, this may entail cutting back on the frequency of services. However, overall spending on early intervention should remain intact, in his opinion.[39]

TABLE 3.
Documented Effects of Early Intervention Programs on Selected
(*indicates that the condition qualifies as an "established risk condition" under KRS 200.654 and is eligible for KEIS First Steps services)

Condition	Intervention Methods Used	Outcomes
***Autism**	Home visits by therapists; highly structured classroom settings at centers; Play therapy; Family support groups	Higher rates of "mainstreaming" into regular education classes; Increases in social, language, and motor skills.
***Blindness and Visual Impairments**	Skills training for parents; Auditory/Tactile therapy; Play therapy with auditory toys	No reliable statistical analysis available; Anecdotal reports from families seem to suggest many benefits
***Cerebral Palsy**	Therapeutic exercise; Task-oriented training	The Early Intervention model for cerebral palsy is shifting. Using therapeutic exercise to achieve motor skills has yielded disappointing results. Therapists now advocate a task oriented rehabilitation model aimed at increasing the child's ability to perform functional tasks. Studies that incorporate these functional outcomes are being initiated.
***Communication Disorders**	Intensive speech therapy; Home visits by therapists	More child initiation of speech; Significant increases in vocabulary; Reduced rates of stuttering
Conduct Problems	Skills training for parents; Training for children in cognitive processes (self control, problem-solving, etc.) and positive social skills development.	Programs that combined parent and child training were significantly more successful than programs that only addressed parents alone or children alone.
***Deafness and Hearing Impairments**	Skills training for parents; Home visits by therapists; family support groups; auditory training for hearing impaired; Training in manual communication	An average four (4) month gain in expressive language skills; An average five (5) month gain in receptive language skills
***Downs Syndrome**	Communication skills training; Training in functional skills; Socialization skills; Family support groups; Physical therapy services	Higher scores on scales measuring personal-social performance; Improved speech intelligibility; Improved parent-child communications; Negligible effect on gross motor skills.
Economic Disadvantage (as determined by federal poverty index guidelines)	Enrichment classes; Home visits; Emphasis on language development in all training.	Significantly higher high school graduation rates; Higher rates of college attendance; Higher employment rates
***Fetal Alcohol Syndrome**	In-depth assessment; Medical interventions; Skills training for parents; Family support groups	Data is limited due to the relative newness of this diagnosis; Programs do report very high levels of consumer satisfaction
HIV Positive Status	Necessary medical interventions; Programs emphasizing socialization skills; Play therapy; Home visits by therapists	No statistical analysis available yet, due to the fact that, until recently, HIV positive children had extremely short lifespans. New drug combinations have changed this; several studies are now underway
Low Birth Weight	Educational programs, instructions, and information sessions for parents; Extra auditory and visual stimulation activities for infants; Home visits by therapists	Higher mental and motor scores on the Bayley scales of Infant Development; Reduced occurrence of developmental delay at ages one (1) and two (2) years
Pre-term Infants in Neonatal Intensive Care Units (NICUs)	Increased family contact; Primary medical team for consistent caregiving; Increased holding and touching; Soothing environmental sounds	Better average daily weight gains; Less respirator use; Shorter hospital stays (an average savings of ($90,000); Less illness after hospital release

Source: The Effectiveness of Early Intervention, by Michael J. Guralnik (Brooks Publishing, Baltimore: 1997)

[39]Interview: Dr. Mark Innocenti, Research Scientist, Early Intervention Research Institute, November 18, 1999.

Dr. Gerald Mahoney, Director of the Family and Child Learning Center in Talmadge, Ohio agreed with Dr. Innocenti's concern that many high intensity programs may be wasteful. He pointed out that it is dangerous to generalize about this subject too much, however. He is currently conducting studies that suggest that increased physical therapy may yield some benefits. He believes each intervention mode should be individually evaluated in terms of intensity, and decreased or increased in treatment protocols according to the findings.[40]

Naturally, the type of in-depth evaluation Dr. Mahoney is calling for would take a considerable amount of time to conduct. Until such extensive research addresses this issue, these experts are counseling early interventionists to rethink old assumptions that more intensive early intervention efforts will yield increased benefits for children. According to both Dr. Innocenti and Dr. Mahoney, increased intensity should never be considered a cure-all, and it should only be initiated on a case-by-case basis if a preponderance of the evidence indicates that it may benefit an individual child.

Successful Programs Share Five Components

A review of early intervention literature compiled by experts in the field points to five aspects that are common to most programs deemed successful. These program components are:

1. A family-centered orientation to the program;
2. A local orientation to the program;
3. An ability to successfully integrate multiple disciplines;
4. The capacity to adequately coordinate services from numerous agencies; and
5. Utilization of home visits in the program.[41]

The first of these five aspects, the family-centered approach to service delivery, was actually a legal mandate. The Education of the Handicapped Amendments of 1986 (PL 99-457) completely redirected the focus of early intervention programs from a child-centered model to a family-oriented model. Although child-focused early intervention efforts did produce some beneficial results, over time a realization emerged that the family's role is central to the child's development. The family-centered approach recognizes that family and home are the primary developmental contexts for very young children. Parents are the child's first teachers. Siblings, if present, provide social support as well as a context for learning emotional control and social skills. Additionally, the entire family unit is influenced by the birth of a child with special needs. If this influence is negative, the resulting high levels of stress in the home are likely to impede the child's pace of development. Since early intervention exists to facilitate optimal child development, it has evolved into a program model that attempts to address these kinds of family realities and concerns. The range of family services offered varies from program to program, but most include three constants: parent-child interactions; skills

[40] Interview with Dr. Gerald Mahoney, Director, Family Child Learning Center, November 17, 1999.
[41] M.J. Guralnick, "Second-Generation Research in the Field of Early Intervention," in *The Effectiveness of Early Intervention*, ed. M.J. Guralnick (Baltimore: Brookes Publishing, 1997), 3-20.

development for parents; and family social networks (for example, parent support groups).

The results of these services are noteworthy. A 1991 study (The Family-Focused Intervention Model: Implementation and Research Findings by P. Caro and J.L. Derevensky) evaluated the effectiveness of the family-focused treatment model. Researchers documented increased child scores on the Battelle Development Inventory and the Movement Assessment of Infants tests. In addition to these statistics, parents reported significant improvements in family interactions. Later studies support these results, leading to professional conclusions that the family-centered approach to intervention does yield increased benefits for children.[42]

The second aspect of a successful program naturally flows from the acknowledgement that the child's immediate environment is key to his or her development. Most researchers agree that locally based programs are preferable to more centralized service delivery models. Although it is essential that local programs comply with the necessary state and federal regulations, actual service options should be local. Local programs are far more accessible, and an accessible program is far more likely to be utilized. Parents of special needs children already face unique stresses and time constraints; they should not have to bear the burden of inaccessible providers as well.

The local service delivery model is a paradigm in which a wide array of community organizations and residents are viewed as potential sources of support and resources. The Commonwealth of Virginia's early intervention approach offers the perfect example of this model. In Virginia a process called "community mapping" is used to identify and geographically locate resources to support an individual family's priorities and goals. Such an approach sometimes requires creative thinking on the part of intervention coordinators. However, viewing the entire community as a potential resource can ease the burden limited funding imposes on many early intervention programs.[43]

After resources are marshaled for a child, it then becomes important that the multiple disciplines brought into play are successfully integrated. (Aspect three of successful programs). Most programs integrate health and education models to meet a child's needs. The results of the best known study on this topic were released in 1992.[44] This research study was designed to test the efficacy of three combined program elements: pediatric (medical) practices; family therapy supports; and early childhood education aspects. A control group was limited to medical monitoring. At the study's end, children in the integrated intervention group scored significantly higher on standard IQ tests. Caregivers also reported far fewer problem behaviors from this group. Later

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[42] M.S. Innocenti, "Utah Parent Involvement Study" (Early Intervention Research Institute study, 1996).
[43] Virginia's Family-Centered Early Intervention Approach, An Overview, Memo, 4-6. Please contact Program Review and Investigations Committee at 504-564-8100, Ext. 397 for a copy.
[44] C.T. Ramey, *et al*. "Infant Health and Development Program for Low Birth Weight, Premature Infants: Program, Element, Family Participation, and Child Intelligence," *Pediatrics,* 89:3 (1992), 354-465.

studies have supported these findings.[45] Clearly, integrating knowledge from different disciplines in a cohesive way yields good results for the child who naturally benefits from the larger knowledge pool.

The fourth desirable aspect for an ideal intervention program is the ability to adequately coordinate services from numerous sources. From identification to assessment to actual intervention, the entire early intervention process involves the personnel of many different agencies. Program managers report that the most frequent complaint they hear from parents is that navigating the maze of services is extraordinarily difficult. Parents who have no prior experience with social services do not know how to identify the appropriate providers and obtain the best services to meet their children's needs. Often, valuable time can be wasted if parents encounter difficulties in this pursuit.

The Part H Service Utilization Research Institute conducted a study in 1997 that compared different service models. The main focus of this study was service coordination; researchers ranked the different systems according to the degree of service coordination and the ease with which services could be accessed by parents. The most comprehensive coordinated service delivery system yielded the best outcomes for children and their families. As the degree of coordination lessened, program outcomes registered corresponding decreases.

The fifth aspect of successful early intervention efforts could be viewed as an outgrowth of the family-centered approach. Studies show uniformly positive responses to any existing home visit components of these programs. The advantages of home visits to the child are obvious. No matter how much effort is put into making clinical environments feel more welcoming and comfortable, they remain essentially foreign, and sometimes intimidating, surroundings to children. Within the familiar surroundings of home, however, children are usually more relaxed and less inhibited, a combination that facilitates better results. Also, in the home setting service providers can observe family dynamics that may influence the child's progress and tailor treatments accordingly. In cases where the children have physical disabilities, the service provider's trained eye might spot beneficial physical adjustments to the home environment (for example, lowering a table or resituating a piece of furniture) that would improve the child's daily functioning.

Although a 1987 study pointed out that some center-based intervention is always necessary for early intervention success, incorporating aspects of the home proved to be equally critical to favorable outcomes.[46] A later study by W.S. Barnett compared four groups of children to prove this point.[47] Children with language disorders were placed

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[45] C.M. McCarton, *et al*. "Results at Age 8 Years of Early Intervention for Low-Birth Weight Premature Infants," *Journal of the American Medical Association*, 277:2 (1997), 126-132.

[46] C.T. Ramey and F.A. Campbell, "Poverty, Early Childhood Education and Academic Competence: The Abecedarian Experiment," in*Children in Poverty: Child Development and Public Policy,* A.C. Huston, ed. (New York: Cambridge University Press, 1991), 190-221.

[47] W.S Barnett, C.M Escobar, & M.T Ravsten, "Parent and Clinic Early Intervention for Children with Language Handicaps: A Cost Analysis,"*Journal of the Division for Early Childhood,*12:4 (1988), 290-298.

into groups that received home-based intervention, clinic intervention, or a combination of home and clinic-based treatments. A fourth untreated control group was also used. Although all three groups receiving intervention services exhibited measurably higher progress than the control group, the difference was significant for the two groups receiving home visits.

Despite the clear advantages to home visits in theory, problems can arise in the actual implementation of such a program component. Due to the travel times inevitably involved, home visiting results in increased workloads. Increased duty, however, does not always lead to increased program funding or service provider pay. This can lead to ongoing program concerns that travel time not exceed instructional time and expenses. Additionally, home visits require parents to let an outside party (albeit a friendly one) into their home. In some cases, especially in lower income areas, parents may be reluctant to do so due to embarrassment about their home surroundings and neighborhood. Given the positive results shown from home visits, however, these obstacles should not be allowed to deter home visits.

First Steps Given Good Reviews
But Absence of Data Limits Specific Conclusions

In interviews with primary service coordinators, preschool coordinators, and regional training center staff, the consensus was that First Steps works. The Coordinator of Early Childhood Programs of Hardin County put it this way: "Zero to three is the time to get things turned around. When you don't, you magnify the problems with a child who has challenges already." However, no one interviewed could provide quantitative data to substantiate the opinion that First Steps is an effective program from a developmental standpoint. As stated earlier, having no control group with which to compare children receiving early intervention services means that professionals involved with these children are left with only anecdotal evidence of progress. Time and again, as they were asked to compare children with similar disabilities in which only one received early intervention through First Steps, the answer was always that every child seems to benefit from early intervention, but there is no easy way to compare one child to another. There is no control group and there are too many variables that cannot be controlled.

Another gap in data collection that hampers the ability to review efficacy of early intervention is the lack of across-the-board tracking of students. Some counties and area development districts track individual students from First Steps into preschool, but most schools cannot show the progress a child has made from First Steps into preschool and then on to primary school. Only a few preschools can track children on an individual basis. For example, Jefferson County officials said they can track individual children through preschool into kindergarten and can identify those which are from First Steps, although they note that because it is time-consuming, they have not done so to date. In Lincoln County, officials track individual students but have done nothing with the data, citing lack of funds, time, and the concern with not having a control group. Covington Independent Schools have just started a program to track students from preschool through their first seven years in public school. Most preschools, however, only compare

children's progress on a classroom-wide, rather than individual, basis. Part of the difficulty stems from two separate agencies having information about the same child at different stages in that child's life. While the few preschools that do track students on an individual basis could potentially track those that are from First Steps, doing so would require going back through each child's record. Also, some children could still be missed, if the child did not transition directly from First Steps to preschool. The transition of data from First Steps to preschool is lacking from a research standpoint, even if preschool coordinators do get the necessary documentation for a child at the time of the child's transition. Without tracking individual children from First Steps into preschool and on to primary school, it is impossible to even use case studies to quantify progress on an individual basis.

First Steps Incorporates Recommended Program Features; Room for Improvement Remains

Family Centered Orientation -- By all accounts, First Steps does a good job of integrating the family-centered approach mandated under the Education of the Handicapped Amendments of 1986. "First Steps works with parents and recognizes them as the primary educator. Parents become aware of the medical terminology and can train the siblings…. It is as important to work with the parents as it is to work with the children," says the Early Childhood Supervisor from Lincoln County. Primary service coordinators and therapists enter the home and use toys and everyday objects familiar to both the parents and children, enabling the parents to continue therapy when the therapist is not present. First Steps also educates the parents about the disabilities their child has and identifies community resources that can assist in meeting the children's needs.

Family-centered delivery also allows the child to interact with the therapist in a setting that is familiar and comforting. The transition from a family-centered environment into the preschool system can be a time of difficulty for both the parents and the child. Many parents are uncomfortable with the idea of their child being an integrated part of the classroom experience. While they often know that the interaction is beneficial, they are hesitant about how their child will adjust to the group setting. One innovative way in which Lincoln County is easing the transition process is by using the mobile education unit they have as part of the Early Head Start program in that county. The mobile education unit is a school bus equipped to provide educational activities for children while sitting right outside of their homes. It provides a place where the child learns to play and interact outside of the home, but not so far away that the parents become concerned. The Early Childhood Supervisor said that transitions go much more smoothly when the mobile education unit can be utilized.

The best transitions seem to occur when PSCs and preschool coordinators work together to slowly integrate both the family and the child into the classroom setting and show the benefits of receiving therapy within the group setting. The Simpson County Regional Training Center, located in Franklin, Kentucky, provides parents with parent consultants that help walk them through the transition process. The parent consultant has been through the system herself and helps explain how preschool will be similar to, and

different from, First Steps. In Hardin County, parents are given a survey at the end of the transition period that is used by both the PSCs and preschool coordinators. This interaction with, and feedback from, the parents is crucial in providing for an easy transition. It is also helpful when it is stressed that preschool, although occurring in a centralized building, is also a family-centered approach because parents can continue to help their child learn and advance.

Local Orientation -- Locally based programs are important, for both the child and the parents. Parents who have to travel too far to gain services for their children are often unlikely to continue seeking out those services. First Steps does have a strong local orientation, such that the director reported that 72 percent of services are delivered in the family's home. Changing from the original capitated system has allowed the program to reduce widespread shortages of providers who were willing to deliver services. Another feature of the program that makes it more responsive to local conditions is the system of District Early Intervention Committees. Some of these local committees have been very active in suggestions to tailor the program to local conditions.

As with most programs, First Steps has faced some limitations in the attempt to deliver services locally because of the lack of providers in some rural areas. For example, it was suggested that a lack of pediatricians in Anderson County contributes to the low number of children identified for First Steps, and a lack of providers in the county decreases the number of families that stay in the program. This is because families are most often sent to Frankfort or Lexington for service, which can prove difficult for the family. Transportation problems and scheduling difficulties with parents' jobs only increases the stress found when families must travel distances to receive services. In the many rural areas of Kentucky, however, providing locally based programs puts a huge strain on First Step providers.

A PSC in Paducah said that, in far western Kentucky, the POE, most PSCs, and most therapists are located in Paducah, while the furthest county in the ADD is 80 miles away. They find it difficult to get providers willing to travel that distance for a one-hour therapy session, and no other providers are available. Another PSC also said that the distance between the POE or PSC and the farthest regions limits the ability for effective child find because there is no one in the community on a daily basis to see the children that need services. Relying solely on referrals from doctors was not deemed sufficient. Some communities, therefore, are underserved. Lack of choice among providers is another problem faced by some localities. In Simpson County, the First Steps program only contracts with one home health care center, limiting parental choices. On the other hand, a PSC in Eastern Kentucky said that breaking up the lock that Comprehensive Care Centers had on First Step services has provided more options for families because they can also use independent providers.

Thus, the conclusion is that First Steps effectively delivers local services in most areas of the state but continues to struggle with local service availability in a few more rural areas. Opening the program to all qualified providers has significantly improved local access and local choice.

Multidisciplinary Approach -- The primary person in First Steps that provides a multidisciplinary approach to service provision is the developmental interventionist. Developmental interventionists specialize in knowing when and how a child develops and learns, and integrating the specific therapies a child is receiving into an overall learning plan. While developmental interventionists primarily have an understanding of the cognitive development of children, they also have a big picture view of how a child develops in all five skills areas. Given this singular vantage point, developmental interventionists often take the lead role in therapy and coordinate the other therapists to better help the child develop. This transdisciplinary approach sometimes shifts to another therapist, such as a physical therapist, if the child's primary disability involves motor skills, for example.

While First Steps is required by law to provide a multidisciplinary approach, the team approach is limited by both time factors and the lack of incentives for therapists to get together and discuss the child's progress because this cannot be billed to the system. One PSC stated that while the idea was to have cooperation between the disciplines, the meetings required by the regulations do not do the job. This PSC went on to say that there needs to be a way to bill for the collaboration time and there needs to be more of a mandate that collaboration is required.

Service Coordination -- The PSC is the administrative coordinator for the team of therapists that assist the child and family in First Steps. After receiving information from the point of entry, the PSC oversees the meeting in which the IFSP is drawn up by the PSC with the therapists' input. Each therapist reviews the evaluation and suggests what types and amounts of therapy a child should receive. The PSC has the power to question the suggestions made by therapists, and when interviewed, most PSCs said that they felt comfortable asking the therapists to justify their recommendations. A few PSCs did not feel as though they had the power to question the professional judgment of the other therapists. Some feel that doing so would hurt their business, especially when they are independent PSCs in small towns. PSCs continue their coordination efforts after the initial IFSP meeting. PSCs are a contact point for families and also make sure the therapists communicate with each other. The idea is that the PSC and therapists work as a team to provide services for the child and family.

A large part of the PSC's responsibility is handling the administrative paperwork that accompanies the intervention with each family. PSCs file the IFSP that authorizes payment through the CBIS. The amount of time spent working with the billing system was frequently listed as a frustration for PSCs, because figuring out billing mistakes or problems is time consuming, but is something for which PSCs cannot bill. The PSCs from Seven Counties Services, Inc. in Jefferson County estimated that 60 -- 70 % of their time is spent on bureaucracy and paperwork while only 30 -- 40 % was spent on actual service to the family.

The director of First Steps acknowledged that the completion of required forms may seem a burden to PSCs but noted that much of the information collection was

instituted after a statewide review showed frequent billing for unauthorized services. The effort to find a proper balance between assuring accountability and minimizing paperwork was acknowledged as a continuing struggle. In particular, the amount of paperwork needed to file a service plan amendment was judged onerous and consideration is being given to loosening requirements and improving training on how to reduce the time required.

The changes in the regulations regarding PSCs have caused some shifts over the past year in who is practicing and how they say their practice is fairing. The billing limitations restrict a PSC to billing 15 hours per child over a six month time period for service coordination, versus a therapist's ability to bill up to 60 minutes of therapy per week per child, and restrict PSCs to only the service coordination role. Many individuals who were acting as both a PSC and performing another therapy have stopped doing PSC work because they say they can make more money doing the therapy. This loss of PSCs has led to a shortage of PSCs in some parts of the state. One independent PSC said that she was about to go bankrupt because the work for which she can actually bill bears no relation to the number of hours she puts in for each child. However, the director of First Steps responded that a PSC who bills only two hours of direct family contact per day "could generate $38,000 per year if the time was spent equally between home services and community and office services."

The discussion of whether PSCs are adequately reimbursed for the services they provide is a critical one. Private service providers cannot be required to participate in the program. If they do not believe reimbursements are adequate, they will not offer their services. Yet, PSCs are a legally required component in a federally approved early intervention system. Thus, assuring adequate numbers of PSCs in local areas must be a continuing priority. While there appears to be no broad shortage of PSCs at this time, program adjustments may be needed to prevent a shortage in the future.

A number of PSCs also discussed the inadequacy of training. While many believe that the two-day training they received was beneficial, there was a general feeling that more was needed. The PSCs from Seven Counties Services, Inc., stated that the training revolved primarily around how to meet the regulation requirements, which was useful, but that training also needed to include other administrative, management, and family interaction issues. New PSCs, especially those not associated with a larger organization, felt that there should be a stronger mentoring program for new PSCs. Going to the IFSP meetings that a more seasoned PSC led was useful, but new PSCs suggested that an ongoing mentoring relationship would help them better serve families and do their job efficiently. One preschool coordinator also suggested that some PSCs need training in running a meeting, because the transition meetings that she has attended do not go well simply because the PSCs do not know how to order the issues and address concerns. While all the PSCs that commented on training believe that it is getting better, they feel that more still needs to be done to help them better do their jobs.

Home-Based Services -- The home visit component of early intervention seems to be a success as well. Transportation was often listed as a concern for parents with

children in First Steps. Having therapists come to the home makes the issue of transportation moot. While the preschool coordinator from Rockcastle County suggested that the idea of a stranger coming into the family home may cause some parents to decline First Steps services, most people involved in early intervention in Kentucky saw a huge benefit in starting therapy in the home and slowly transitioning children into preschool when they turn three. Home visits also provide the invaluable opportunity for family members to interact in positive ways with their developmentally delayed sibling or child and learn how to work with the child to further progress.

Transition to Preschool is a Weak Link

The transition from the First Steps program under the Cabinet for Health Services to the preschool program under the Department of Education is a weak point in the Kentucky system. The goal should be to make this a seamless process. The child goes from the home-based system with the PSC and the other therapists in the home, to the center-based system at the school.

Transition from First Steps to preschool occurs at the child's third birthday. Within 90 days prior to the birthday, there is supposed to be a transition planning meeting. The Kentucky Transition Project has been jointly funded by First Steps and the Department of Education to facilitate the transition process. Although this is a review of the First Steps program, it is not implied that transition problems should be perceived as arising only from that program. Rather, the problems appear to result from differences in procedures and deficiencies in communication between the two programs. Among the major problems raised regarding transition were limitations in information sharing, differences in schedule, and differences in focus.

Confidentiality requirements means that there is no automatic transfer of records from First Steps to preschool. The parents must give consent for the child's records to be transferred. The Department of Education's eligibility requirements are similar, but not exactly the same, as First Steps and often the child must be reevaluated. If a First Steps evaluation is less than a year old, then the preschool may draw upon that evaluation, although some school systems do not allow use of First Steps evaluations; otherwise, a completely new evaluation must be completed. In the past, some IFSP teams would authorize new evaluations just prior to transition to facilitate the process. However, First Steps managers limited this practice because they were, in effect, reimbursing providers for services that were the legitimate responsibility of the preschool program.

The possibility exists that a child may qualify for First Steps but not for preschool. A child may have progressed to the point where he or she is at an age appropriate development level or the child's disabilities or delays may not be adverse to the child's educational advancement, which is a requirement for services under the preschool program.

The transition is frequently difficult for the family used to working with the PSC and to having the therapies provided for the child in the home. The parents can be apprehensive of this big change in the child's life, including the need to ride a bus to school. Parents often feel that their child is losing services because the child was receiving one-on-one attention from therapists, then transition into a group setting where individual therapy may no longer be provided. With better coordinated efforts between the PSC and the preschool coordinator, parents can be put at ease and the transition process could go more smoothly.

There can be service gaps for the child if there are delays in the transition process. The success of the transition varies, depending on the program structure, the quality of communication between the primary service and preschool coordinators, and the availability of services to enable a quick evaluation. Even when the process is not timely, however, the needs of the child usually can be met through cooperation between the PSCs and preschool coordinator.

One problem that complicates transitions, and can lead to gaps in services for children, can arise when the child's third birthday occurs during the summer months when preschool is not in session. Unlike First Steps, which works on a full-year calendar, preschool follows the school district calendar. In most schools this includes a summer break. Without adequate preparation, which may mean having transitions prior to the 90-day requirement, children can turn three during the summer and have no one to coordinate services. As the director of the Simpson County Regional Training Center stated, "Even a month without services is almost a crime." In Simpson County, the director has the resources to contract individually with the therapists who had worked with that the child in First Steps, but warned that this was not possible in many areas in the state.

Another factor which hampers some transitions is that it is not easy to get a quick evaluation of a child in some rural areas of the state. Families must often travel a number of miles to the central location to get evaluations, or the evaluators must find time to travel to the families. This can slow the process if schedules do not coincide or transportation is a difficulty. Comparatively, in urban areas such as Jefferson County or Covington, even if the transition conference does not occur until two weeks before the child turns three years old, it is likely that there will be no gaps in service because these areas have the resources and accessibility to get evaluations done in a matter of days, so the Individualized Education Plan (IEP) required by preschool can be developed more quickly.

One Regional Training Center director reported that of the nine children entering preschool in 1998 from First Steps, only three went through the transition process. When questioned about why this happened, she pointed to a number of different reasons, including that PSC turnover was very high, those PSCs still working had varying degrees of training and expertise, and sometimes parents were not ready to have their child placed immediately upon the child's third birthday. She went on to say that the gaps in service that are a consequence of having no transitions are detrimental to the child, and that it

also costs the schools more money because they cannot avail themselves of the First Steps documentation and evaluations and must duplicate the entire evaluation process.

Better Coordination of Information Needed Between First Steps and Preschool

Professionals in both First Steps and the preschool programs across the state commented that coordinating the transfer of information from First Steps to preschool can sometimes be as complicated as setting up transition meetings. Confidentiality restrictions, different forms, and the need for different types of information all cause tension in the transition process and sometimes affect the services the child receives.

Confidentiality concerns are obviously a consideration for First Steps and preschool programs, and the law mandates that parents give consent to any information that is transferred from First Steps to preschool, including the IFSP. When First Steps contracts with home health organizations for therapy services, preschool coordinators who may want to review the home health organizations' records must get parental approval each time. The Parent Consultant from Simpson County said that it would be helpful to have a form that parents could sign that allows the release of all information except any specifically excluded. Now parents must sign a release for each agency, and often agencies do not get signatures until some other entity requests information. Even then, it may not be a priority, which can increase the delays in transitions. While confidentiality must be protected, coordinating the flow of information between the service agencies is in the best interest of the child who needs to have services continued.

Another complication to the transition process can be attributed to the differences between the IFSP used by First Steps and the IEP used by the preschool system. The IFSP sets forth activities and goals that the child has received through First Steps therapy sessions and also incorporates the family's role in helping the child develop. The IEP, on the other hand, focuses on the educational goals for the child through classroom development. Some of the important information on the IFSP is irrelevant for the IEP. More than once during staff interviews of people in the preschool system it was suggested that one form that could transition with the child from First Steps to preschool would be helpful for a number of reasons. With a single form, the preschool providers and therapists would have a better idea of how the child has progressed since he or she began receiving therapy, the information would be consistent and would allow tracking of progress from one program to another, and it would make transition go more smoothly because all the information would be located on one form. The Parent Consultant from Simpson County suggested that the part of the IFSP that addresses how the family can aid in First Steps could be a separate section of the form that would then only apply to First Steps, but would provide helpful additional information for preschool teachers because the teacher would then know how active the family has been in the child's development training.

Another suggestion regarding the transition from the IFSP to the IEP was that it would be helpful if preschool coordinators were able to continue using the IFSP for a

limited period of time after the child turned three and until the evaluation process was complete and the IEP developed. As preschool coordinators pointed out, the First Steps therapists have a much better understanding of the child's current abilities and progress at age three than the preschool personnel do. It takes time to get to know the abilities of a child and determine what reasonable, attainable goals would be for that child. Even if the preschool coordinators were given only 30 days, many suggested this would be helpful, especially in those cases in which transition is occurring right before the third birthday of the child and the need for an entirely new evaluation could cause a delay in services. This is an issue that should be addressed by the preschool program.

Other Issues in Program Quality

Efficacy of services to children is only one measure of program quality. Other program issues are monitoring, parent satisfaction, and provider satisfaction. These are considered next.

Statewide Provider Review Reveals Compliance Problems

In the spring of 1998, First Steps conducted a provider review that detected widespread problems with the system. The file of each child that had received over $6,000 in services during the fiscal year was reviewed. First Steps staff reviewed 996 files, or 24% of the total. In some regions, all of the files fell into this category. At that time, First Steps estimated that the average cost per child was $5,800. According to First Steps, a concern about excessive expenditures prompted the review.

This provider review found many problems with program compliance. According to First Steps documentation, the following problems existed in at least twelve area development districts.

- Some children received unnecessary services.
- Evaluations did not indicate that the child needed services in a particular skill area, such as speech, but the child received the services anyway.
- Service plans were not individualized.
- Even though a child was judged ineligible in the primary evaluation because no significant delay was identified, the child received intensive services.
- Assessments showed that the child had reached a developmental milestone, but intensive therapy continued.
- Services exceeded IFSP specifications.
- Service plans did not relate to stated outcome goals.
- Providers billed for individual services when group services were provided.
- Agencies billed for supervision of paraprofessionals.
- Reviewers found excessive use of medical therapies and little use of developmental intervention.
- There was no indication that parents were being taught intervention skills.
- Providers paid little attention to scheduling needs of the family.

- First Steps was billed for Medicaid-eligible services.
- Amendments to service plans were not reflective of team decisions.
- Plans were backdated and changed without notification to IFSP team.

First Steps Took Corrective Actions

First Steps management took several corrective actions in response to these findings. These actions include quarterly training meetings and more inservice days for PSCs, establishment of payment controls in CBIS, and complete reviews of some providers. At the time of the statewide review, there was a regulation limiting allowable service to no more than three hours per discipline per week. In April 1999, these limits were electronically incorporated into CBIS. Before these controls, the billing system paid whatever invoices were submitted, even if they exceeded the specified limits. In July, First Steps adopted a new regulation that reduces the payment limit to one hour per discipline per week. This change has also been incorporated into CBIS. Another regulatory change created dedicated primary service coordinators who cannot perform any other First Steps services.

Additionally, First Steps held area district-wide meetings to discuss the findings. According to First Steps personnel, many providers did not understand the First Steps program and believed that more services were preferred. Also, many providers did not know that they were supposed to teach the families the skills so that the family could work with the child to embed the skills in the child's natural environment. According to First Steps, some of these problems were agency specific. In addition, First Steps introduced the individualized family service plan statewide form for the first time. First Steps had one full day of training on the IFSP, too.

Some of the program consultants who train the providers found the statewide review very effective. These program consultants did extensive training after the provider review. Some parent consultants believe that it would be beneficial to conduct another provider review because it shows the areas in which technical assistance teams need to focus training.

Parents Appear Satisfied

When a child is born with developmental disabilities, the family can be devastated. Informing the family about how to help the child and negotiate the myriad service programs is very important. Federal law emphasizes that the family is to be considered the customer of services. Although very few parent satisfaction surveys in Kentucky have been done, several sources told LRC staff that parental satisfaction with the program is high. According to First Steps management, there are many anecdotal reports of individual families who are highly satisfied. First Steps management has plans to develop a parent satisfaction survey.

Seven Counties Services, Inc., a nonprofit organization in Louisville, conducted a series of eight parent satisfaction surveys concerning the services of the POEs and the

primary service coordinators. All averaged above 95 percent satisfaction with program elements, with the most reporting 100 percent satisfaction.

LRC staff interviewed five parent consultants. They expressed the need for more networking between families. Currently, there are two organizations that bring parents together: Parent Information Network of Kentucky (PINK) and Kentucky Special Parent Involvement Network (KY-SPIN). Families need to meet with other families who have had similar experiences. According to the parent consultants, there are confidentiality restrictions that prevent them from sending a newsletter to all parents.

In an interview with a group of primary service coordinators from Jefferson County, there was a concern raised about the use of substitute professionals by some agencies, when it is not convenient for the regular therapist to complete a service. This practice of substitution may not be appropriate in the family-centered approach, where continuity with the therapist is preferred. The First Steps director acknowledged the problem but said that some steps have been taken to reduce its occurrence. The IFSP team is now required to identify, on the IFSP, the individual professionals who are to deliver the authorized services. This does not restrict substitution, but makes it easier to identify providers that use the practice excessively. There is some reluctance to impose an inflexible rule that could create more disruption that it resolves.

Another concern, according to the parent consultants, is the new sliding scale fees, where parents must pay a specified amount for services and transition. It was suggested that some families might find these payments difficult to afford.

Providers See Room For Improvement
Program is Responding

The providers that Program Review Staff interviewed expressed a high level of satisfaction with the First Steps program as an effective program for the children. During the course of interviews with LRC staff, there were frequent statements of dissatisfaction with the initial ability of the centralized billing system to pay the bills in a timely manner. There is now a general consensus among the providers interviewed that the system has improved in its ability to pay its bills. The new summary sheet for the service plan was also mentioned as a helpful change.

Now that the claims processing system has improved, the three major complaints raised by providers were paperwork they consider excessive, lack of adequate training in the features of the program, and inconsistent communication from the First Steps central office. The First Steps director acknowledges the difficulty of finding the proper balance between the paperwork required to assure accountability in the system and that which overburdens those who deliver services. Additional steps to reduce the paperwork burden, particularly that associated with filing amendments to service plans are under consideration. The limitations of the training system were also acknowledged, but were said to be difficult to resolve, given the current budget and resource constraints.

Another area of concern raised by providers is the communication from the First Steps central office to the practitioners in the field. In a letter from a DEIC Chair, it was stated that there is "no consistent policy about dissemination of new procedural information. Some providers receive letters instructing them about new policies while other providers never receive the instructions. When these two groups of providers communicate with each other, confusion exists." Other providers expressed problems with the dissemination of new policies and different interpretations concerning a particular procedure. For example, one point of entry states that First Steps management will send different answers at different times in response to the same question. Communications were criticized as not giving adequate information so that time is wasted. This was also said to result in inconsistency among regions. The First Steps response is shown below.

> **We fully agree with your concern and commit ourselves to communication of all changes through the Quarterly Communication Packet. We realize that procedural changes have been coming to the field from several sources and that has led to confusion. The communication Packet will be the only method by which we communicate. On occasion, we may issue a Special Edition in order to address a change more quickly, but by using the packet all parties will receive the same information and the changes will be official.**[48]

In general, program managers acknowledge the legitimacy of the concerns raised by providers and say that they are taking steps to address them. When resources allow, one suggestion that might help would be to put full program information and regulations available on an Internet site that providers could access on an as-needed basis. Quarterly mailings may be less effective.

Primary Service Coordinators Need More Oversight

Primary service coordinators need to be more closely supervised. These providers have a key role as service coordinators and family advocates. The PSCs are supposed to serve as key players in the team that develops the IFSP, which specifies the services to be provided to each child.

Additionally, the PSCs are to work closely with the family in the home, coordinate the scheduling of services, and handle the transition to the preschool program. According to First Steps management, the PSC should determine if the services recommended are actually needed by requesting a rationale for the service and the particular outcomes the service will achieve. The primary service coordinator should keep the focus on the family's needs in the IFSP meeting. The PSC should attempt to facilitate a team decision, with the family having the greatest control. According to First Steps management, the goal of the PSC is effective and efficient service decisions.

[48] Letter from James Henson to Barbara Borie, October 21, 1999.

According to First Steps management, the provider review last year found that the primary service coordinators did not do their jobs well enough. The PSC is supposed to be the watchdog for the system. Starting July 1999, First Steps began requiring that a primary service coordinator only provide primary service coordination services. Formerly, a PSC could provide other First Steps services such as physical therapy, occupational therapy, developmental intervention and other therapies. First Steps management stated that good physical therapists might not necessarily be good coordinators and might favor the physical therapy role over the coordinator role.

According to many of the First Steps staff, the Primary Service Coordinators need to be more adequately trained and monitored. One suggestion advanced by program consultants is for the program consultant to attend the IFSP meeting as a control to ensure that training is working. The program consultant, however, is serving such a wide geographic section of the state and is so busy training providers that attending IFSP meetings is almost impossible.

Those interviewed said that PSCs have varying levels of performance. Some are excellent, others not so good. The change restricting primary service coordinators to that specific service was said to have weeded out some of the poor performers, but it has also led to a shortage of coordinators in some areas of the state. According to the KIPDA POE, in July 1999, 44% of the coordinators in that region will elect to stay with their primary therapy discipline rather than do only service coordination. The lack of coordinators has lessened and the problem is not as serious now. Shortages of coordinators, however, do occur.

Excess Services a Concern

A continuing issue of concern is the extent to which providers drive the system to increase their own payments. In one area development district, the provider review revealed that some agencies consistently over billed for authorized services. In response, First Steps personnel conducted program reviews of numerous agencies and took some corrective actions. LRC staff was provided a list indicating that as a result of the statewide review, a total $43,381 was recouped from 24 providers for inappropriate billing. The individual amounts recouped ranged from a low of $10 to a high of $22,454. The program director indicated that other recoupments were reflected in the Centralized Billing and Information System, but these could not be separated from those where providers have voluntarily returned inappropriate payments they had identified themselves. No provider contracts were cancelled because of a demonstrated pattern of abuse.

One of the parent consultants interviewed stated that some of the bigger agencies provided all eligible services to every child, even when the services were not needed. According to two program consultants, some of the services provided are questionable. These two program consultants expressed the view that the new training and administrative changes, which limit services to one hour per week per child for each discipline, would help in these areas. However, several of the primary service

coordinators interviewed stated that providers continue to have the ability to perform services in excess of the needs of the child.

One RTC discussed an extension contract for a First Steps child until the transition could be accomplished. It was stated that it cost three times as much for the First Steps service as it does for salaried preschool staff to provide the same service. The RTC expressed the concern that there are many hidden costs in the First Steps program that are not adequately monitored. Another concern voiced was that home health care agencies have a monopoly on services when other providers in the community could be employed. Another RTC stated that First Steps makes responses inadequately to provider abuses. The RTC noted that some providers established new business simply to provide lucrative services to First Steps.

First Steps management has taken steps to reduce the excess provision of services. The major step has been to limit the number of service hours that the Centralized Billing and Information System will reimburse to one hour per child per week for each discipline. A professional panel has been established to consider, on a case-by-case basis, requests to exceed these limits. According to the program director, 20 percent of the requests have been approved. Program monitors are supposed to monitor program effectiveness on an ongoing basis and to review IFSPs to ensure they only authorize appropriate services. There are only four full-time equivalent monitors available, however, to review 3,700 currently active IFSPs. This critical function is seriously understaffed.

First Steps Lacks Quality Assurance Controls

First Steps lacks quality assurance controls that would ensure program accountability for services and other program features. According to First Steps managers, the original intent was to include three system components: quality assurance; effectiveness of performance; and compliance.

The program, however, with its insufficient monitoring staff, has had to focus so much on compliance that management has never established an evaluation component. Some of the program consultants believed that they would be doing program evaluation. Instead, these half-time staff have had to work totally on compliance monitoring in large geographic areas of the state. Program evaluation is needed to provide management information for program improvement.

The program has a new opportunity to move toward this goal. The U.S. Department of Education awarded First Steps a State Improvement Grant to conduct program evaluation. The grant will give the state $75,000 per year for the next four years. First Steps managers have begun working with an advisory group of university researchers who are assisting in the research design. A research director for the project has also been retained.

In the development of this research project, it is recommended that managers not complete an evaluation focused on demonstrating the efficacy of services delivered by First Steps. While useful as a justification for continued funding, this type of evaluation would have little value for program improvement. Given the past research in the efficacy of early intervention, it is unlikely that the overall services delivered in this program would be found to have no effect.

Much more useful would be research to refine practice parameters for children with particular developmental delays. By conducting research to increase knowledge about what types and amounts of services are most helpful, First Steps could improve both the effectiveness and accountability of the services it provides.

The Number of Children and Small Staff Have Limited Responses to Quality Problems

From all information received by staff, First Steps managers have demonstrated great commitment to the goals of the program, under difficult conditions. The original significant underestimate of the number of children who would be served resulted in too few resources being devoted to this entitlement program. First Steps and CBIS managers were required to devote nearly all their time to organizing resources to meet the unexpectedly large demand. Monitoring and compliance issues were one of several other program features that were given less attention than warranted.

In an unusual occurrence, practitioners in the field suggested that First Steps central office receive additional staff, even at the expense of service dollars. The reason given was that the central managers have too many on-going responsibilities to spend the time necessary to improve program operations for the benefit of providers and families. As will be discussed in the following section, this problem extends to managers' ability to adequately ensure fiscal accountability as well.

There are currently four staff in the central office of First Steps. The positions are

- State Coordinator of First Steps (Program Director)
- 2 Program Coordinators
- Administrative Assistant
- Administrative Secretary (vacant)
- State Developmental Intervention Consultant (vacant 1 year).

Also, there are four full-time equivalent monitors to review the 3,400 current IFSPs for appropriateness of services. It is recommended that the number of monitors be increased to eight FTE, that the vacant positions be filled as soon as possible, and that two positions be added. These positions should be one full-time monitoring supervisor and a fiscal analyst.

SECTION IV: FISCAL ACCOUNTABILITY IN FIRST STEPS

The third major question raised by the Committee was whether there is adequate fiscal management of the funds appropriated to First Steps. This question is reasonable, given the explosive growth in the cost of this entitlement program. Plus, there are indications from the statewide review and anecdotal comments that the program may be paying providers for inappropriate services. This section presents a review of First Steps appropriations and expenditures, summarizes payment data from the centralized billing and information system, and provides the results of a review of the operation of that system.

Rapid Increases and Repeated Shortfalls Continue as a Feature of KEIS Budgets

Although the First Steps program was created in FY 1987, the program budget does not appear as a separate line item until FY 95, when the General Assembly first directly appropriated General Funds for the program. According to information gathered from the Department for Medicaid Services, prior to FY 1995 the services provided through the First Steps program were paid through what was referred to as the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program.[49] With the establishment of the separate budget line-item, payments for services provided through First Steps were transferred to the Department of Mental Health and Mental Retardation Services (MH/MRS).

KEIS receives funding from three sources: state General Funds, Part C, federal education funds, and Medicaid. The state General Funds are a combination of funds appropriated to the Department of Mental Health/Mental Retardation Services (MH/MRS) and the Department of Public Health (DPH), with the majority of funding in MH/MRS. MH/MRS is responsible for the overall administration of the program and covers some administration and service costs. DPH provides part of the support for POE staffing, training, evaluation, and some administrative support. The Part C, federal education funds are used to support the technical assistance and training functions, some administrative costs, and services. Medicaid reimburses only for services provided to Medicaid eligible children through the First Steps program. Medicaid does not cover any administrative costs.

Table 4.1 presents the FY 1995-FY 2000 budgets for KEIS. In 1997, the Medicaid state plan was amended to provide funding for First Steps. The agency funds reported in FY 1998 through FY 2000 are Medicaid dollars.

[49] Information provided by Lynn Flynn, Beth Jennings, Karen Doyle, and Kaye Kirkland, Kentucky Department for Medicaid Services, October 15, 1999.

Table 4.1					
Dept. for Mental Health/Mental Retardation Services					
First Steps					
Fiscal Year	Original Budget	Amendments to Budget	Total Budget	Expenditures	Difference Between Original Budget & Expenditures
FY 95					
Federal Funds	$2,862,400		$2,862,400	$1,251,731	$1,610,669
General Funds	1,875,000		1,875,000	2,130,509	(255,509)
Total	4,737,400		4,737,400	3,382,240	1,355,160
FY 96					
Federal Funds	3,138,000		3,138,100	3,309,200	(171,200)
General Funds	5,200,000		5,200,000	4,540,533	659,467
Total	8,338,100		8,338,100	7,849,733	488,367
FY97					
Federal Funds	3,943,000	$3,876,538	7,819,538	7,277,802	(3,334,802)
General Funds	5,464,495		5,464,495	6,448,162	(983,667)
Total	9,407,495	3,876,538	13,284,033	13,725,964	(4,318,469)
FY 98					
Federal Funds	4,000,000		4,000,000	2,637,187	1,362,813
Agency Funds*	5,000,000	3,320,000	8,320,000		
General Funds	6,165,495	2,180,000	8,345,495	16,373,323**	(5,207,828)
Total	15,165,495	5,500,000	20,665,495	19,010,510	(3,845,015)
FY 99					
Federal Funds	4,300,000	949,000	5,249,000	3,536,447	763,553
Agency Funds*	6,250,000	4,000,000	10,250,000		
General Funds	6,165,500	3,500,000	9,665,500	19,827,216**	(7,411,716)
Total	16,715,500	8,449,000	25,164,500	23,363,663	(6,648,163)
FY 00					
Federal Funds	4,500,000	146,900	4,646,900		
Agency Funds*	7,500,000	4,000,000	11,500,000		
General Funds	6,165,500		6,165,500		
Total	18,265,500	4,146,900	22,312,400		
Source: Department for Mental Health/Mental Retardation Services					
* Agency funds reflected are Medicaid dollars.					
** General Funds and Agency Funds are combined in this total. No breakdown of the separate funds is available.					

As the table indicates, appropriations have increased each year, with budget shortfalls experienced in the last three fiscal years – FY 1996-FY 1999. Total appropriated funds were $4.7 million in FY 1995 and $8.3 million in FY 1996. Expenditures were less in both fiscal years – $3.4 million in FY 1995 and $7.8 million in FY 1996, which allowed the program to show a surplus in both years. Although the budget ended with a surplus for these fiscal years, the percentage increase was higher for expenditures (132%) than the increase in appropriations (76%).

In FY 1997, expenditures continued to increase to the point that the program faced a budget shortfall of about $4.3 million. The initial appropriation was $9.4 million; however, expenditures were $13.7 million. An appropriation amendment of $3.87 million in federal funds was made to the budget in order to resolve the shortfall. Despite the additional funds, the program budget showed a deficit of about $400,000 at the end of the fiscal year. It is important to note that while expenditures increased during this period, the number of children served in the program also increased.

Additional funds also had to be appropriated in FY 1998 to fund a budgetary deficit. Expenditures were $19.0 million while the total funds appropriated initially were $15.2 million, leaving a deficit of about $3.8 million. An additional appropriation of $5.5 million — $3.3 million in federal funds and $2.2 million from Medicaid — was made to address the deficit. According to data from CBIS, a total of 5,463 children received initial screening or actual services in FY 1998.

The budgetary shortfall for FY 1999, the most recent fiscal year completed, was nearly double that of the previous year. Expenditures ($23.3 million) outstripped appropriations ($16.7 million), resulting in a shortfall of $6.6 million. The amendments to the appropriation were $949,000 from Federal Funds, $4.0 million from Medicaid, and $3.5 million from MH/MRS. These amendments brought the total budget for First Steps up to $25.1 million for FY 1999. The CBIS figures indicate that 7,050 children received initial screening or actual services in FY 1999.

Total appropriated funds for FY 2000 are $18.2 million. Of this total, federal funds are $4.5 million, Medicaid funds are $7.5 million, and general funds are $6.2 million. No data on expenditures is available to date; however, it might be expected that expenditures will continue to grow and that an additional appropriation increase will be requested, given the experience from previous fiscal years. With the exception of one year, FY 1998, the percentage increase in expenditures was greater than the percentage increase in total appropriated funds.

Another funding change anticipated in FY 2000 is the imposition of a sliding fee for parents for the services delivered to their children. However, this has not been implemented yet due to difficulties experienced in finding a contractor to be the billing agent. This has only recently been resolved. First Steps officials plan to implement the sliding fee sometime early in calendar year 2000. When implemented, in addition to providing a source of funds for a program experiencing continuing shortfalls, the fee paid by parents may make them more active monitors of service needs. If parents bear no cost of an increase in services, they may be willing to accept provider suggestions of services that they may not really believe are necessary, on the theory that more services can't hurt. However, if parents bear some of the financial burden for additional services, they may require IFSP team members to provide a convincing rationale for those services. Shifting some financial incentive for program monitoring to parents could improve the efficiency of service decisions, although it has been noted by Parent Consultants that this fee may represent a significant burden to some families.

Medicaid Funds Reimburse Some KEIS Services
But More Medicaid Funds Could be Accessed

Various personnel involved with the First Steps program estimated that about half of the children served through the program are covered by Medicaid. Data from the CBIS bears out these unofficial estimates. In FY 1999, there were 2,958 children with Medicaid cards served in the First Steps program, which accounts for about 42% of the total number of children eligible for services. In FY 1998, there were 2,356 children

covered by Medicaid served in First Steps, which accounted for about 43% of the total 5,463 children served in that fiscal year.

The Medicaid link is important to First Steps and to federal and state policymakers. IDEA, Part C language specifically instructs states to maximize use of Medicaid dollars to fund early intervention services. Many early intervention services are eligible for reimbursement under either traditional Medicaid, or under EPSDT rules. The federal government bears 70 percent of the cost of all early intervention services reimbursed by Medicaid. Thus, correct identification of Medicaid eligibility for First Steps children can free significant state resources for program expansion or other important uses.

Although the CBIS data indicates that about one-half of the children receiving services through First Steps are enrolled in Medicaid, there are a couple of factors that indicate the number of children actually eligible for Medicaid may be higher. First, officials with the First Steps program reported that there is no formal screening process for Medicaid enrollment. Families are only questioned as to whether children have a Medical card. If they say yes, the Department for Medicaid Services is asked to certify enrollment for reimbursement purposes. If a family says no, there is no further check. The Commissioner of Mental Health and Mental Retardation has requested that First Steps be given access to Medicaid enrollment records to determine if Medicaid enrollment is underreported for First Steps children.

Second, federal officials report that, nationwide, in 1996, about 23% of uninsured children were eligible for Medicaid but not enrolled.[50] Data from the 1997 Kentucky Health Insurance Survey indicated that, based on reported household income, about 45,000 uninsured Kentucky children were eligible for Medicaid.[51] These figures indicate that possession of a Medicaid card may not accurately indicate all those who are actually eligible. Families may be referred to the Cabinet for Health Services if a POE or PSC thinks they might be eligible for Medicaid. But, again, there is no formal screening process. There is also some indication that staff at the POEs has been lax about recording information on family income that might be used to help identify Medicaid eligible children.

Similarly, the Kentucky Children's Health Insurance (KCHIP) program could represent a significant source of federal dollars for First Steps. KCHIP extended Medicaid coverage to children in families up to 150% of the federal poverty level effective July 1999. A separate "Medicaid look-alike" program was made available to children in families with incomes between 150 and 200 percent of the federal poverty level, effective November 1999.

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[50] *Medicaid: Demographics of Nonenrolled Children Suggest State Outreach Strategies* (Washington, D.C.: General Accounting Office, GAO/HEHS-98-93, March 1998), 2.

[51] It should be noted that this might represent an underestimation of the number of Medicaid eligible children. The survey data available only allows estimation of the number of children who meet the age and family income guidelines to qualify for Medicaid. The data do not allow for estimation of the number of children who may qualify by other criteria.

According to officials with KCHIP, the Medicaid expansion of KCHIP should result in a decrease in the demand for state general funds for First Steps. Children ages birth to one year with family income up to 185% of the federal poverty level and children ages one to three years old with family income up to 133% of the federal poverty level are eligible for Medicaid. With the Medicaid expansion, KCHIP will now cover one to two year olds with family incomes falling into the range between 133% and 150% of the federal poverty level. These are children who may not have been eligible for Medicaid previously. First Steps will now be able to use Medicaid funds rather than state general funds to provide services to these children, assuming they are correctly identified and enrolled.

Another important factor in the children's health insurance program is that the children eligible for coverage through KCHIP will be funded at an enhanced match rate. The federal government will match state spending at a 79/21 rate, which is higher than Kentucky's current Medicaid match rate of 70/30. The state will be able to leverage more federal dollars for those children receiving First Steps services which are reimbursed through KCHIP.

As with Medicaid, identifying and enrolling children eligible for KCHIP coverage has been problematic. Again, the national trend indicates that states have not met federal targets for enrolling children in the Children's Health Insurance Program. Kentucky's efforts to enroll children in KCHIP also have fallen short of program goals. Currently, about 20,594 children have been enrolled of the 78,000 estimated to be eligible.

Officials with the First Steps program report that they have begun outreach efforts to identify and enroll children who may be eligible for KCHIP. However, given the strong fiscal incentive for the state, it is recommended that First Steps make parental submission of information sufficient to determine Medicaid and KCHIP eligibility a requirement for program participation, along with actual enrollment if children are determined to be eligible. POEs and PSCs should be required to correctly collect such data and submit it in a timely fashion.

More Effort Should be Directed to Identifying Other Federal Fund Sources

First Steps management reports significant attempts to identify and tap other sources of federal funds to support the program. Additional efforts, however, could be undertaken. One issue related to Medicaid is reimbursement of a share of First Steps administrative costs. In Kentucky, Medicaid does not currently allow reimbursement of administrative costs, but some programs in other states have obtained Medicaid waivers to allow such reimbursements to occur. First Steps and the Department for Medicaid services should work together to explore this option for Kentucky.

Basically, there are two sources of federal funds currently being used to support Kentucky's early intervention services: the Part C, federal education funds, and

Medicaid. Table 4.2 below provides a breakdown of federal funds. As the table indicates, Medicaid accounts for most of the federal funds. While it may appear that this may not have as much of a budgetary impact as the General Fund allocation, it must be noted that the state provides 30 cents of every Medicaid dollar. Thus the direct state contribution was $2.49 million in FY 1998, $3.09 million in FY 1999, and $3.45 million thus far in FY 2000 for the Medicaid funds. This is in addition to the General Fund dollars allocated to the program.

Table 4.2
Estimated Share of Federal Funds (millions)

Source of Federal Funds	Fiscal Year					
	FY 1995	**FY 1996**	**FY 1997**	**FY 1998**	**FY 1999**	**FY 2000**
IDEA, Part C	$2.9	$3.1	$7.8	$4.0	$5.2	$4.6
Medicaid	0	0	0	$8.3	$10.3	$11.5
Total	$2.9	$3.1	$7.8	$11.3	$15.5	$16.1

Source: Department for Mental Health and Mental Retardation Services

Given the above discussed problems in identifying and enrolling uninsured Medicaid eligible children, there is some question as to whether the First Steps program is maximizing the funds available from federal sources. In a study of finance systems for early intervention services, the researcher found that while IDEA, Part C funds, and Medicaid were the major funding sources, states were tapping a number of additional federally funded programs to support early intervention services.[52]

For example, the Department of Education offers additional funding to states for early intervention services through both Section 619 Preschool and Grants to States of IDEA, Part D. These resources can be used to partially fund Part C services. Kentucky has not chosen to access these funds because they are considered to offer minimal funds that require complex management. The demonstration, outreach, and in-service grants under Part D also can be used to fund early intervention demonstration projects, but not on-going services. Other Department of Education funding streams include Bilingual Education, Technology Related Assistance, and Migrant Education.

For those children who qualify, some intervention services are provided through Maternal and Child Health, Children with Special Health Care Needs under Title V of the Social Security Act. These services are provided directly and do not flow through First Steps. The Child Care Development Fund is receiving increased attention as a funding source due to the reinforcement of the requirement for providing services in natural environments in the 1997 reauthorization of IDEA, Part C.[53]

A funding source that can be used in some areas with military bases, such as Fort Knox, is the Civilian Health and Medical Program of the Uniform Services or CHAMPUS. This program represents a key resource for families of uniformed personnel. The Program for Persons with Disabilities is a supplemental funding stream of CHAMPUS that may support some early intervention services. Imposition of a family

[52] Donald A. Kates, "Constructing an Interagency Funding System for Early Intervention Services," *Infants and Young Children*, 11: No. 2 (1998), 74.
[53] Kates, 75.

fee for services, however, makes a state ineligible for reimbursement under CHAMPUS, so Kentucky did not apply. A program that applies to all families is the Special Supplemental Food Program for Women, Infants, and Children (WIC) in the Department of Agriculture, providing nutrition services and some lab tests for eligible infants and toddlers, although there has not been great demand for such services in First Steps.

Other funding sources identified by the researcher include family fees (now imposed by First Steps), private health insurance, TANF, Title IV-E of the Social Security Act, and Family Preservation. Families may be encouraged to access private insurance for service reimbursements, because insurance reimbursements can substitute for the family fee. According to the First Steps director, two national consultants have advised that TANF would provide little additional funding because of the state's comprehensive Medicaid coverage. The consultants did advise that Title IV-E funds could be accessed for training and technical assistance costs. A decision has not yet been made to pursue that avenue. In addition, the Substance Abuse and Mental Health Services within DHHS is beginning to target some discretionary funds to early intervention services with infants and toddlers. Of course, some of these funding sources are already in place in the First Steps program. However, there appear to be alternative federal funding streams that could be accessed to fund a portion of early intervention services.

While these funding streams may enable some services to be supported by other means, there are important issues that emerge when combining resources to support early intervention services. Identifying the payer of first and last resort is one such issue. In many instances legislation sets the order of preference for determining which funding source should be the prior payer. Other issues include service coordination, the use of a family's own resources, and determination of medical necessity.[54]

Centralized Billing and Information System

The University of Louisville Urban Institute operates the Central Billing & Information System (CBIS) for First Steps. Since April 1997, First Steps has used CBIS to coordinate payments to its service providers. CBIS accepts invoices from the providers and uses this notice of service provision to authorize payment to the providers for those services. In addition to its bill paying responsibilities, CBIS compiles information from the Individualized Family Service Plan (IFSP) and from the providers enrollment form. The IFSP information along with the individual billing records are stored in the CBIS database. The managers of CBIS provided staff with the database containing all their records on service events, payments, providers, and children since the inception of CBIS in April 1997 through July 7, 1999.

Summary Information from CBIS Database

Analysis of the CBIS data has provided the following insights:

[54] Kates, 78-80.

- The average time billed each week by a service provider was fairly constant in 1997 and 1998. Instituting control parameters for group services in the Spring of 1998 does not appear to have an impact on the billed service event units per week. A service event unit represents a quarter of an hour for most of the disciplines. Thus, four event units represent an hour of service. Regulations were implemented at the beginning of 1999 that restricted the number of service units a child can receive per week per discipline. These new regulations do appear to have an impact on the average billed event units by providers as shown in Table 4.3.

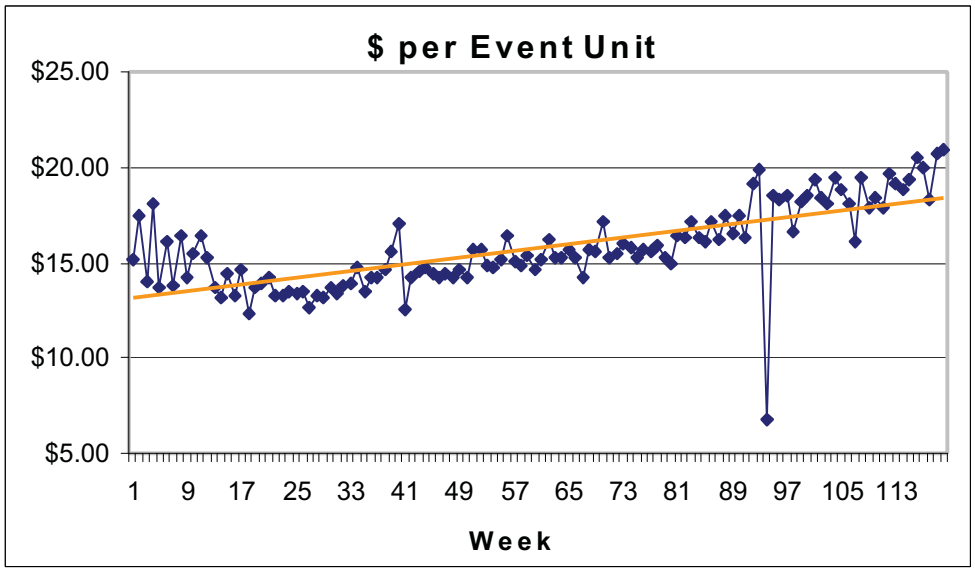
Table 4.3
Average Billed Service Event Units per Week

4/1/97 to 12/31/97	1/1/98 to 12/31/98	1/1/99 to 7/1/99
11.83	11.50	9.14

Source: CBIS Database

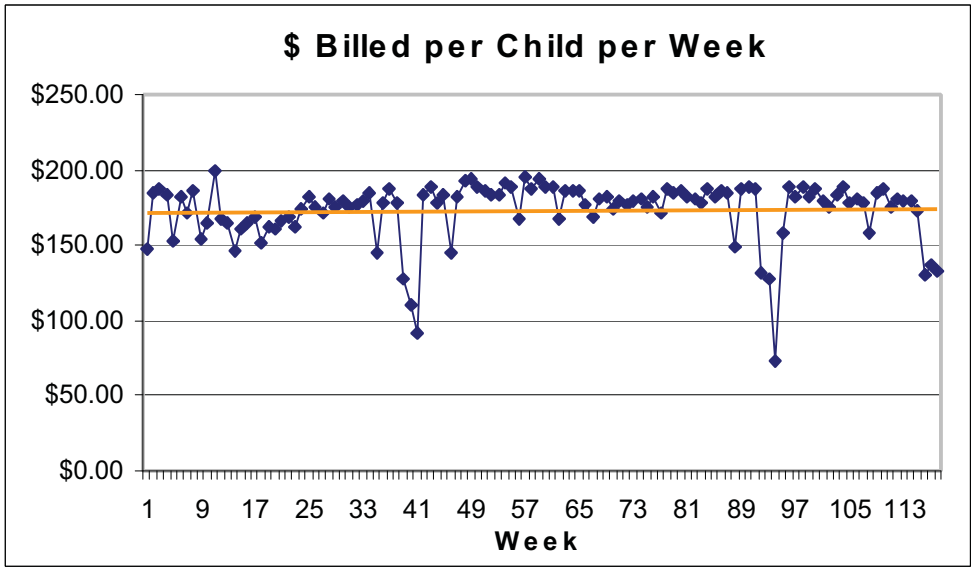
- Despite reductions in the average service event units billed per week, the total dollars billed per child per week by providers was relatively unchanged. There was, however, an increase in the dollar amount billed per event unit. This increase offset the reduction in the billed event units. The two figures below show how the dollars billed per child remains relatively constant, while the dollars billed per event unit are rising.

Figure 4.A



Source: CBIS Database

Figure 4.B



Source: CBIS Database

The database also allows for analysis of the types of services received by First Steps children and the payments for those services. Appendix A contains tables which provide information by service type for the fiscal years 1998 and 1999 for the total payments, payments per child, payments per service unit (one unit represents a quarter of an hour), and service units per child.

Total Payments

- The total payments for services in FY 1999 were $21,082,612, an increase of 28% over FY 1998.
- Total payments per child fell in FY 1999 by $24.55 from $3014.99 to $2990.44.
- The total number of children receiving screening or services increased from 5,463 to 7,050. Thus, the slight reduction in per child spending was more than offset by the increase of 1,587 children receiving screening of services in FY 1999.
- Overbilling of services was recorded as recoupments in the payment database. Overbilling can occur when the services provided conform with the IFSP Summary Sheet, but the services were not performed or performed in less time than the invoice states. Recoupment for overbilling can result from monitoring by First Steps personnel or self-reporting. There is little monitoring in place to detect for over-billing of services. Thus, First Steps is primarily dependent on the provider to notify CBIS personnel of the overbilling of services.

Disciplines

The disciplines represent the different types of services a child can receive.

- There are thirty-one separate disciplines. Speech therapy received the most payments and comprised 27% of the total payments for all services. The next three service

disciplines ranked by total payments were developmental interventionist (16.6%), occupational therapist (11.75%), and physical therapist at (11.2%).

- The two group disciplines realized major increases in total payments. This increase coincides with the increase of children in group therapy, which increased from a combined total of 132 children in FY1998 to 613 children in FY1999. Because of changes to group billing procedures in FY 1998, all of the increase may not be attributable to the increase in children served. Even with the increase the two disciplines only account for 4% of the total payments for services in FY1999.
- Overall, the average payment per service unit increased $2.09 in FY1999, which equates to an hourly increase of $8.36.
- Three disciplines received substantially higher average payments per service unit in FY1999. The primary evaluator discipline rose from $140 to $178, teacher of the deaf/hard of hearing increased from $11 to $23, and developmental associates increased from $9 to $14. The primary evaluator is paid a flat fee per evaluation, thus the increase represents a reduction in the time to evaluate children. The other two disciplines are paid hourly. The changes in payments per service unit are influenced by where the services take place, the type of service, and the hourly rate paid the discipline. The hourly charges are higher for home and community based services as opposed to office and center based services, and assessments are more per hour than intervention and collateral services. Therefore, a change in the place where services are provided and the type of service provided will impact the average payment per service unit.
- Table 4.4 provides a breakdown of the payments to home based services, office/center based services and other services. Other services include transportation, respite care, assistive technology and primary evaluation. For FY1999, home based services, the highest hourly rate services, represented 71.6% of the total payments for services, increasing from 67.0% in FY1998.

Table 4.4
Service Payments

Service Type	FY 1998 Payments	FY 1999 Payments	FY 1998 Percent of Total Payments	FY 1999 Percent of Total Payments
Home Based	$11,039,768	$15,096,084	67.0%	71.6%
Office/Center Based	$4,608,184	$5,045,995	27.9%	23.9%
Other	$823,029	$940,532	5.1%	4.5%
Total	$16,470,981	$21,082,611	100%	100%

Source: CBIS Database

- Some disciplines' total payments were less in FY1999, but only the developmental associate discipline had a relatively significant reduction of $108,702. This

represented a 50% drop in payments from FY1998. This reduction coincided with the decline of 126 children for whom services were provided. A total of 10 disciplines had lower payments in FY99 equaling $252,466.41, which was only 1.5% of FY1998's total payments.

Units of Service per Child

- Examining the units of service per child showed a significant increase in the two group disciplines. There was an increased effort to utilize group therapy in FY1999, and the increases were not unexpected. Also, two of the transportation categories service units per child rose significantly, but with such few children utilizing transportation any one child could skew the comparison.
- Overall, event units per child fell by 30.31 units or approximately 7.5 hours for the year. Part of this reduction can be attributed to implementing billing limitations into CBIS at the beginning of 1999.

Providers and Professionals

- Providers are the agencies who deliver services to First children. They are often large agencies, but can also be a single, independent provider. Before providers can invoice First Steps for services, they must enroll with First Steps through CBIS. In FY 1999, 371 providers received payments from First Steps. Table 4.5 list the top 15 providers in FY 1999, ranked by total payments. Except for Seven County Services, which received 79% of its total payments for service coordination, the top providers are delivering intervention and therapy services. Three of these top providers are providing both therapeutic and coordination services.

Table 4.5

Top Providers for Fiscal Year 1999

Provider	Provider City	Predominant Service(s)	Total Payments FY 1999	Number of Children	Payments per Child
Lifeline Priv Duty Svcs	Somerset	Developmental Intervention and Speech Therapy	$1,165,776	396	$2,944
Horn, Richardson & Assoc	Lexington	Speech, Physical and Occupational Therapy	$776,001	308	$2,519
New Perceptions Inc	Edgewood	Developmental Intervention and Speech Therapy	$713,928	240	$2,975
Visiting Nurse Assoc.	Louisville	Speech, Physical and Occupational Therapy	$692,891	219	$3,164
Baptist East Home Health	Louisville	Speech, Physical and Occupational Therapy	$687,589	204	$3,371
Carriage House Cons Svcs	Louisville	Developmental Intervention and Primary Service Coordinator	$687,137	612	$1,123
Lou. Easter Seal Ctr	Louisville	Speech Therapy, Developmental Intervention, Physical Therapy	$682,149	601	$1,135
Seven Co Services, Inc.	Louisville	Initial Service Coordinator and Primary Service Coordinator	$651,827	1372	$475
Pathways, Inc.	Ashland	Developmental Intervention and Primary Service Coordinator	$647,549	374	$1,731
Cumb River MH/MR Board	Corbin	Integrated Discipline, Developmental Intervention and Primary Service Coordinator	$550,166	355	$1,550
Communicare, Inc	Elizabethtown	Multidisciplinary Group, Single Group and Physical Therapy	$469,435	233	$2,015
Lifeskills, Inc.	Bowling Green	Developmental Intervention and Multidisciplinary Group Therapy	$403,249	319	$1,264
Child Dev Ctr of Blgrass	Lexington	Integrated Disciplines	$396,504	175	$2,266
Redwood	Ft. Mitchell	Integrated Disciplines	$341,963	129	$2,651
Pediatric Rehab Solutions, Inc.	Louisville	Speech, Physical and Occupational Therapy	$340,079	183	$1,858

Source: CBIS Database

Professionals are the individual service providers, such as speech therapists or audiologists. These professionals typically work for provider agencies, but some professionals work independently. A professional who is not associated with an agency may be categorized as both a provider and a professional in the CBIS database. The highest paid professional, a speech therapist, received $126,832 from First Steps for FY

1999. In that year, 1752 professionals received payment for First Steps services. Of those professionals, 102 received at least $50,000 in payments for the year.

First Step Children

Because little attention has been given to the collection of data on the children served by First Steps, the database from CBIS can provide little insight regarding these children.

- The average age of children referred to First Steps is one year and seven months. The average remained constant from FY 1998 to FY 1999.
- Limitations of the diagnoses data on children are discussed below.
- Table 2.4 displays the county where the children of First Steps reside.

A Report on Kentucky Early Intervention Services' Billing and Information System: CBIS

The University of Louisville Urban Institute operates the Central Billing & Information System (CBIS) for the Kentucky Early Intervention Services (KEIS). CBIS operates under a memorandum of agreement and program administration contract (MA 019825). Since April 1997, First Steps has used CBIS to pay its service providers. Under the agreement, CBIS accepts invoices from the providers and uses this notice of service provision to pay the providers of those services. In addition to its bill paying responsibilities, CBIS performs additional functions.

- Through the primary service coordinator, it coordinates reports on each child in the system including warnings of incomplete invoices, inconsistencies with planned services and invoices, and plan ending dates for the child.
- It serves as a Management Information System providing monthly, quarterly and annual financial and institution reports.
- It provides an electronic database to list eligible providers, describe the children, the services the children receive, and the cost of those services.

Prior to using a centralized billing system, comprehensive care centers were the fiscal agents as well as service providers under a capitated system. There was little contract monitoring and control over these fiscal agents. There was no complete and consistent data collected on how many children were served or how much it cost to serve each child. One of the greatest difficulties with the early intervention services was how to move money through the system. Comprehensive care centers were part of the problem because some would spend all their money early in the year and would need more, while others had money left over at the end of the year. The director of First Steps stated that moving the money around was a real challenge because it took about six to eight weeks to move dollars through the contractual process. The comprehensive care centers system was weak overall on the allocation of funds. Also, while using the comprehensive care

centers, First Steps could not clearly describe the size of the program, the number of children receiving services, or the number and nature of services received.

A centralized billing and information system was intended to alleviate many of the problems associated with the capitated system and to allow available sources of funding for early intervention to be pooled, in order to ensure that eligible children receive the authorized services. CBIS now coordinates the pooling and expending of those funds. CBIS is a central point for providers to submit their invoices and for those invoices to be verified, authorized, and paid. As invoices are received, CBIS uses a revolving fund for receiving and dispensing federal and state funds to reimburse providers for early intervention services. Thus, all service invoices are submitted to and paid through CBIS.

In addition to claims processing, CBIS was intended to provide a central source of information on First Steps and for coordinating the provision of billing information to providers, families, the Department of Medicaid Services, and Kentucky Early Intervention Services. Also, CBIS was to provide the necessary data for assessing service costs and service utilization and for all financial reporting requirements of the various fund sources. CBIS authorizes payments for services provided through the use of an authorizing document, the Individualized Family Service Plan (IFSP).

As stated above, CBIS was intended to perform as a billing and information service for First Steps. To successfully fulfill its role, CBIS must perform as a billing system, an accountability system, and as a reporting and information system. Staff examined how CBIS has performed in these three areas. The managers of CBIS provided staff with a database that contained all their records on service events, payments, providers, and children since the inception of CBIS in April 1997 through July 7, 1999.

Billing System

Handling the complexities of providing accurate billing information, responding to invoices, coordinating invoices with the IFSP, and satisfying Medicaid billing requirements have represented the majority of work on CBIS to date. Appendix B details the major innovations to improve the ability of CBIS to fulfill its role as a central billing and information system. As of July 1999, over 400 providers have performed services for First Steps. These providers use a variety of methods to submit their bills to CBIS. Invoices may be from major hospitals which use computer generated invoices, individual providers, who may submit hand written invoices, and a myriad of other types of invoices from a variety of sources. Making invoicing uniform for all providers is currently not feasible because of their varied systems. Smaller providers often do not have the business systems in place to complete standardized billing formats, while large providers may have complex systems not flexible enough to accommodate external formats. Since invoices are received in a variety of formats, manual data entry is often required. Data entry errors were observed in the CBIS database, but these did not exceed 1% to 2% of all entries.

One common standard for evaluating a billing system is the time between the invoice date and the actual payment. For example, the Social Security Act requires that 95 percent of completed electronic claims by providers of Medicare services are to be paid no later than 14 days after receipt of invoice and that 95 percent of paper claims be paid no later than 30 days after receipt. CBIS does not record the date invoices are received in the database, therefore, an evaluation of timeliness based on this criteria is not possible.

The date services were provided was compared to the date payment was made and used as a proxy measure of the timeliness of bill processing. It should be understood, however, that this is a flawed measure because there is no way to determine how long it took from the date of service for a provider to submit an invoice.

Table 4.6 shows the number of days between the service date and the payment date, for fiscal years 1998 and 1999. The number of invoices paid less than thirty days from the service date increased from 15.7% in FY 1998 to 27.3% in FY 1999. Since there was a decline in the percentage of invoices paid more than thirty days after service was provided, a larger share of invoices are being paid quicker. Still, most invoices are not paid until one to three months after service is provided. As noted, because CBIS does not record the date it receives the invoice, it is not possible to tell whether the improvement is caused by improvements in CBIS responsiveness or because providers are invoicing CBIS more quickly.

Table 4.6.
Time Between Service Date and Payment Date

Fiscal Year	Total Payments	30 Days or Less (% of Total)	Between 30 and 60 days (% to Total)	Between 60 and 90 days (% to Total)	Over 90 Days (% of Total)
1998	280,155	43,981 (15.7%)	132,667 (47.3%)	52,089 (18.6%)	51,409 (18.3%)
1999	344,953	94,186 (27.3%)	165,191 (47.9%)	34,369 (10.0%)	51,207 (14.8%)

Source: CBIS Database

In FY 1999, 15 percent of invoices were not paid within the first ninety days from the service date. This time lag can be attributed partly to the need for CBIS to function as an accountability system. Part of the CBIS role as a billing and accountability system for First Steps is to decline payment for an incorrect or unauthorized invoice. In fact, invoices which do not match the type and number of services specified on the IFSP are to be rejected, which can lead to non-payment or delays if there was an error in the invoice. Before a payment is made by CBIS, invoices must correspond with the child's IFSP Summary Sheet. Additionally, invoices not submitted within 60 days of service cannot be paid by CBIS without approval by the director of First Steps. These two factors

can lead to delays between the time of service delivery, the invoice, and the payment. Despite the increase in accountability constraints in the system, CBIS has reduced problems relating to delays between the service date and payment.

CBIS is the only entity authorized to bill Medicaid for First Step services. This arrangement allows non-Medicaid providers to provide services to Medicaid enrolled First Steps children and allows First Steps to access Medicaid funds. Thus, CBIS pays providers for Medicaid children with First Step funds and then seeks reimbursement from Medicaid. On July 7, 1999, there were 10,384 invoices, totaling $578,497.98, that had been submitted for Medicaid reimbursement. In order to seek reimbursement, CBIS must be able to provide Medicaid with accurate and complete information. The CBIS billing system is able to provide the information required for payment reimbursements from Medicaid.

In addition to coordinating billing with Medicaid, CBIS is also responsible for incorporating into the billing system changes in First Steps regulations that affect service provision levels and charges for those services. CBIS has been able to incorporate those changes in the payment system parameters and to assist First Steps in communicating those changes to the First Steps providers. Recent limitations on the number of weekly services units per discipline were successfully incorporated. CBIS personnel revised the IFSP Summary Sheets, trained PSCs and performed internal programming of the billing system, in order to accommodate those changes. The billing system is flexible enough to allow for regulation changes and for those changes to be successfully incorporated into the authorization process.

Accountability System

The time and resources necessary to make CBIS an efficient and responsive billing system has detracted energies from developing it as an information system. Managers told staff that they have had to delay efforts to improve the information capabilities of CBIS in order to spend time making the billing system responsive to providers and accountable to First Steps. The managers have research backgrounds and say they recognize the value of developing the information features of CBIS.

As with all CBIS functions, the accountability function has developed over time. For a billing system to be accountable it should have an integrated means to detect incomplete invoices, duplicate billing, overbilling for services, billing for improper services or non-billable services, and unauthorized providers.

CBIS is now able to satisfy all of those criteria through controls linked to an electronic version of the Individualized Family Service Plan (IFSP). Initially, CBIS was not designed to provide the level of accountability outlined above. Clearly ineligible children were screened out and service plans needed to be current, but no attention was paid to the type and frequency of services billed. Primarily, these items were not included because First Steps had not recognized the need to account for these controls on billing. As noted elsewhere, the statewide review revealed a pattern among some providers of

billing for services beyond what was authorized by the IFSP. Once the need for greater control was acknowledged, CBIS undertook the steps to implement those controls into the payment system.

As noted above, the IFSP is the authorizing document for all early intervention services and is the source for the IFSP Summary Sheet. From the IFSP Summary Sheet, information pertaining to the child, the family, funding sources available, and the services authorized by the IFSP team are stored electronically within CBIS. CBIS then generates the "authorization to bill" for services within its system for each provider of each individual service listed on the IFSP Summary Sheet. Thus, a provider will be reimbursed for only those services pre-authorized in the IFSP Summary Sheet. It is important to recognize that CBIS cannot be used as a source to monitor the appropriate level of services for a child. It is the role of the IFSP team to determine the proper level of services to meet the child's needs. CBIS does, however, reject any service provisions that are not allowed by First Step regulations.

Once the IFSP Summary Sheet has been entered into the system and the plan implemented, services of a different type or frequency than those included in the plan are not authorized for payment. Also, before a provider is authorized to bill First Steps he or she must complete an enrollment form which is entered into the CBIS database. Thus, CBIS determines whether the services billed match the IFSP and whether the provider is an authorized First Steps provider before the invoice is paid.

Even before the current accountability system was in place CBIS was able to uncover problems in the billing system. After the first nine months of using CBIS, some irregularities in service provision were found. As a result of these findings, and in accordance with best practices, a new regulation on service levels was implemented. CBIS now has an edit system by which the system automatically rejects the invoice if the frequency of the service goes over a specified number. In addition to checking for allowable service provision frequency, CBIS can reject payments to providers if the IFSP is not current (it must be renewed every six months) or the child is no longer eligible because of age.

Since the originating IFSP can be amended during the six month plan period, maintaining continually updated records on a child is necessary to assure that only appropriate invoices are paid. Efforts to keep the billing and accountability system current with the IFSP and its other billing responsibilities has required the majority of the CBIS managers' resources to date. As an independent check of the system, LRC staff obtained an electronic copy of the full CBIS database and conducted reasonableness checks on the payments for services. Staff could not identify any instances in the data where payments were made outside the control parameters that had been implemented. However, staff did not have the resources or expertise to conduct a financial audit of the system. Thus, there was no check to ensure that invoices were for actual services delivered in the specified amount. A complete audit of the billing system would be needed to ascertain whether the originating IFSP, the IFSP Summary Sheet, and the data

programmed into the CBIS system are identical. It is recommended that the State Auditor be asked to complete such an audit.

The use of the IFSP, the legal authorizing document, as a limiting document for billing First Steps has enhanced CBIS's role as an accountability system. CBIS appears to have matured into a complete billing system for First Steps by providing efficiency, timeliness, and accountability in receiving and dispensing the funds available to First Steps. Completion of a financial audit is expected to enhance that performance.

Information System

CBIS was also intended to perform two additional tasks. One was to become a Management Information System for providing accounting reports and billing summary reports. The other was to become an information database regarding the children and families who use First Steps. It is important for the information system to convey accurate, relevant billing reports. Likewise, it is important for the information system to report information on the providers of First Steps services and the families who receive those services. These reports are necessary to inform decision makers about the First Steps program. The Director of First Steps stated that the design of CBIS did not originally include an emphasis on collecting information. The Director also states that CBIS management should not be made responsible for incomplete data since CBIS personnel must process the IFSP for billing purposes even if non-mandatory information is incomplete.

As a centralized source of information on the children and families involved in First Steps, CBIS has not performed satisfactorily. It is important to gather information on those who receive services so that the appropriateness and efficacy of those services can be better monitored. Information is needed to better understand the needs of the families in First Steps. Currently, CBIS does not contain accurate, basic geographic and demographic information on the enrolled children and families in First Steps.

There are two primary reasons for the information deficiencies. The first reason is that the majority of the emphasis and effort has been expended to develop CBIS as a billing and accountability system, as discussed above. The second reason is that referring points of entry and primary service coordinators, who collect and report this information to CBIS, often do not place a high priority on obtaining and reporting accurate and complete information, rendering the data of little value for analysis. Since CBIS has devoted its efforts to building a sound billing and accountability system, information on the children served has not been adequately developed.

The majority of data entry problems can be attributed to both CBIS personnel and the originators of the information, such as the Primary Service Coordinators. With respect to the accounting data there does not appear to be significant data entry problems, but with respect to enrolled children, data is poorly collected and validated.

Currently, even the child's county of residence is not fully and accurately documented. This suggests that besides the data entry problems, primary service coordinators do not fully recognize the importance of providing accurate and complete information on the children and their families. For example, out of 7,050 children, 207 children could not be clearly identified as to county of residence in FY 1999. The missing county data constitutes a little less than 3% of all the children for FY 1999. The omissions are not believed to be random, but systematic, and are therefore significant. CBIS managers explained how this occurred by stating "that the PSC did not bother to fill in the 'county' space." Clearly, if CBIS is to be a usable source of information on the children in First Steps, then more attention to detail on behalf of the primary service coordinators and CBIS personnel will be required. At least two other areas of information on the children needs to be enhanced; the diagnosis (or reason the child is receiving services), and where the children go when they leave First Steps.

CBIS currently uses ICD-9 codes to categorize the diagnosis a child is given upon entering into the First Steps program. Appendix C provides a list of the most frequent diagnoses for children in First Steps. The codes most used in the data are broad diagnostic codes which provide little insight into why individual children are receiving services. The most notable example is the use of the ICD-9 code 783.4. This diagnosis is defined as a "lack of normal physical development" and is assigned to a child with "failure to thrive, lack of growth, failure to gain weight, physical retardation, short stature." Nearly 58% of all children have received this as their sole diagnosis in the CBIS data. This makes it impossible to clearly discern the different types of children receiving services, the reason for the services, and to track the efficacy of specific services for children with particular delays. Additionally, 7% of the children in the database received a sole diagnosis of "developmental delay". Together, these two broad, general diagnoses were used as the sole description of 65% of the children who have received First Steps service since the inception of CBIS. Thus, it is difficult to gain insight into the type of children receiving services based on these broad diagnostic descriptions.

This problem is compounded by the many data entry problems related to this information. In addition to accurately recording the ICD-9 diagnosis code into the database, it would be beneficial to utilize information from the primary evaluation. The ICD-9 codes are general diagnostic codes that do not clearly define why the child is eligible for First Steps services. The eligibility criteria from the primary evaluation would provide a more complete description of the reason a child is receiving early intervention. By incorporating this information into the CBIS database program managers could have a much clearer diagnostic description of the children in order to better monitor their service needs and developmental progress.

In order to evaluate the efficacy of the services delivered, its is necessary to collect information on children after they leave First Steps. This would necessitate an even greater effort by the primary service coordinators who are the source of the information pertaining to the family and child. Currently, the data only indicate whether the child is "no longer in need of services" or is "too old." Knowing that the services were no longer needed provides some insight into the efficacy of the program, but

recording that the child is no longer eligible leaves many questions unanswered. Table 4.7 provides a breakdown of all the children in the CBIS database and their eligibility status as of July 7, 1999. As of that date, 36.5% of the children leaving CBIS are merely categorized as "Too Old."

Table 4.7
Children Evaluated in First Steps From April 7, 1997 to July 7, 1999

Child Status as of July 7, 1999		
Status	**Number of Children**	**Percent**
Currently Active	3,267	31.9%
Current Pending	1,182	11.5%
CBIS ID changed	12	0.1%
Deceased	50	0.5%
Ineligible	923	9.0%
Moved	182	1.8%
No Longer in Need of Services	270	2.6%
No Response From Parents	133	1.3%
Parents Decline Services	479	4.7%
Too Old to Continue Eligibility	3,736	36.5%
Total Number of Children	10,234	100.0%

Source: CBIS Database

Improvements in data entry by CBIS personnel, and accuracy and completeness of all information from primary service coordinators will be necessary before CBIS can satisfactorily function as an information system.

Conclusions Regarding CBIS

- **Except for its role as an information system, CBIS appears to be performing its duties sufficiently.** As a billing system, CBIS has performed reasonably well. It has obviously improved in its accuracy over the last two years, and CBIS represents a vast improvement over the original capitated system. A centralized billing and information system provides First Steps with oversight of billing procedures and promotes efficiency in moving funds through the system. The improvements to the billing system that have taken place since its inception should now allow for more effort to be expended toward building a reliable database on children and the services they receive. The primary reason for the information system's shortcomings is that CBIS managers have spent the majority of their efforts developing a centralized billing and accountability system. Handling the complexities of providing accurate billing information, responding to invoices, coordinating invoices with the IFSP, and satisfying Medicaid billing requirements have represented the majority of work on CBIS to date.
- **CBIS continues to evolve with improvements to the billing and accountability system, and incorporation of program changes in First Steps.** Some of the major

changes are highlighted in Appendix B. Because of this evolution of CBIS it is difficult or impossible to perform longitudinal analysis using the CBIS data. In fact, the lack of sufficient, consistent data collection on the children has made it difficult to fully describe the children that have been served by First Steps. In-depth analysis of the children in First Steps across time is not possible. As the managers of CBIS are able to turn more of their attention to the information side, it is hoped that the data will become more complete and accurate, and they will be able to improve the type of information collected on the children and their families.

- **CBIS will continue to provide inadequate and unreliable information about First Steps' children unless there are improvements in IFSP data collection and input.** An increased focus by First Steps providers and CBIS personnel to improve collection of information could enhance future efforts to evaluate what children are being served and how they are being served.
- **It is important to recognize that CBIS cannot be used as a source to monitor the appropriate level of services for a child.** It is the role of the IFSP team to provide the proper level of services to meet the child's needs and the role of monitoring specialists to ensure those services are legitimate. The role of the managers of CBIS is to provide accurate and efficient billing and data collection for First Steps. The system is not designed to determine appropriate service levels for the children enrolled in First Steps.
- **With respect to the accounting data there does not appear to be any significantly detectable level of data entry problems, but with respect to information on the child data, entry is poorly performed by all involved.** A complete audit of the billing and accountability system may reveal problems not uncovered in this investigation, but the database provided by CBIS was reviewed for internal consistency, and reasonableness checks were performed. Inconsistent data collection on children and families made analysis of the information system useless.

Recommendations Regarding CBIS

- **Recommendation #1: An annual financial audit of the billing system should be performed.** The director of First Steps confirmed that there has not been an audit of CBIS. Any system responsible for the transfer of funds should undergo an independent audit to assure credibility of the system. The State Auditor should undertake a complete financial audit of First Steps. The audit should include in its report whether CBIS should continue as the billing and information system for First Steps.

A financial audit could provide significant benefits. It could

- Identify internal control and financial management problems;
- Identify savings of resources;
- Improve the accounting information;
- Provide a clearer picture of financial conditions and operating costs; and

- Highlight means for improving management accountability and financial information.

- **Recommendation #2: CBIS must develop the information system so that First Steps can be fully evaluated and a better understanding of the program's efficacy can be obtained.** In order for CBIS to fulfill its role as an information system the following recommendations are made:
- **Recommendation #2A: It would be greatly beneficial to understand where the children go next after leaving the First Steps program.** Current reporting does not provide this answer.
- **Recommendation #2B: Efforts to better describe the children and the families should include family incomes, ethnicity, gender, and family characteristics (i.e., foster parents, single-parent, etc).** This data will allow the managers of the program to gain a better understanding of the children and families being served by First Steps.
- **Recommendation #2C: Tighter controls on data entry are necessary for more accurate information emanating from the CBIS database.** In order for CBIS to become a source of information on the children in First Steps more effort will need to be expended in training primary service coordinators and the other providers who are the source for this information. CBIS personnel must become more precise with their data entry procedures.
- **Recommendation #2D: It would be beneficial to not only include a diagnosis code accurately recorded into the database, but also to utilize information from the primary evaluation that allowed the child to receive services from First Steps.** This information will enhance our understanding of what types of children require the services provided by First Steps and of the amounts of services differently diagnosed children receive.
- **Recommendation #3: The entire CBIS system needs to be stabilized for there to be meaningful longitudinal research into the First Steps program.** Currently, studies of the program across time periods are not possible due to the many changes in CBIS, as well as KEIS and First Steps. It appears that the billing and accountability systems have undergone most of the major changes, therefore any other changes should take into consideration how they will impact the ability to perform longitudinal studies of the program and back-date changes whenever possible.
- **Recommendation #4: In order for the demographic and geographic information to improve there needs to be a continued emphasis on improving the training of point of entry providers and primary service coordinators.** CBIS managers should continue to develop an IFSP Summary Sheet that can be transmitted and input electronically into the CBIS database. This could free CBIS personnel of manual data entry and allow for an emphasis on data collection. Because of the wide array of providers in the system it may not be possible to

extend an electronic version of the IFSP Summary Sheet to all providers, and this may limit the ability of CBIS to fully automate its data entry processes.

SECTION V: CONCLUSIONS AND RECOMMENDATIONS

As requested by the Program Review and Investigations Committee, staff reviewed the operations of the Kentucky Early Intervention System, also known as First Steps. This program coordinates family-centered early intervention services to children from birth to 36 months who are diagnosed with significant developmental delays. The program reimburses private providers, such as speech and physical therapists, for supplying home-based intervention services. Organizing services in this fashion allows Kentucky to receive a federal grant under the Individuals with Disabilities Education Act, Part C. In FY 1999, that grant was $4.3 million.

Under the terms of the grant, First Steps is established as an entitlement program and must conduct outreach to identify as many infants and toddlers who are eligible for services as possible. The total program budget has grown from $4.7 million in FY 1995 to $25.1 million in FY 1999. Appropriations of state General Funds increased from $1.9 million to $9.7 million during the same period. The program experienced budget shortfalls during each of the last three fiscal years, ranging from $3.9 million to $6.6 million.

Before FY 1998, the number of children in the program was evaluated using a count of the number with active service plans on a particular day. In FY 1995, there were 1,336 active service plans on the child count day, compared to 3,402 in FY 1999. Starting in FY 1998, it was possible to track the number of children for whom payments were made anytime during the year. Just over 7,000 infants and toddlers had screening or intervention services reimbursed in FY 1999, up 29% from the previous year. Of those, 5,098 had active service plans, a 27% increase over FY 1998, and 1,952 were screened but determined to be ineligible for services, a 34% increase.

In requesting the study, the Committee specifically asked staff to

1. estimate the percentage of eligible children who are actually receiving services;
2. examine the efficacy of the early intervention services provided by the program; and
3. evaluate the fiscal accountability of the program, particularly the Centralized Billing and Information System (CBIS).

The remainder of this section presents the conclusions and recommendations derived from the review.

Conclusions

1. **First Steps managers and other professionals associated with the program exhibit a strong commitment to achieving the goal of improving the developmental progress of Kentucky's infants and toddlers, and often work under difficult conditions.** The tasks associated with finding, screening, and serving

infants and toddlers with developmental delays in a home-based program are complex and demanding.

Conclusions Regarding Number of Children

1. **It is not possible to determine the percentage of eligible children who receive services from First Steps.** Statewide comprehensive data on the incidence of established risk conditions and the incidence of developmental delays does not exist. Therefore, it is not possible to reliably estimate the number of infants and toddlers in Kentucky who have developmental delays that would meet the eligibility criteria set for First Steps. This prevents calculation of the percentage of eligible children who are actually served.

2. **The original estimate of the number of infants and toddlers expected to be served in the program during the current fiscal year was significantly low.** The estimation procedure incorporated national prevalence rates for conditions known to be associated with developmental delays in infants and toddlers. Kentucky has prevalence rates much higher than the nation for several of these conditions. Kentucky has the highest prevalence of Spina Bifida and the second highest birth defects infant mortality rate in the nation. Births to teenaged mothers, mothers who smoke or use alcohol during pregnancy, mothers who are poor, and parents who are related by blood to at least the fourth degree are all known to be significantly more prevalent in Kentucky than in the nation.

3. **There are various indications that a significant number of eligible children are not being identified for service, although no percentage estimate can be made.** There is substantial variation in the percentage of the total population of infants and toddlers in First Steps among counties. While some of this variation may be due to variations in socioeconomic and medical factors related to the incidence of developmental delays, it is also apparent that some of the variation is due to weaker program penetration in some counties. The absence of pediatricians in an area was mentioned by several points of entry as one factor that might reduce the number of referrals. Also, prevalence experts interviewed by staff indicated widespread underreporting of delays associated with particular conditions, such as fetal alcohol syndrome. Finally, the percentage of 3-5 year olds receiving services in the preschool program (9.5%) is much higher than the percentage of 0-2 year olds receiving services from First Steps (4.6%). Department of Education officials estimate that only about one-third of the three year-olds in the preschool program came from First Steps, although the two programs have very similar eligibility criteria. Part of this difference can be explained by the fact that some delays manifest after 36 months or become apparent in a group setting where variations from age norms are more pronounced. However, several preschool coordinators also stated that many infants and toddlers, particularly those with less severe developmental delays, are not being referred to First Steps.

4. **Child find activities of the points of entry are hampered by limited resources.** The fact that many more children than expected have been served by the program has hampered the child find effort in two ways. First, continuing budget deficits have severely limited the resources available for outreach materials and activities. Second, point of entry staff have had to spend the bulk of their time in initial screening and service coordination and have had less time to devote to outreach.

5. **Changes in state policies could significantly alter the number of infants and toddlers with developmental delays and the percentage of them referred to First Steps. This makes accurate projection of the number of children who will need services during the next budget cycle difficult.** Data on the number of children served for the past two years could serve as a reasonable basis for estimating the number of children who will enter this entitlement program during the next budget cycle. However, if the Commonwealth adopts the recommendations of the Governor's Early Childhood Taskforce and mounts aggressive prevention campaigns to increase maternal consumption of folic acid and reduce consumption of tobacco and alcohol, the number of infants and toddlers with developmental delays could be reduced. Adoption of the recommendation for universal audiological screening at birth could increase the number of children who receive intervention services. If KCHIP increases access to medical services and screening, it could both reduce the number of children with delay and increase the percentage referred to First Steps.

Conclusions Regarding Efficacy of Services

1. **In general, the early intervention services provided by First Steps do improve the developmental progress of the infants and toddlers with significant delays.** This conclusion is supported by a preponderance of the research literature on the efficacy of early intervention services of the type offered by First Steps and by the uniform observations of the preschool coordinators and regional training center staff who work with 3-5 year olds. Those interviewed consistently reported that they could see a demonstrable difference in the progress of children who had received services from First Steps.

2. **However, the absence of data that allows description of the characteristics of children in First Steps and that tracks their progress through preschool and elementary school and beyond prevents specific evaluation of the size and nature of developmental improvements that can be attributed to the program.** Virtually no valid data is collected on the children receiving services from First Steps, including that which specifies the particular delays exhibited or the developmental goals sought and achieved. There is also no system established to allow tracking of individual First Steps children into the educational system so that long-term developmental progress can be evaluated.

3. **More is not shown to be better. Well-controlled research and expert opinions received by staff indicate that general increases in the number of units of service**

received do NOT result in significant improvements in developmental progress. Apparently, it is as effective to provide a basic level of intervention services, as it is to provide intensive services, and is much less costly. Ongoing research, however, suggests that this result may vary somewhat for particular types of delays. These results heighten the importance of high-quality, individualized service plans.

4. **There is a broad perception among those familiar with the program that First Steps pays for some amount of intervention services that are not needed.** The statewide review conducted by First Steps determined that many service plans developed by providers included unnecessary services and that some providers exhibited a pattern of overbilling for services. Some corrective actions were taken in response to these problems. Among these corrective actions were

    - Preventing primary service coordinators from being reimbursed for any other type of service;
    - Restricting reimbursements to only those services authorized in the IFSP document; and
    - Restricting reimbursements to no more than three hours per week per child for each discipline (since lowered to one hour per week).

    Even with these measures, many individuals interviewed stated that providers can, and do, continue to bill for unneeded services and inappropriate services.

5. **The positions intended to supply oversight of the appropriateness of services are understaffed and may be underfunded.** The three groups with primary responsibility for ensuring that only legitimate services are reimbursed include First Steps managers, primary service coordinators, and monitoring specialists. There are currently four staff in the First Steps central office. They have responsibility for coordinating all aspects of the program and have little time, and may lack the expertise, to monitor program fiscal accountability. Primary service coordinators are supposed to ensure that only appropriate services are included in the IFSP. In the past, they could also act as service providers and may have let professional bias affect their opinion of how many services were "appropriate." In the face of new program restrictions that prevent them from providing services, many have chosen to drop service coordination activities for the more lucrative categories of service provision. There are indications that this will either lead to a shortage of primary service coordinators or may leave the function staffed by those less knowledgeable of best practices. Some primary service coordinators interviewed said they were reluctant to challenge the opinions of more experienced service providers on the IFSP team. Finally, there are only four full-time equivalent monitoring specialists charged with reviewing the appropriateness of all 3,400 service plans currently in effect. This number is believed to be insufficient for the task.

6. **Transition of children between First Steps and preschool suffers from lack of communication and sharing of information.** When they attain age three, children are no longer eligible for services from First Steps and must transition to the

preschool program to continue receiving services. Differences in approach (home-based versus school based), paradigm (intervention model versus educational model), forms (IFSP versus IEP), and schedule (year-round versus school year) were said to result in communication problems that hamper the transition process.

Conclusions Regarding Fiscal Accountability

1. **The budget for First Steps has more than tripled in the last three years, from $7.8 million in FY 1996 to $23.4 million in FY 1999, but budget deficits continue to occur.** One reason for budget deficits has been that the number of children in the program is more than twice the estimate on which the budgets were based. Managers note that while the number of children is larger, the average payments per child have declined. This is true, but can be explained, at least in part, by the fact that there has been an increase in the number of children screened but found to be ineligible for services. Analysis indicates that limitations on the number of service units have been offset by increases in average charges per unit, so total program expenditures continue to grow.

2. **First Steps managers have not taken all steps to maximize federal funds available through Medicaid and KCHIP.** Parents are asked if their child has a Medicaid card, but no verification of underreporting is conducted, although the Commissioner of MH/MR has requested access to Medicaid enrollment records. There is currently no formal screening to identify First Steps children who are eligible, but not actually enrolled, in Medicaid or KCHIP, and application for the programs is not required for First Steps participation. This is important because the federal government pays 70% of the cost of eligible services provided for children in Medicaid, and 79% of the cost for children in KCHIP.

3. **First Steps managers have not taken all available steps to tap other available sources of federal funds.** First Steps management reports significant attempts to identify and tap other sources of federal funds to support the program. Additional efforts, however, could be undertaken. One issue related to Medicaid is reimbursement of a share of First Steps administrative costs. In Kentucky, Medicaid does not currently allow reimbursement of administrative costs. Some programs in other states, however, have obtained Medicaid waivers to allow such reimbursements to occur. First Steps and the Department for Medicaid services should work together to explore this option for Kentucky. National consultants have advised that Title IV-E funds could be accessed for training and technical assistance costs. A decision has not yet been made to pursue that avenue. In addition, the Substance Abuse and Mental Health Services within DHHS is beginning to target some discretionary funds to early intervention services with infants and toddlers. Of course, some of these funding sources are already in place in the First Steps program. However, there appear to be alternative federal funding streams that could be accessed to fund a portion of early intervention services.

4. **The Centralized Billing and Information System (CBIS) developed by the University of Louisville has greatly improved the ability of First Steps managers to monitor program utilization and costs, compared to capitated arrangement with the comprehensive care centers.** In the capitated system, comprehensive care centers received grants to provide all early intervention services in the region. First Steps collected no information on the number of children served or the actual services delivered. Now, it is possible to track each unit of service provided for each child, who provides it, and how much it costs.

5. **After a rocky start, CBIS now appears to perform acceptably as a claims processing system.** Bills are paid in a timely manner and the data entry error rate of 1-2% is reasonable.

6. **CBIS also appears to function acceptably as an accountability system.** The system has the ability to prevent payment for services not authorized in the IFSP and prevent payment for services outside of program regulations. For example, staff performed internal reasonableness checks of the database and found no non-allowable payments for children over three, or payments beyond the service limits specified by regulation.

7. **Staff could find no evidence, however, that the system has been subjected to an external verification of the integrity of the invoices processed by the system.** Staff did not have the resources or expertise to conduct a financial audit of the system and was told by the First Steps director that no such audit has been completed. Thus, it is not possible to determine whether the electronic version of the IFSP matches the written version, whether the services billed were actually performed, or whether provider and child ID numbers match to actual eligible participants.

8. **CBIS does not function acceptably as an information system.** The little data contained in the system on the children and families who receive services was found to be so incomplete and inaccurate as to be virtually useless for describing the children receiving services or for evaluating the efficacy of those services.

Recommendations

The overall conclusion is that managers and professionals associated with First Steps exhibit a strong commitment to the goal of improving the developmental progress of infants and toddlers suffering from developmental delays. Because of the complicated nature of the task and the fact that about twice as many children as expected received services during the current budget period, these professionals have been successful in only some parts of program administration. It does appear that children are receiving services that improve their developmental progress. There are serious questions, however, regarding the efficiency and fiscal accountability of the processes used to reimburse providers for those services.

Based on its review of the program, staff developed the following recommendations for the committee's consideration. These recommendations are presented in two sets. The first set contains the recommendations considered to have the highest priority. Most of these concern improvements in the efficiency and accountability in the use of program resources. These are considered the highest priority because of the large opportunity cost of expending resources in an inefficient manner. Every dollar spent for an unnecessary or inappropriate service is lost for use in prevention and recruitment activities shown to yield impressive returns. Therefore, it is suggested that the priority recommendations be implemented before those in the second set.

Priority Recommendations

2. **The Commissioner of the Department for Mental Health and Mental Retardation Services should provide immediate assistance to First Steps for a complete review of fiscal procedures and the development of a plan for improvements in fiscal accountability.** The Financial Management Branch of the Division of Administration and Financial Management should be assigned to work with the program to review all current fiscal and financial procedures, such as estimation of the number of enrollees in the upcoming budget period, provider billing compliance, external validation of CBIS payments, and cost saving measures. The result should be a written plan for improvement.

   6.1.1. A fiscal officer should be assigned to work with the program on a permanent basis to implement and update the plan on an ongoing basis.

   6.1.2. Vacant positions in the First Steps central office should be filled as soon as possible. An additional program consultant for monitoring supervision and a fiscal analyst should be added to the staff roster.

   6.1.3. The Program Review and Investigations Committee should recommend to the Budget Review Subcommittee on Human Resources that it request submission of the written fiscal operations improvement plan when it considers the First Steps budget during the 2000 Session of the General Assembly.

7. **The Commissioner of the Department for Mental Health and Mental Retardation Services and the Commissioner of Medicaid Services should establish a team to identify all feasible means for First Steps to maximize its access to federal Medicaid and KCHIP matching funds.** This team should consider whether it is advisable to require the completion of an application for Medicaid and KCHIP as a criterion for participation in First Steps. It should also include consideration of a waiver that would allow Medicaid to reimburse some of the administrative costs of the program.

8. **The Commissioner of the Department for Mental Health and Mental Retardation Services should dedicate the necessary resources and expertise to explore the identification of other sources of federal funds for program services.**

9. **Immediate attention should be given to the development of a workable organization of the primary service coordination function.** The assignment of a primary service coordinator (PSC) to each child is required under federal law. How that function is organized is left to the states. As a reaction to the inclusion of unnecessary services in the IFSP, First Steps regulations now prevent PSCs from providing other intervention services. There is some logic in that. The problem is fewer professionals are now willing to provide service coordination. It is not clear how the program will successfully address this problem.

10. **The number of full-time equivalent monitoring specialists should be increased.** These are the professionals most qualified to assess the reasonableness of the services authorized in the IFSP. There are currently four full-time equivalent monitoring positions, which is judged too few to adequately perform the monitoring function. It is recommended that an additional two to four full-time equivalent positions be established, at least on a temporary basis. While this may seem expensive, it has the potential to result in significant program savings.

11. **The Program Review and Investigations Committee should request that the State Auditor of Public Accounts perform an external audit of the Centralized Billing and Information System.** In an internal review of the database, staff did not identify any obvious accountability problems with the payment of invoices. However, there appears to be a lack of external control procedures, a situation that could compromise the integrity of the system. This audit should specifically address whether the billing system should continue to be maintained outside the state accounting system.

Secondary Recommendations

1. **Child find efforts should be expanded and targeted to geographic areas and developmental delay conditions that are believed to be underreported.**

2. **Consideration should be given to using existing First Steps' outreach structure for the dissemination of prevention efforts.**

3. **The Commissioner of Mental Health and Mental Retardation Services and the Director of the Division of Exceptional Children Services in the Department of Education should focus on improving the operations of the transition project. They should develop a plan to improve communication and the sharing of information between First Steps and the preschool program, to ease the transition for children and families. Consideration should be given to funding an additional full-time transition employee.**

4. **Research funded by the State Improvement Grant should focus less on demonstrating that the early intervention services funded by the program, in total, improve developmental progress, and should focus more on validating best practices to guide monitors and PSCs in their evaluation of service plans.**

5. **Specific efforts should be focused on improving the collection, validation, and analysis of data on the characteristics of the children and families who receive services from First Steps, including those screened but found ineligible for the program. This data could significantly improve the ability of managers to monitor program effectiveness and make program improvements that benefit children and their families.**

6. **First Steps should contract with an independent entity to conduct regular valid surveys of family and provider satisfaction. Survey results should be used to improve program responsiveness.**

7. **First Steps should take a more active role in facilitating communication and contact between families of First Steps children.**

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Appendix A

Comparison of FY98 and FY99 by Discipline				
Discipline	**FY98 Payment**	**FY99 Payment**	**Payment Differential**	**% Change form FY98**
Speech Therapist	$4,217,455.42	$5,698,370.78	$1,480,915.36	35%
Occupational Therapist	$1,761,554.64	$2,471,446.20	$709,891.56	40%
Physical Therapist	$1,921,611.86	$2,370,523.86	$448,912.00	23%
Multidisciplinary Group Therapist	$52,711.50	$484,893.69	$432,182.19	820%
Single Discipline Group Therapist	$32,788.00	$365,914.83	$333,126.83	1016%
Primary Service Coordinator	$1,671,102.88	$1,986,153.64	$315,050.76	19%
Developmental Interventionist	$3,224,025.83	$3,498,962.42	$274,936.59	9%
Initial Service Coordinator	$935,591.25	$1,156,513.75	$220,922.50	24%
Integrated Disciplines Service Provider	$548,849.00	$769,145.50	$220,296.50	40%
Physical Therapy Assistant	$491,533.68	$625,377.65	$133,843.97	27%
Primary Evaluator	$497,163.50	$607,822.50	$110,659.00	22%
Assistive Technology Spec.	$74,221.30	$133,062.63	$58,841.33	79%
Occupational Therapy Assistant	$235,100.40	$290,685.10	$55,584.70	24%
Teacher of the Visually Impaired	$112,596.13	$140,453.25	$27,857.12	25%
Audiologist	$29,775.35	$51,646.50	$21,871.15	73%
Dietician	$2,217.75	$8,504.50	$6,286.75	283%
Nutritionist	$18,297.50	$24,424.50	$6,127.00	33%
Psychological Associate	$340.00	$4,164.50	$3,824.50	1125%
Non-Commercial Group Carriers	$11,903.00	$13,392.35	$1,489.35	13%
Psychologist	$14,887.75	$15,897.25	$1,009.50	7%
Cab/Taxi	$2,364.80	$2,902.98	$538.18	23%
Teacher of the Deaf/Hard of Hearing	$8,440.00	$8,256.00	($184.00)	-2%
Orientation and Mobility (O&M) Specialist	$945.00	$702.00	($243.00)	-26%
Certified Psychologist	$3,918.50	$1,297.25	($2,621.25)	-67%
Social Worker	$35,359.00	$23,492.50	($11,866.50)	-34%
Private Automobile	$59,875.75	$47,073.11	($12,802.64)	-21%
Developmental Assistant	$21,504.69	$2,429.14	($19,075.55)	-89%
Family Therapist	$37,229.50	$12,992.50	($24,237.00)	-65%
Registered Nurse	$53,601.53	$19,713.39	($33,888.14)	-63%
Respite Provider	$177,567.10	$138,720.85	($38,846.25)	-22%
Developmental Associate	$216,378.54	$107,676.46	($108,702.08)	-50%
Totals	**$16,470,911.15**	**$21,082,611.58**	**$4,611,700.43**	**28%**

Comparison of FY98 and FY99 by Event Units per Child			
Discipline	**FY98 Event Units per Child**	**FY99 Event Units per Child**	**Differential**
Cab/Taxi	145.105	781.500	636.395
Private Automobile	1,025.209	1,319.715	294.506
Multidisciplinary Group Therapist	66.095	155.258	89.164
Single Discipline Group Therapist	72.069	136.090	64.021
Integrated Disciplines Service Provider	188.571	225.250	36.679
Psychological Associate	4.000	23.857	19.857
Occupational Therapy Assistant	56.272	65.399	9.127
Occupational Therapist	49.608	53.727	4.119
Teacher of the Visually Impaired	30.836	34.659	3.823
Social Worker	25.574	27.784	2.210
Dietician	10.200	11.567	1.367
Family Therapist	11.586	12.891	1.305
Assistive Technology Spec.	3.154	3.178	0.024
Audiologist	5.254	5.242	(0.012)
Primary Evaluator	1.799	1.414	(0.385)
Primary Service Coordinator	24.570	24.183	(0.388)
Speech Therapist	68.993	68.064	(0.930)
Initial Service Coordinator	14.336	13.170	(1.166)
Nutritionist	16.200	14.855	(1.345)
Orientation and Mobility (O&M) Specialist	8.750	6.500	(2.250)
Non-Commercial Group Carriers	342.843	340.518	(2.325)
Certified Psychologist	12.500	9.500	(3.000)
Physical Therapy Assistant	68.471	65.211	(3.260)
Registered Nurse	16.847	11.573	(5.274)
Physical Therapist	51.953	46.582	(5.370)
Respite Provider	170.874	160.374	(10.500)
Psychologist	29.333	18.600	(10.733)
Developmental Interventionist	71.773	56.303	(15.471)
Developmental Associate	75.541	39.332	(36.210)
Developmental Assistant	75.560	34.500	(41.060)
Teacher of the Deaf/Hard of Hearing	129.500	51.571	(77.929)
Totals	**218.688**	**188.380**	**(30.309)**

Comparison of FY98 and FY99 by Payments per Child

Discipline	FY98 Children	FY99 Children	Children Differential	FY98 Payments per Child	FY99 Payments per Child	Payments per Child Differential
Multidisciplinary Group Therapist	74	302	228	$712.32	$1,605.61	$893.29
Integrated Disciplines Service Provic	219	244	25	$2,506.16	$3,152.24	$646.08
Single Discipline Group Therapist	58	311	253	$565.31	$1,176.58	$611.26
Cab/Taxi	19	4	(15)	$124.46	$725.75	$601.28
Psychological Associate	2	7	5	$170.00	$594.93	$424.93
Occupational Therapist	1,642	2,064	422	$1,072.81	$1,197.41	$124.60
Occupational Therapy Assistant	250	281	31	$940.40	$1,034.47	$94.06
Teacher of the Visually Impaired	159	176	17	$708.15	$798.03	$89.88
Assistive Technology Spec.	254	366	112	$292.21	$363.56	$71.35
Private Automobile	234	144	(90)	$255.88	$326.90	$71.02
Dietician	10	30	20	$221.78	$283.48	$61.71
Social Worker	61	37	(24)	$579.66	$634.93	$55.28
Speech Therapist	2,860	3,773	913	$1,474.63	$1,510.30	$35.67
Family Therapist	133	46	(87)	$279.92	$282.45	$2.52
Audiologist	291	496	205	$102.32	$104.13	$1.81
Primary Evaluator	1,970	2,410	440	$252.37	$252.21	($0.16)
Primary Service Coordinator	3,715	4,495	780	$449.83	$441.86	($7.97)
Non-Commercial Group Carriers	70	83	13	$170.04	$161.35	($8.69)
Nutritionist	50	69	19	$365.95	$353.98	($11.97)
Respite Provider	556	457	(99)	$319.37	$303.55	($15.82)
Initial Service Coordinator	3,338	4,500	1,162	$280.28	$257.00	($23.28)
Developmental Assistant	184	30	(154)	$116.87	$80.97	($35.90)
Orientation and Mobility Specialist	4	4	0	$236.25	$175.50	($60.75)
Physical Therapist	1,727	2,286	559	$1,112.69	$1,036.97	($75.71)
Physical Therapy Assistant	416	573	157	$1,181.57	$1,091.41	($90.16)
Developmental Interventionist	2,454	2,922	468	$1,313.78	$1,197.45	($116.33)
Developmental Associate	316	190	(126)	$684.74	$566.72	($118.02)
Registered Nurse	144	82	(62)	$372.23	$240.41	($131.83)
Certified Psychologist	8	4	(4)	$489.81	$324.31	($165.50)
Teacher of the Deaf/Hard of Hearinc	6	7	1	$1,406.67	$1,179.43	($227.24)
Psychologist	15	25	10	$992.52	$635.89	($356.63)
Totals	5,463	7,050	1,587	$3,014.99	$2,990.44	($24.55)

Appendix B: Overview of Changes to CBIS

Summer 1997

- Implemented sytem programming to allow for electronic billing
- Added provider enrollment status to the Provider database
- Undertook Extensive revisions to permit automatic determination of the ending dates of the IFSP

Fall 1997

- Initiated extensive development to facilitate Medicaid billing

Spring 1998

- Changed discipline codes on group billing pursuant to regulation change in group billing. (Providers notified effective date was 6/1/98; providers were slow to respond to change.)

Fall 1998

- Corrected programming codes that created Medicaid files, placed CBIS invoice numbers on all claims to Medicaid

Winter 1999

- Implemented billing limitations per regulations
- Changed billing status wording from "Best Practice Violation" to "Duplicate Billing"
- Alleviated possibility of two children with same ID number
- Added an "effective date" field to Professional table
- Changed the expiration letters to primary service coordinators to be generated on the "plan end date," eliminating redundancy of notification

Summer 1999

- Implemented new IFSP Summary Sheets
- Added gestational age, income category, and ethnicity fields to IFSP Summary Sheet
- Implemented new billing limitations pursuant to regulation changes
- Incorporated new service and discipline codes to allow billing for Intensive Level Evaluations

APPENDIX C

ICD-9 Code	ICD-9 Description	Number of Children
783.4	LACK NORM PHYSIOL DEVEL	6029
315.9	DEVELOPMENT DELAY NOS	743
758.0	DOWN'S SYNDROME	221
343.9	CEREBRAL PALSY NOS	92
741.9	SPINA BIFIDA	71
315.39	SPEECH/LANGUAGE DISORDER NEC	70
315.31	DEVELOPMENTAL LANGUAGE DISORDER	65
760.75	COCAINE - NXS INFL FETUS	61
784.5	SPEECH DISTURBANCE NEC	58
742.1	MICROCEPHALY	56
315.4	COORDINATION DISORDER	51
432.9	INTRACRANIAL HEMORR NOS	41
331.4	OBSTRUCTIVE HYDROCEPHALUS	35
742.3	CONGENITAL HYDROCEPHALUS	32
315.3	SPEECH/LANGUAGE DISORDER*	31
767.6	BRACH PLEXUS INJ-BIRTH	31
996.1	MALFUNCTION VASC DEVICE/GRAF	29
362.21	RETROLENTAL FIBROPLASIA	28
000.01	HEARING LOSS AT LEAST 40db	27
759.89	SPECIFIED CONG ANOMALY NEC	26
299.0	INFANTILE AUTISM*	25
780.3	CONVULSIONS	25
765.1	OTHER PRETERM INFANTS*	23
349.9	CNS DISORDER NOS	22
772.1	NB INTRAVENTRICULAR HEM	22
995.55	IN DATABASE BUT NO ICD-9 CODE	21
742.2	REDUCTION DEFORM	19
345.6	INFANTILE SPASMS*	18
765.0	EXTREME IMMATURITY*	18
799.9	UNKN CAUSE MORB/MORT NEC	17
759.7	MULT CONGEN ANOMALIES NEC	14
315.8	DEVELOPMENT DELAYS NEC	13
436	IN DATABASE BUT NO ICD-9 CODE	13
655.3	FETAL DAMAGE DUE TO VIRUS*	13