Washington's Infant Toddler Early Intervention Program Study: December 1, 1998

Enrollment of Washington Children with Disabilities and Special Health Care Needs in Washington State Public Programs

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July 1999

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ACKNOWLEDGMENTS

This report was prepared for and funded by the Infant Toddler Early Intervention Program, Division of Developmental Disabilities, Department of Social and Health Services, in coordination with the State Interagency Coordinating Council for Infants and Toddlers with Disabilities and their Families. This study represents a collaborative effort between the Department of Social and Health Services, the Department of Health, and the Office of the Superintendent of Public Instruction. Assistance and support are also provided by the Department of Trade and Economic Development and the Department of Services for the Blind.

Sincere thanks and appreciation go to the members of the State Interagency Coordinating Council (SICC) for Infants and Toddlers with Disabilities and Their Families, to the SICC Data/Services Committee, and to the individuals from the child development programs, neurodevelopmental centers, local school districts, and local health jurisdictions, private therapists, and the Family Resources Coordinators who completed the survey forms. Without their contributions this report could not have been written.

Special thanks go to the members of the First Steps Database team who contributed to this report. Callie Sundarum provided the extensive programming expertise and support necessary to process a large amount of complex data. Karen Thorson helped with design and layout, and supported many additional activities which helped to produce this report.

Elizabeth Kohlenberg, Acting Director of Research and Data Analysis, Department of Social and Health Services, provided oversight and overall project management.

John Haskett, of Division of Developmental Disabilities, Department of Social and Health Services, gave invaluable assistance in providing data from the Common Client Database and the County Human Resource Information System. Sincere thanks go to Anne Shureen and Lou Colwell, of the Office of Superintendent of Public Instruction, who thoughtfully reviewed this report. Our gratitude goes to Civillia Hill and Patsy Shumway of the Department of Health, Community and Family Health, for their assistance with the Child Health Intake Form database for the Children with Special Health Care Needs Program.

Special thanks go to the staff of the Infant Toddler Early Intervention Program.

Many thanks go to Diana English of the Children’s Administration, Toni Krupski of the Division of Alcohol and Substance Abuse, and Ann Egerton and Sharon Lehnert-Reddick of the Medical Assistance Administration for reviewing this report.

Jason Fry, Greg Kirkpatrick, and Francia Reynolds have our sincere appreciation for maintaining the Research and Data Analysis computer network, a system that meets the diverse demands of the agency’s managers, researchers, analysts, programmers, and talented support staff. Many thanks go to Lisa Weber who extracted and analyzed respite care data from the Division of Developmental Disabilities’ Trends and Patterns Database.

The First Steps Database would not exist without the contributions of the Center for Health Statistics, Department of Health, which provides birth certificate files, and the Medical Assistance Administration, Department of Social and Health Services, which provides Medicaid claims data.

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ACRONYMS

AFDC	Aid to Families with Dependent Children
CAMIS	Case and Management Information System
CCDB	Common Client Database
CFH	Community and Family Health
CHIF	Child Health Intake Form
CHRIS	County Human Resource Information System
CSHCN	Children with Special Health Care Needs
DDD	Division of Developmental Disabilities
DOH	Department of Health
DSHS	Department of Social and Health Services
EPSDT	Early Periodic Screening, Diagnosis, and Treatment
FPL	Federal Poverty Level
FRC	Family Resources Coordinator
FS	First Steps
FSDB	First Steps Database
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Plan
IFSP	Individualized Family Service Plan
ISP	Individualized Service Plan
ITEIP	Infant Toddler Early Intervention Program
NHIS	National Health Interview Survey
OFM	Office of Financial Management
OSPI	Office of Superintendent of Public Instruction
RDA	Research and Data Analysis
SE	Special Education
SICC	State Interagency Coordinating Council
SSI	Supplemental Security Income
TANF	Temporary Assistance for Needy Families
TARGET	Treatment and Report Generation Tool

EXECUTIVE SUMMARY

An estimated 2.5% of children under the age of three in the state of Washington have developmental delays or disabilities. Infants and toddlers with disabilities and their families are eligible to receive an array of public early intervention services, although all those eligible may not seek enrollment in state programs. State agencies, families, and local communities share a common vision for a service system of coordinated, comprehensive, family-centered and culturally relevant early intervention services for eligible children and their families.

This report presents information on infants and toddlers, ages birth to three, with developmental delays or disabilities, who were enrolled in Washington State public services. A child was defined as enrolled if the child 1) was determined to be eligible for services, 2) was receiving services, and/or 3) had a completed service plan.

Summary of Findings: December 1, 1998 Unduplicated Enrollment Count

- In Washington State, 5,332 infants and toddlers under three years of age were found to be enrolled in public early intervention services for developmental delays or disabilities as of December 1, 1998. Over the last five years the *number* of children served has increased by 31% from 4,055 to 5,332, and the *proportion* of children enrolled has risen from 1.6% to 2.3%.

- The 1998 rate of enrollment in services in Washington (2.3%) was similar to the rate found in the National Health Interview Survey (NHIS) for children with limitations in some daily activity (2.3%).

- The enrollment rate (3.4%) for Medicaid-eligible children, with family incomes up to 200% of the FPL, was greater than that for non-Medicaid children (1.3%). The proportion of enrolled children who were Medicaid-eligible (71%) was significantly greater than that for all children in Washington (47%). These patterns are similar among children in the NHIS with reported limitations.

- The enrollment rate for children of mothers with no prenatal care (6.6%) was over three times higher than that for children of mothers who received first trimester prenatal care (2.1%).

- Characteristics of infants at birth that were associated with high enrollment rates include low birthweight (11.0%), preterm birth (6.2%), and Apgar score less than 8 (10.2%). Male children had a higher enrollment rate than female children (2.6% versus 2.0%).

- Among children who were Medicaid-eligible with diagnosed medical conditions, enrollment rates were highest for those with cerebral palsy (91.3%), Down syndrome (91.0%), cleft lip and/or palate (69.6%), developmental speech and language disorder (57.1%), and other developmental disorders or delays (40.8%).

- Children of mothers with diagnosed substance abuse had an enrollment rate of more than three times that for all other Medicaid children in Washington (11.6% versus 3.0%).

- The proportion of children enrolled in publicly-funded early intervention who receive other publicly-funded services is much higher than that for all other children.

- Rates of Supplemental Security Income (SSI) eligibility for children enrolled in early intervention services were more than 100 times greater than for all other children.

- Rates of out-of-home placement, children affected by drugs and alcohol, and mortality between ages one and three for early intervention enrolled children were generally around ten times greater than those for all other children.

- The proportion of children eligible for medical assistance during the first year of life has shown continuing increases from 1992 to 1997; however, the rate of increase has been smaller for enrolled children than for all other children. The proportion of enrolled children who were Medicaid-eligible during the first year of life has increased from 42.0% for children born in 1992 to 55.4% for children born in 1995. This represents an increase of 32%. For all other children, the Medicaid-eligible proportion increased from 22.2% in 1992 to 33.3% in 1995. This represents an increase of 50%.

- Managed care enrollment rates among Medicaid-eligible children in early intervention programs resembled those for other low-income children over time. Most low-income children born after 1993 were enrolled in a Medicaid managed care plan at some point before their second birthday. Approximately nine of every 10 low-income children born in 1996 enrolled in a Medicaid managed care plan before their first birthday.

CHAPTER 1

INTRODUCTION

This report presents information on infants and toddlers, ages birth to three, with developmental delays or disabilities who were enrolled in Washington State public early intervention services.

Chapters three through seven describe the population of children reported to be enrolled on December 1, 1998. The following measures are examined: unduplicated enrollment count, state enrollment rates and patterns compared to national prevalence rates and patterns, and the relationship of risk factors to the enrollment of children in early intervention programs.

Chapter eight presents expanded characteristics of enrolled infants and toddlers in order to portray a broader view of the characteristics and needs of enrolled children and their use of publicly-funded services other than early intervention. Children included in these analyses were born in 1992 through 1997 and were included in at least one of seven child enrollment counts. The following variables are examined by birth cohort: Infant and Child Mortality, Children Affected by Drugs and Alcohol, Out-of-Home Placement, Medicaid Enrollment and Grant Status, Managed Care Enrollment, and Supplemental Security Income.

This report provides enhanced information to Washington's early intervention programs for infants and toddlers with developmental delays or disabilities, in order to facilitate program planning and the development of future priorities at both state and local levels.

Washington's Infant Toddler Early Intervention Program Study, an extension of the Birth to Three Study, is funded by the Department of Social and Health Services Infant Toddler Early Intervention Program.

BACKGROUND

During infancy and early childhood the connections between neurons in the brain, or neural synapses, reach their highest density, well above that of adults, and remain at that level until late childhood (Huttenlocher, l990; Chugani et al., 1987). This is a period of great potential, as sensory experience during this time helps determine the pattern of wiring between the neurons in the brain (Greenough and Black, 1992; Weiler et al., 1995). This link between brain activity and brain structure points to the importance of the critical early years of life.

Research on the effectiveness of early intervention programs has found positive impacts associated with early intervention services provided to infants and children with *established disabilities* (Casto and Mastropieri, l986; Shonkoff and Hauser-Cram, l987), preschoolers *environmentally at-risk* (Casto and White, 1984; Lazar and Darlington, l982; Ramey and Campbell, l992; Wasik et al., 1990) and preschoolers at *biological risk* due to low birthweight and prematurity (Blair et al., l995; McCarton et al., l997; Ramey et al., l992; Rauh et al., 1988; Scarr-Salapatek and Williams, l973).

Policy makers at the federal level, recognizing the importance of early referral and intervention for infants and toddlers under the age of three and their families, passed amendments to the 1986 Education of the Handicapped Act, establishing what has currently been reauthorized as Part C of the Individuals with Disabilities Education Act (IDEA). The Infant Toddler Early Intervention Program administers the IDEA Part C program in Washington State.

In Washington State, various public early intervention services for infants and toddlers birth to three with developmental delays or disabilities have been provided by school districts, neurodevelopmental centers, developmental centers, county health and human service agencies, Tribal programs, and other local and state agencies. The IDEA Part C program acts as an umbrella and provides linkages and enhancement of these services to ensure a statewide system of comprehensive, multi-disciplinary, coordinated services to infants and toddlers with disabilities and their families. In October 1994, Washington State began full implementation of Part C. The Washington Birth to Six State Planning Project shifted programmatic home to the Division of Developmental Disabilities and was renamed as the Washington Infant Toddler Early Intervention Program. The services available to eligible infants and toddlers are listed in Appendix B.

CHAPTER 2

METHODS

Infants and toddlers under the age of three enrolled in public early intervention programs were identified as part of the *Birth to Three Study,* performed by Research and Data Analysis, on the following dates: December 1, 1993; May 1, 1995; December 1, 1995; May 1, 1996; December 2, 1996; December 1, 1997; and December 1, 1998. Enrollment status for each point in time was determined based on data from a provider survey and three agency databases.

For children reported in the December 1, 1998 enrollment count, additional information from the First Steps Database allowed analysis of relationships between early intervention program enrollment and characteristics of the population including income level, risk factors, and medical diagnoses. National prevalence estimates for disabilities among children under three were generated using data from the National Health Interview Survey.

The expanded analyses presented in chapter eight are based on a listing of children who were reported in any of the seven enrollment counts above. Client records were unduplicated across counts and matched with the First Steps Database (FSDB). After matching with the FSDB, the listing of enrolled children (N=12,915) was matched to three additional databases and compared to similar information for non-enrolled children (N=453,604).

DATA SOURCES

Provider Surveys for the December 1, 1998 Count

Providers of early intervention services through public programs were asked to list every child under the age of three who was enrolled in services on December 1, 1998. A child was defined as enrolled if the child 1) was determined to be eligible for services, 2) was receiving services, or 3) services were contracted out and the child had a completed service plan (an Individualized Family Service Plan (IFSP) or an Individualized Education Plan (IEP)).

Provider surveys were mailed to 37 child development programs, 5 neuorodevelopmental centers, 9 combined child development programs and neurodevelopmental centers, 35 Infant Toddler Early Intervention Program contractors, of which 10 were also child development programs and/or neurodevelopmental centers, and 296 school districts, of which 108 reported they were providing services either directly or through a contract with another provider. An additional 64 school districts reported that no children were identified as eligible at this time, but that if children were identified, they would be served. Completed surveys were received from 100 percent of service providers contacted. The types of service providers surveyed are described in the table on the following page.

Service Providers

Existing public services are provided and/or funded through the following agencies: the Department of Social and Health Services (DSHS) Infant Toddler Early Intervention Program (ITEIP) including Family Resources Coordinators (FRCs); the DSHS Division of Developmental Disabilities (DDD); the Department of Health (DOH) Children with Special Health Care Needs (CSHCN); and the Office of Superintendent of Public Instruction (OSPI) Special Education. Washington has also received several local Early Head Start grants which provide additional resources for families and their children.

ITEIP (DSHS) is responsible for the coordination of ongoing planning, development, and the implementation of collaborative interagency and multi-disciplinary delivery of early intervention services to infants and toddlers with disabilities and their families as defined in the Individuals with Disabilities Education Act (IDEA), Part C. Program implementation occurs through local contracts with a variety of local contractors and a state interagency agreement. Specific contractors are locally determined in coordination with County Interagency Coordinating Councils, Indian Tribes, and the Washington Migrant Council.

Family Resources Coordinators (FRCs) are available in each geographic area of the state to assist families who have concerns about their child's development. Their tasks are to support families, to seek and provide information about community organizations, to coordinate child find, to ensure evaluations and assessments, to facilitate Individualized Family Service Plans (IFSPs), and to coordinate services and activities with community and agency resources. These federally funded services must enhance and may not duplicate existing services.

DDD (DSHS) funds early intervention services for young children from birth to age three through contracts with county governments as locally prioritized by county planners. The county developmental disability branch selects and contracts with service providers for child development services. These services, designed to maximize a child's developmental potential, include developmental therapy, parent education and training. There are 46 child development programs in the state of Washington.

CSHCN (DOH) serves a population that includes children under the age of 18 who have disabilities and handicapping conditions, chronic illnesses, and health related educational or behavioral problems, or who are at risk for these conditions. The services provided include early identification, multi-disciplinary assessment, diagnostic and treatment services, neurodevelopmental therapies, care coordination and referral. These services are provided for the birth-to-three population by CSHCN local contractors including 33 local health jurisdictions and 14 neurodevelopmental centers.

OSPI administers and funds special education programs provided by local school districts and educational service districts. For the December 1, l998 count, 108 school districts reported they were providing services to children with disabilities ages birth to three, either directly, through another district or district cooperative, or by contract with a child developmental center (DDD) or neurodevelopmental center (DOH). An additional 64 districts reported that no children were currently identified as eligible, but that if children were identified, they would be served.

Additionally, birth-to-three early intervention services are funded by private organizations, private insurance, DSHS Medical Assistance Administration programs, other DSHS programs (e.g., Children's Administration, Division of Alcohol and Substance Abuse, and Mental Health), Tribal authorities and programs, the military and non-profit service organizations such as the Elks, Shriners, United Way, and others.

Agency Databases Providing Additional Enrollment Information

The Department of Social and Health Services Division of Developmental Disabilities Common Client Database provided a list of Division clients who were under the age of three as of the enrollment count date. The County Human Resource Information System provided information about the disability-related service(s) in which these individuals were enrolled.

The Department of Health Community Family Health database included data from the Child Health Intake Form and the providers' Health Services Authorization Form (Children with Special Health Care Needs) for children under three years old who were enrolled in at least one disability-related Department service as of the enrollment count date.

First Steps Database

The First Steps Database (FSDB) is a single repository for information taken from birth certificates, infant death certificates, Medicaid claims records for maternal and infant services, and Medicaid eligibility histories. Birth certificates and death certificates, provided by the Department of Health Center for Health Statistics, contain data about prenatal care, pregnancy outcomes, and maternal and paternal demographic characteristics for all births to Washington State mothers. Within the FSDB, individual birth certificates are linked to Medicaid claims and eligibility histories, providing information on medical procedures, medical diagnoses, and Medicaid payments for maternal and infant care. The FSDB was created and is maintained by Research and Data Analysis, Department of Social and Health Services. It is currently updated to include births from mid-1988 (a year prior to the implementation of First Steps) through 1997.

CAMIS (Case and Management Information System)

The Case and Management Information System (CAMIS), maintained by the Children's Administration of DSHS, contains information on referrals to Child Protective Services and out-of-home placements. The CAMIS database was started in July 1991 and was implemented on a statewide basis in early 1992. Information from CAMIS was linked to the listing of enrolled children born 1992 through 1997 to determine the frequency of children in out-of-home placement during the following periods: birth to one year, one to two years, and two to three years. Placement duration for these children was also measured.

TARGET (Treatment and Report Generation Tool)

The Treatment and Report Generation Tool (TARGET) is the management information system used by DASA to record information on publicly-funded treatment services for substance abusers in Washington State. TARGET contains assessment, admission, service provision, demographic and discharge data from treatment agencies across the state.

DOH Center for Health Statistics Matched Infant Death File and Death Certificate File

Children in the FSDB were linked to the DOH Center for Health Statistics (CHS) Matched Infant Death File and, for children over the age of one, to the Death Certificate file (DOH CHS).

UNDUPLICATION AND MATCH

A single child may need services from more than one provider and may be reported on multiple submissions. Records were therefore unduplicated to obtain a count of enrolled children with only one entry per child. Enrollment records were matched to the First Steps Database using reported information including name, date of birth, gender, and family residence zip code. For a more detailed description of the matching process, see Appendix C.

NATIONAL PREVALENCE RATES

National comparisons are based on child limitations as reported by respondents in the National Health Interview Survey, an annual comprehensive survey of health conditions in a sample of households throughout the United States, conducted by the U.S. Bureau of the Census under the direction of the National Center for Health Statistics.

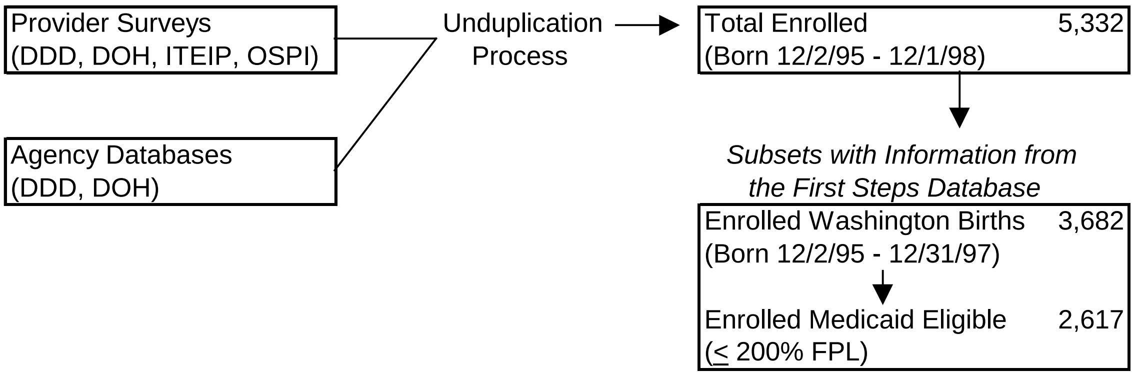
ANALYSIS GROUPS

Enrolled Children. This group contains all 5,332 children from age birth to three identified in the December 1, 1998 count as being enrolled in early intervention services.

Enrolled Washington Births. This group contains the 3,682 enrolled children whose mothers were residents of Washington at the time of the child's birth and who were matched with the First Steps Database. Since birth certificate information is available only through 1997, children born in 1998 were too young to be matched. Additional reasons that children could not be matched with birth certificates included adoption, name changes, and movement into or out of Washington State. Of the 4,388 enrolled children born before 1998, 84% were matched with the FSDB.

Enrolled Medicaid-Eligible. This group contains only those 2,617 children in the *Enrolled Washington Births* group who were Medicaid-eligible. Medicaid-eligible children included those whose mother was Medicaid-eligible during pregnancy (i.e., whose family income was less than or equal to 185% of the Federal Poverty Level (FPL)) and those with family incomes less than or equal to 200% FPL who received Medicaid paid services within the first two years of life with a total cost of $100 or more. Medicaid information for this group provided diagnostic and expenditure data not available for non-Medicaid children.

Description of Analysis Groups



LIMITATIONS

Enrolled Children

Being enrolled is a convention used to count the number of children who sought and were found eligible for early intervention services funded through the state. Being enrolled generally implies that the child has been assessed, determined eligible and/or has been provided with a plan of service, defined somewhat differently by the Division of Developmental Disabilities/DSHS, the Infant Toddler Early Intervention Program/DSHS, the Department of Health, and the Office of Superintendent of Public Instruction.

Enrollment counts of children in public early intervention programs are limited to children enrolled on the count date. Because counts are based on a single point in time, some children who had received and completed services prior to the count date(s) for that year were not included; nor were those who enrolled after the count date(s) for a given year.

These numbers do not include all children under three years of age experiencing developmental delays, disabilities, and special health care needs in Washington. They reflect only those children and families needing, requesting, and found eligible for services provided through the agencies described on page four. These numbers do not include those who may have been eligible for services but, for whatever reason, were not enrolled, nor those who received services through other sources (e.g., private, military services, Tribal and Indian Health Services, migrant services, non-profit service organizations, and others).

NHIS National Prevalence Rates

In the National Health Interview Survey (NHIS), respondents are asked to identify persons in their households with limitations in major or minor activities. These limitations may only partially correspond to what is defined as developmental delays or disabilities in public law and program policies. National comparison values used in this report are for 1995 and 1996 (the most recent years for which NHIS data are available).

The 1995 and 1996 NHIS data have changed compared to previous years. In 1995 a new sampling design derived from the 1990 census was implemented, including a revision in the oversampling of minorities. In 1996 reported racial categories changed, with the addition of categories for ‘Other Race’ (which included Eskimo and Aleut) and ‘Multiple Race.’ Since FSDB racial values, based on birth certificate categories, do not include ‘multiple race,’ these values from the NHIS were joined in a single category with ‘other’ and ‘unknown’ values. Also in 1996, the NHIS sample size was reduced when part of the sample was used to test a redesigned computer assisted questionnaire.

CHAPTER 3

WASHINGTON STATE UNDUPLICATED COUNT

This chapter presents the Washington State unduplicated count of infants and toddlers under the age of three with developmental delays or disabilities who were enrolled on December 1, l998 in early intervention services through the Infant Toddler Early Intervention Program (DSHS), or in early intervention, education, or health services provided through the Division of Developmental Disabilities (DSHS), the Department of Health, or the Office of Superintendent of Public Instruction.

Washington State Children under Three
Enrolled in Public Early Intervention Services
December 1, 1998

Children Enrolled in Early Intervention Services	5,332
Washington State Population under Three*	235,903
Washington State Enrollment Rate	2.3%

Washington State Children under Three
Enrollment in Public Early Intervention Services over Time
Number Enrolled and State Enrollment Rate*

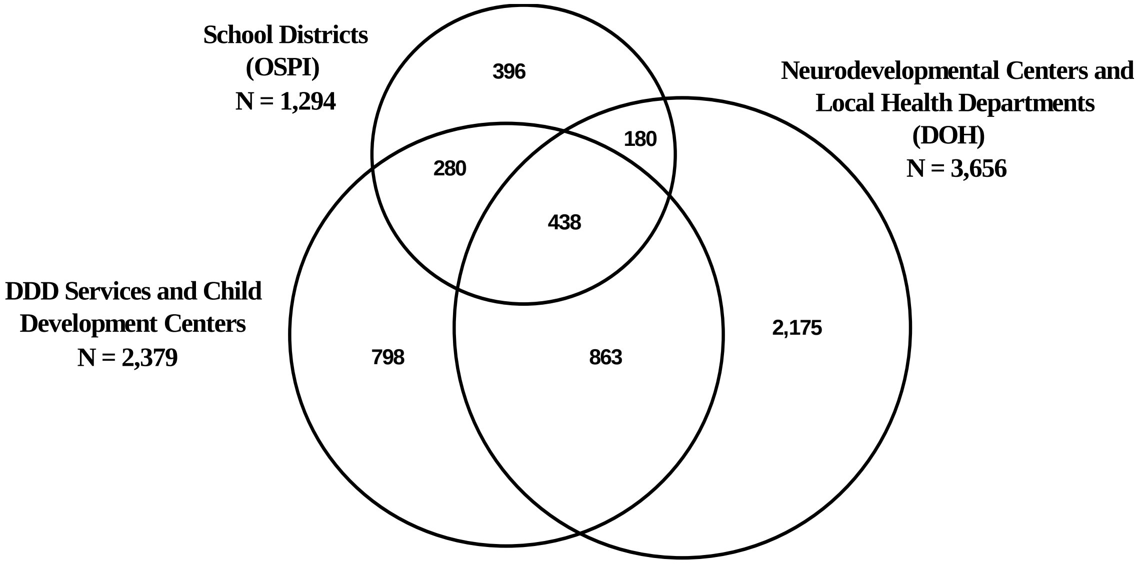
	Dec. 1, 1993	Dec. 1, 1995	Dec. 2, 1996	Dec. 1, 1997	Dec. 1, 1998
Enrolled:	4,055	4,138	4,472	5,007	5,332
Population:	245,182	238,314	234,894	236,042	235,903
Rate:	1.65%	1.74%	1.90%	2.12%	2.26%

**The Washington state population estimates are for April 1 of that year (Source: OFM).*

A total of 5,332 individual children, 2.3% of the Washington State population under three, were reported enrolled in public early intervention services on December 1, 1998. Since 1993—one year before Washington State began full implementation of IDEA Part C—the number of children reported enrolled has increased by 31%.

These children represent a range of complexity of needs and severity of disabilities, health care needs, or delays. Children with less complex problems may have their needs met by one provider. Children with more complex needs are more likely to need coordinated service from more than one provider. The diagrams and tables on the following pages portray the distribution of enrolled children by service agency.

DISTRIBUTION OF ENROLLED CHILDREN BY SERVICE AGENCY



		Number of Children	Percent of Total
Children enrolled with one provider:	DDD Only	798	15.0%
	DOH Only[*]	2,175	40.8%
	OSPI Only	396	7.4%
Children enrolled with two providers:	DDD and DOH, not OSPI	863	16.2%
	DDD and OSPI, not DOH	280	5.3%
	DOH and OSPI, not DDD	180	3.4%
Children enrolled with all three providers:	DDD, DOH, and OSPI	438	8.2%
Additional children reported by:	ITEIP only	202	3.8%
	Total Children Reported	**5,332**	**100%**

A total of 2,443 children (45.8%) were reported to have an IFSP (Individualized Family Service Plan) in place at the time of the Count. A total of 2,579 children (48.4%) were reported to be receiving enhanced services through ITEIP. Distribution of these children by service agency is detailed on the following page.

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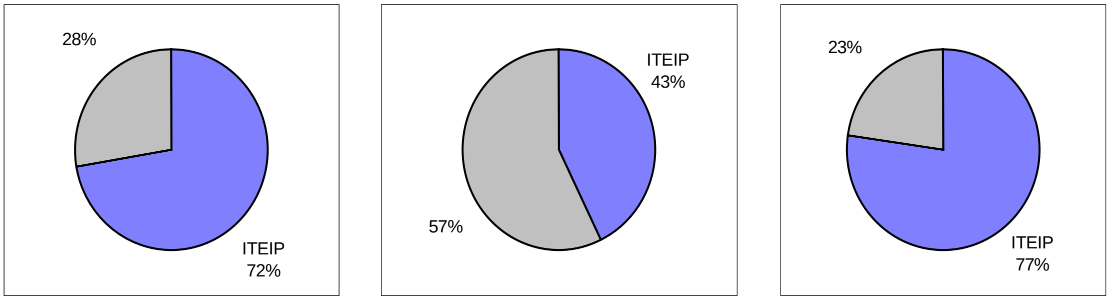
[*] Not all DOH enrolled children with medical conditions are eligible for ITEIP because they may not demonstrate developmental delays or developmental disabilities.

DISTRIBUTION OF ENROLLED CHILDREN RECEIVING SERVICES THROUGH THE INFANT TODDLER EARLY INTERVENTION PROGRAM

The Infant Toddler Early Intervention Program (ITEIP), the IDEA Part C program in Washington State, provides linkages and enhancement of existing early intervention services with the goal of ensuring a statewide system of comprehensive, multi-disciplinary, coordinated services to infants and toddlers with disabilities and their families.

Proportion of Children Served by DDD, DOH, and/or OSPI
Also Receiving Services through ITEIP



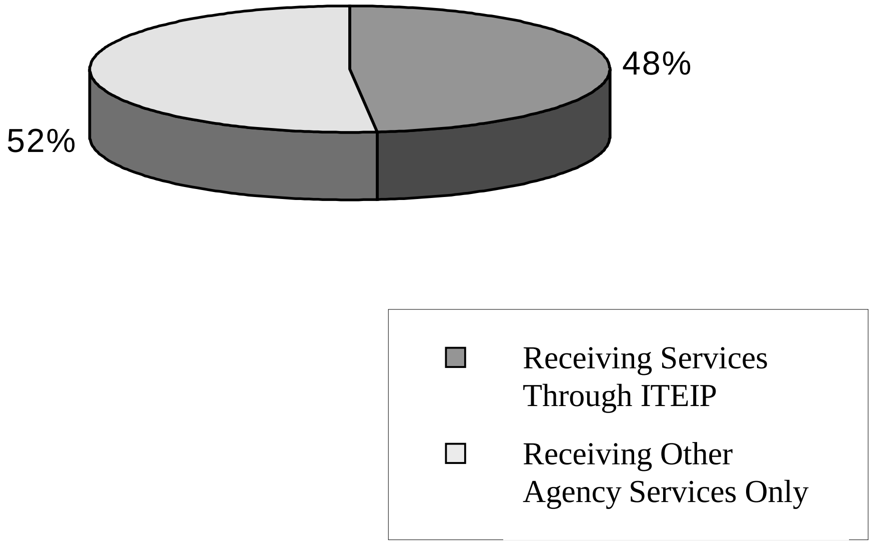
DDD **DOH** **OSPI**

- Seventy-two percent of those children reported enrolled in DDD programs were reported to be receiving one or more services through ITEIP.
- Forty-three percent of those children reported enrolled in DOH programs were reported to be receiving one or more services through ITEIP.
- Seventy-seven percent of those children reported enrolled in OSPI programs were reported to be receiving one or more services through ITEIP.

		Number of Children	Percent of Total
Children enrolled with ITEIP only:	ITEIP Only	202	3.8%
Children enrolled with ITEIP and one other provider:			
	ITEIP and DDD	370	6.9%
	ITEIP and DOH	314	5.9%
	ITEIP and OSPI	200	3.8%
Children enrolled with ITEIP and two other providers:			
	ITEIP, DDD, and DOH	693	13.0%
	ITEIP, DDD, and OSPI	241	4.5%
	ITEIP, DOH, and OSPI	145	2.7%
Children enrolled with all four providers:	ITEIP, DDD, DOH, and OSPI	414	7.8%
Total children reported to be receiving services through ITEIP:		**2,579**	**48.4%**

Washington State began full implementation of Part C (formerly Part H) in October 1994. Three percent of children included in the December 1, 1993 unduplicated count were reported to be receiving services through the Infant Toddler Early Intervention Program. For the December 1, 1998 unduplicated count, forty-eight percent were reported to be receiving Infant Toddler Early Intervention Program services. The chart below depicts the current proportion of children receiving one or more services through the Infant Toddler Early Intervention Program.

RECEIPT OF SERVICES THROUGH ITEIP
December 1, 1998



- Among the 5,332 children reported to be enrolled in public early intervention services, 2,579 (48.4%) were reported to be receiving services funded by IDEA Part C, coordinated and administered through the Infant Toddler Early Intervention Program.

Note: Not all children reported as having IFSPs (2,443 children) were reported to be receiving services funded through ITEIP. For these children, FRC services may not have been reported as ITEIP services, or may have been provided in kind. Not all children reported as receiving ITEIP services (2,579 children) were reported to have IFSPs in place. These children were in the process of IFSP development.

CHAPTER 4

WASHINGTON STATE ENROLLMENT AND NATIONAL PREVALENCE

This chapter compares Washington State early intervention program enrollment with national estimates of the prevalence and characteristics of children with developmental delays in the United States.

The *prevalence rate* is the estimated percentage of the general population with developmental delays or disabilities. In this report, national prevalence rates are estimated using information from the 1995 and 1996 editions of the National Health Interview Survey (NHIS). The National Health Interview Survey, conducted by the National Center for Health Statistics, surveys a stratified sample of households in the United States and asks respondents to provide health information about household members.

Prevalence rates are the percentages of children in the National Health Interview Survey reported to have limitations in major or minor activities. These limitations may only partially correspond to defined developmental delays or disabilities in public law or policies followed by early intervention programs.

Washington State Enrollment Rate and National Prevalence Rate
Children under Three *

Washington State Enrollment Rate	2.3%
National Prevalence Rate	2.3%
NHIS Adjusted for Washington Poverty	2.1%

** NHIS adjusted for Washington poverty is calculated by applying national prevalence rates to Washington State's poverty profile as determined from 1990 census data.*

- The 5,332 children enrolled in Washington State constitute an enrollment rate of 2.3%. This rate is slightly higher than the state enrollment rates in previous years. Washington's rate (2.3%) is similar to the estimated national prevalence rate (2.3%). When the estimated national rate is adjusted for Washington's 1990 poverty profile, Washington's rate exceeds the estimated national prevalence rate (2.1%).

Limitation or disability is difficult to estimate for many infants and toddlers. Mild developmental delays in very young children may not be recognized or identified by their parents or caregivers; on the other hand, very severe conditions may result in removal from the households on which NHIS information is based. As a consequence, the national rates of reported limitations are considered to be conservative.

ENROLLMENT RATE FOR WASHINGTON BIRTHS

The analysis group *Enrolled Washington Births* is a subset of all enrolled children living in Washington. Data are available in the First Steps Database for all children born to Washington mothers between July 1988 and December 1997.

Many of the analyses appearing in this report are based on information in the First Steps Database. The *enrollment rate for Washington births* is the percent of children in the First Steps Database who were enrolled in early intervention programs.

Washington Children Enrolled in Early Intervention Programs
Children under Three Born to Washington Residents

Enrolled Children	5,332
Enrolled Washington Births	3,682
Total Washington Births	161,139
Enrollment Rate	2.3%

Please note: The number of children identified as *Enrolled Washington Births* is lower than the number of enrolled children because not all enrolled children could be matched to birth certificates. For additional information, see Enrolled Washington Births, p. 6.

DISTRIBUTION OF CHILDREN BY AGE

The following table compares Washington State enrollment rates and national prevalence rates by age group.

Washington State Enrollment and National Prevalence Rates
Children under Three Living in Washington and in the NHIS
Distribution by Age*

	Washington State		NHIS
	Number	Rate	Rate
0 – 1 Years Old	1069	1.4%	1.4%
1 – 2 Years Old	1688	2.1%	2.6%
2 – 3 Years Old	2575	3.2%	3.0%
Total	5332	2.3%	2.3%

**Population estimates for Washington are for April 1, 1998 (*Source: OFM). *National figures are estimated from a stratified sample of households surveyed in the 1995 and 1996 NHIS.*

- As children become older, developmental delays may become more evident. For children 2 – 3 years old, the Washington State enrollment rate (3.2%) and the national prevalence rate (3.0%) are higher than the rates for children 0 – 1 years old (1.4%) and for those 1 – 2 years old (2.1% and 2.6%, respectively).

DISTRIBUTION OF CHILDREN BY FAMILY INCOME

Medicaid Eligibility Among All Children and Enrolled Children
Children under Three Born to Washington Residents

	Enrolled Washington Births (N = 3,682)	All Washington Births (N=161,139)
Medicaid-Eligible	71%	47%
Not Medicaid-Eligible	29%	53%

Poverty Status Among All Children and Children with Reported Limitations
Children under Three in the NHIS*

	Children Under Three with Limitations	All Children Under Three
At or Below 200% FPL	64%	43%
Above 200% FPL	36%	57%

**Data are from the 1995-1996 NHIS.*

- Medicaid eligibility was much higher among Washington-born children *enrolled in public early intervention programs* (71%) than among *all* children in Washington State (47%). Similarly, more NHIS children under three *with reported limitations* had family incomes at or below 200% of the federal poverty level (64%) than did *all* children under three (43%).

DISTRIBUTION OF CHILDREN BY MOTHER'S RACE/ETHNICITY

	Children Under Three Born to Washington Residents		**Children Under Three in the NHIS***	
Mother's Race / Ethnicity	**Enrolled Children** (N = 3,682)	**All Washington Births** (N = 161,139)	**Children with Reported Limitations**	**All Children**
White	70.5%	73.3%	50.1%	63.7%
Hispanic	12.9%	10.5%	21.8%	17.0%
Asian/Pacific Islander	3.7%	6.4%	0.6%	3.1%
African American	4.6%	3.8%	26.8%	15.2%
Native American	4.6%	2.2%	0.7%	0.9%
Other/Unknown	3.7%	3.8%	0.0%	0.1%
Total	100%	100%	100%	100%

**Data are from the 1995-1996 NHIS.*

- The proportion of White *enrolled* children (70.5%) was similar to the proportion of White children among *all* children born in Washington State (73.3%).

- The proportion of Asian/Pacific Islander *enrolled* children (3.7%) was lower than the proportion of Asian/Pacific Islander children among *all* children born in Washington State (6.4%).

- The proportions of African American, Hispanic, and Native American *enrolled* children (4.6%, 12.9%, and 4.6%, respectively) were higher than the proportions for those groups among *all* children born in Washington State (3.8%, 10.5%, and 2.2%).

- The state enrollment pattern by race/ethnicity is similar to the national pattern of limitations by race/ethnicity, with the exception of the Native American category.

DISTRIBUTION OF CHILDREN BY INCOME LEVEL AND MOTHER'S RACE/ETHNICITY

Enrollment Rates by Mother's Race/Ethnicity *Medicaid-Eligible* Children Under Three Born to Washington Residents and National Prevalence Rates for Children under Three in the NHIS* with Incomes at or below 200% FPL

Mother's Race/Ethnicity	Enrolled Children	All Washington Births	Enrollment Rate	% Reported Limitations*
White	1,689	47,777	3.5%	3.0%
Hispanic	443	14,454	3.1%	3.6%
Asian/Pacific Islander	88	4,415	2.0%	1.0%
African American	150	4,285	3.5%	4.6%
Native American	159	2,884	5.5%	3.4%
Other/Unknown	88	2,303	3.8%	0.0%
Total	2,617	76,118	3.4%	3.4%

**Data are from the 1995-1996 NHIS.*

For *Medicaid-eligible* children (Washington State) and *those with incomes at or below 200% FPL* (National Health Interview Survey):

- The State enrollment rate for White children (3.5%) was slightly higher than the national prevalence rate (3.0%).
- The State enrollment rate for Hispanic children (3.1%) was slightly lower than the national prevalence rate (3.6%).
- The State enrollment rate for African American children (3.5%) was lower than the national prevalence rate (4.6%).
- The State enrollment rates for Asian/Pacific Islander and Native American children (2.0% and 5.5%, respectively) were higher than the national prevalence rates for these groups (1.0% and 3.4%, respectively).

Enrollment Rates by Mother's Race/Ethnicity *Non-Medicaid Eligible* Children Under Three Born to Washington Residents and National Prevalence Rates for Children Under Three in the NHIS* with Incomes above 200% FPL

Mother's Race/Ethnicity	Enrolled Children	All Washington Births	Enrollment Rate	% Reported Limitations*
White (Non-Hispanic)	907	70,259	1.3%	1.2%
Hispanic	31	2,419	1.3%	2.0%
Asian/Pacific Islander	48	5,943	0.8%	0.0%
African American	21	1,906	1.1%	3.3%
Native American	11	725	1.5%	0.0%
Other/Unknown	47	3,769	1.2%	0.0%
Total	1,065	85,021	1.3%	1.5%

**Data are from the 1995-1996 NHIS.*

- Among *Non-Medicaid Eligible* Washington children and *NHIS children with family incomes above 200% FPL,* Washington State enrollment rates were similar to the national prevalence rate for White children, lower than the national prevalence rates for African American and Hispanic children, and higher than the national prevalence rates for Asian/Pacific Islander and Native American children.

Poverty and ethnicity are linked determinants of health status. Analysis of enrollment rates by race/ethnicity while controlling for the relative level of income portrays a different picture than when focusing on racial/ethnic group alone.

- The enrollment rates for Medicaid-eligible children were consistently higher than the enrollment rates for Non-Medicaid eligible children. Similarly, the national prevalence rates of reported limitations for children in lower income families were greater than the prevalence rates for children with family incomes above 200% FPL.

- In Washington State, the variability in enrollment rates across racial/ethnic groups is much smaller for Non-Medicaid eligible children than for Medicaid-eligible children.

CHAPTER 5

COUNTY ENROLLMENT RATES

Washington State includes a diverse collection of geographic areas. Varying economic, demographic, and programmatic conditions have resulted in differences across Washington in the need for and delivery of publicly-funded early intervention services. This chapter examines early intervention enrollment rates for each of the thirty-nine counties in Washington State, showing the extent of geographic variation.

In addition to considering each county separately, this chapter also groups Washington's counties into three categories based on population density. *Metropolitan* counties have the largest and most concentrated populations. *Small urban* counties have smaller, although still concentrated populations. *Rural* counties have the smallest populations and no large population centers. Summary enrollment figures are presented for these categories.

Because county of residence was assigned only for children matched with the First Steps Database, analysis of enrollment by county was limited to children born in 1997 or earlier. *County of residence* is the *mother's residence at time of birth*. Children may or may not be enrolled with providers in their county of residence.

Enrollment by county and county groups is shown for all children born to Washington residents and for Medicaid-eligible children born to Washington residents. Poverty is associated with an increased risk of developmental delay and disability. (*Please see* ENVIRONMENTAL RISK FACTORS *in* CHAPTER 6: RISK FACTORS.) Analyzing enrollment for Medicaid-eligible children across counties compares populations with similar poverty profiles, reducing the impact of differences in socioeconomic status on enrollment rates. Geographic variations in Medicaid-eligible enrollment rates are more likely to reflect differences among counties not related to income. In counties with small populations, however, enrollment rates may fluctuate widely, as the enrollment or exit of a single child can change enrollment rates dramatically.

The table on the following page shows enrollment rates by county grouped by population density. The *Index* measure compares the county or group enrollment rate with the overall state enrollment rate. An index of less than 1.00 indicates that the enrollment rate is lower than the state rate. An index greater than 1.00 indicates that the rate is higher than the state rate.

- Among all Washington births, rural and small urban groups have higher enrollment rates than metropolitan areas.
- The incidence of poverty (as measured by Medicaid eligibility) is higher among rural and small urban counties. Approximately 41% (41,745÷102,619) of children born in metropolitan counties are Medicaid-eligible, while 56% (22,095÷39,233) of children from small urban and 64% (12,275÷19,281) of children from rural counties are Medicaid-eligible.
- When enrollment rates are compared among similar income groups (i.e. Medicaid-eligible), rural, small urban, and metropolitan counties have similar overall rates.

Enrollment on December 1, 1998, by County of Residence at Birth
All Children and Medicaid-Eligible Children
Born to Washington Residents December 1, 1995, to December 31, 1997

	Medicaid				All Births			
County	Enrolled Births	WA Births	Enroll. Rate	Index	Enrolled Births	WA Births	Enroll. Rate	Index
Clark	105	4,186	2.5%	0.73	177	10,009	1.8%	0.77
King	453	16,673	2.7%	0.79	722	44,628	1.6%	0.71
Pierce	339	8,976	3.8%	1.10	495	19,978	2.5%	1.08
Snohomish	231	6,092	3.8%	1.10	363	16,508	2.2%	0.96
Spokane	273	5,818	4.7%	1.36	378	11,496	3.3%	1.44
Metro Total	**1,401**	**41,745**	**3.4%**	**0.98**	**2,135**	**102,619**	**2.1%**	**0.91**
Benton	85	2,068	4.1%	1.20	129	4,186	3.1%	1.35
Cowlitz	64	1,431	4.5%	1.30	82	2,469	3.3%	1.45
Franklin	82	1,595	5.1%	1.50	89	2,116	4.2%	1.84
Kitsap	82	2,486	3.3%	0.96	124	6,762	1.8%	0.80
Lewis	73	1,165	6.3%	1.82	86	1,838	4.7%	2.05
Skagit	53	1,623	3.3%	0.95	71	2,729	2.6%	1.14
Thurston	52	2,126	2.4%	0.71	87	4,984	1.7%	0.76
Walla Walla	30	899	3.3%	0.97	40	1,471	2.7%	1.19
Whatcom	76	1,956	3.9%	1.13	107	3,963	2.7%	1.18
Yakima	180	6,746	2.7%	0.78	202	8,715	2.3%	1.01
S.U. Total	**777**	**22,095**	**3.5%**	**1.02**	**1,017**	**39,233**	**2.6%**	**1.13**
Adams	20	447	4.5%	1.30	25	578	4.3%	1.89
Asotin	20	366	5.5%	1.59	23	542	4.2%	1.86
Chelan	45	1,365	3.3%	0.96	56	2,040	2.7%	1.20
Clallam	31	868	3.6%	1.04	36	1,323	2.7%	1.19
Columbia	***	61	***	***	***	98	***	***
Douglas	21	605	3.5%	1.01	23	911	2.5%	1.10
Ferry	***	118	***	***	5	158	3.2%	1.38
Garfield	8	21	38.1%	11.08	11	36	30.6%	13.37
Grant	58	2,009	2.9%	0.84	64	2,805	2.3%	1.00
Grays Harbor	55	1,231	4.5%	1.30	69	1,805	3.8%	1.67
Island	25	841	3.0%	0.86	40	2,016	2.0%	0.87
Jefferson	13	276	4.7%	1.37	16	417	3.8%	1.68
Kittitas	***	345	***	***	5	663	0.8%	0.33
Klickitat	9	331	2.7%	0.79	10	487	2.1%	0.90
Lincoln	***	110	***	***	***	236	***	***
Mason	30	678	4.4%	1.29	36	1,097	3.3%	1.44
Okanogan	45	872	5.2%	1.50	49	1,106	4.4%	1.94
Pacific	11	290	3.8%	1.10	13	442	2.9%	1.29
Pend Oreille	***	168	***	***	***	257	***	***
San Juan	***	121	***	***	***	223	***	***
Skamania	***	82	***	***	***	175	***	***
Stevens	18	626	2.9%	0.84	19	926	2.1%	0.90
Wahkiakum	7	44	15.9%	4.63	8	83	9.6%	4.22
Whitman	8	400	2.0%	0.58	12	857	1.4%	0.61
Rural Total	**439**	**12,275**	**3.6%**	**1.04**	**530**	**19,281**	**2.7%**	**1.20**
State Total*	**2,617**	**76,118**	**3.4%**	**1.00**	**3,682**	**161,139**	**2.3%**	**1.00**

****Number and rate or percent not included because the number of events was less than five.*

** Some children could not be assigned a county of residence, and some children were not included in county and regional totals due to low numbers (regional enrollment rates were not affected). State totals include all children. As a result, state totals may be slightly higher than the sums of counties.*

The Index measure compares the county or group enrollment rate with the overall state enrollment rate. An index of less than 1.00 indicates that the enrollment rate is lower than the state rate. An index greater than 1.00 indicates that the rate is higher than the state rate.

CHAPTER 6

RISK FACTORS

Tjossem's (1976) framework for risk factors that may lead to developmental delay and disability includes three categories of risk: established, biological and environmental. These categories are not mutually exclusive. This chapter examines the relationship between biological and environmental risk factors and enrollment of children under the age of three with developmental delays or disabilities in public early intervention programs. Information in this chapter is for *Enrolled Washington Births* (enrolled children with Washington State birth certificates prior to 1998). Enrollment rates for children with established risk conditions are examined in Chapter 7 of this report.

BIOLOGICAL RISK FACTORS

Biological risk conditions include prematurity, low birthweight, prenatal drug exposure or serious illness. In these conditions an insult to the central nervous system is suggested by a history of complications in prenatal, perinatal, neonatal or early development. Infant characteristics at birth and maternal prenatal high-risk behaviors may put the infant at risk for a variety of conditions associated with poor developmental outcome (Hanson and Lynch, l995). The following tables depict the relationship of enrollment in early intervention programs to these risk conditions.

Infant Characteristics at Birth

Infant characteristics at birth that may be associated with enrollment in early intervention services include low birthweight, prematurity, Apgar score less than 8, and male gender.

Low Birthweight

Birthweight is a primary indicator of the health of the newborn infant. Low birthweight is associated with increased risk of death and a wide range of disorders, including neurodevelopmental conditions, learning disorders, behavior problems, and lower respiratory tract infections (US Public Health Service, l991).

- The enrollment rate for very low birthweight infants (25.5%) was fifteen times higher than that for normal birthweight (singleton) infants (1.7%).

- The enrollment rates for medium low birthweight infants (7.8%) and infants from multiple gestations (7.7%) were more than four times higher than the enrollment rate for normal birthweight (singleton) children (1.7%).

- Low birthweight infants (very low and medium low birthweight combined) had an enrollment rate (11.0%) more than six times higher than that for normal birthweight (singleton) infants (1.7%).

Infant Characteristics at Birth

	Enrolled Children		All Washington Births		Enrollment Rate
Risk Factor	3,682	(100 %)	(N = 161,139)	(100 %)	(2.3%)
Birthweight					
Very Low (< 3.3 lbs)	319	8.7%	1,251	0.8%	25.5%
Medium Low (3.3 - 5.5 lbs)	451	12.2%	5,766	3.6%	7.8%
Normal (> 5.5 lbs)	2,587	70.3%	149,755	92.9%	1.7%
Mult. Gestation (Twins, etc.)	308	8.4%	4,025	2.5%	7.7%
Unknown Birthweight	17	0.5%	342	0.2%	5.0%
Gestational Age at Birth					
Extreme Preterm (< 28 wks)	200	5.4%	729	0.5%	27.4%
Mod. Preterm (28 - 36 wks)	1,074	29.2%	19,708	12.2%	5.4%
Full Term (37+ wks)	2,352	63.9%	138,367	85.9%	1.7%
Unknown	56	1.5%	2,335	1.4%	2.4%
Apgar Score					
less than 8	535	14.5%	5,250	3.3%	10.2%
8	628	17.1%	14,505	9.0%	4.3%
9	2,279	61.9%	128,772	79.9%	1.8%
10	202	5.5%	11,847	7.4%	1.7%
Unknown	38	1.0%	765	0.5%	5.0%
Gender					
Female	1,555	42.2%	78,445	48.7%	2.0%
Male	2,127	57.8%	82,692	51.3%	2.6%
Unknown	0	0.0%	2	0.0%	0.0%

Gestational Age

The gestational age of a newborn infant is a measure of the maturity of the newborn at delivery. Infants with a gestational age of 37 weeks or greater are considered full-term. Infants with a gestational age of less than 37 weeks are considered premature. Preterm delivery is a major cause of low birthweight.

- Preterm infants had an enrollment rate (6.2%) over three times that for full term infants (1.7%).

- The enrollment rate for extremely preterm infants (27.4%) was over sixteen times higher than that for full term infants (1.7%)

Apgar Score

The Apgar score rates the overall health of an infant. The Apgar score uses a scale of 1 to 10, with 10 indicating optimum health status. The Apgar score determined at 5 minutes after delivery was used for this analysis. In a research study examining the relationship between biologic risk factors and environmental variables, Apgar scores < 8 were associated with significantly poorer cognitive performance in the control group; however, children with Apgar scores < 8 in the educationally treated group did not show such poor cognitive performance (Breitmayer and Ramey, l986).

- The enrollment rate for children with an Apgar score of less than 8 (10.2%) was more than five times higher than that for children with an Apgar score of 8 or more (2.0%).

Gender

Previous studies have shown that males were more prone to developmental difficulties (Rojahn et al., 1995) and more likely to be placed in special education programs than females (Andrews et al., 1995).

- Male children had a higher enrollment rate (2.6%) than females (2.0%).

Prenatal Care and Maternal Behaviors

Inadequate prenatal care, maternal smoking, and maternal substance abuse may also be risk factors associated with enrollment in early intervention services.

Prenatal Care and Smoking Status

Risk Factor	Enrolled Children (N = 3,682)	(100 %)	All Washington Births (N = 161,139)	(100 %)	Enrollment Rate (2.3%)
Trimester Prenatal Care Began					
No Prenatal Care	86	2.3%	1,309	0.8%	6.6%
1st Trimester	2,524	68.5%	123,091	76.4%	2.1%
2nd Trimester	503	13.7%	19,510	12.1%	2.6%
3rd Trimester	113	3.1%	3,718	2.3%	3.0%
Unknown	456	12.4%	13,511	8.4%	3.4%
Mother Smoked During Pregnancy					
Yes	862	23.4%	23,594	14.6%	3.7%
No	2,625	71.3%	130,984	81.3%	2.0%
Unknown	195	5.3%	6,561	4.1%	3.0%

Prenatal Care

Prenatal care includes monitoring for specific medical conditions and information about environmental and health risks or benefits to fetal development.

- The enrollment rate for children of mothers who did not receive prenatal care (6.6%) was over three times higher than that for children of mothers who received prenatal care in the first trimester (2.1%).

Smoking Status

Smoking during pregnancy is the single most important preventable cause of low birthweight (Mullen, 1990).

- The enrollment rate for children born to women who smoked during pregnancy (3.7%) was nearly twice that for children born to nonsmoking women (2.0%).

Substance Abuse

The abuse of alcohol or drugs during pregnancy endangers infant and maternal health. It is associated with low birthweight, infant mortality, developmental delay, and medical complications (Jones and Lopez, 1990).

The First Steps Database uses diagnoses on Medicaid claims to identify maternal substance abuse. As a result, analysis of maternal substance abuse in this report is limited to children whose mothers received Medicaid paid maternity services. This is a unique group within the context of the report because these children have family incomes equal to or less than *185%* of the federal poverty level, which is a subgroup of the children with family incomes equal to or less than *200%* of the federal poverty level.

Diagnosed Maternal Substance Abuse among Medicaid Served Women

	Enrolled Children		**All Medicaid Births**		**Enrollment Rate**
Risk Factor	(N = 2,321)	(100 %)	(N = 68,184)	(100 %)	(3.4%)
Diagnosed Substance Abuse					
Alcohol Only	*13*	*0.6%*	*177*	*0.3%*	*7.3%*
Drugs Only	*164*	*7.1%*	*1,248*	*1.8%*	*13.1%*
Both Alcohol and Drugs	*194*	*8.4%*	*1,784*	*2.6%*	*10.9%*
Any Diagnosed Substance Abuse	371	16.0%	3,209	4.7%	11.6%
No Diagnosed Substance Abuse	1,950	84.0%	64,975	95.3%	3.0%

- For children of Medicaid served mothers, the enrollment rate for those born to women with any diagnosed substance abuse (11.6%) was nearly four times higher than that for children born to women without diagnosed substance abuse (3.0%).

ENVIRONMENTAL RISK FACTORS

Environmental risks include conditions in the infant or toddler's life that interfere with healthy development such as inadequate nutrition, neglect, physical or psychological abuse. Poverty is believed to be one of the major environmental risks in the United States today (Hanson and Lynch, 1995). Adverse socio-environmental conditions can put a biologically sound infant at increased risk of developmental delay and eventual school failure (Bennett, 1991). The individual environmental risk variables most often cited in research studies are poverty (Children's Defense Fund, l994), maternal education, maternal age, and caregiving practices (King et al., l992). The combination of biologic and environmental predictors as a powerful tool in predicting developmental outcome has been emphasized by a number of authors (Hanson and Lynch, 1995; King et al., 1992; Rojahn et al., l995). Sameroff and Chandler (1975) point to the powerful effects of the environment, especially the caregiving environment, in compensating for, or negatively interacting with, other risk conditions, such as biological risk conditions.

The following tables examine the relationship of enrollment in early intervention programs to selected environmental risk conditions including age, marital status, education, number of prior births, income status, and race/ethnicity.

Age

One of the environmental risks frequently cited as having value in predicting developmental outcome is maternal age (King et al., l992).

- Children of women who were younger than 15 years old at the time of delivery had an enrollment rate (5.2%) more than twice the rate for all children born in Washington (2.3%). The relation between enrollment rate and parent's age is similar for both maternal and paternal age group. Children with parents in the youngest age group are enrolled at the highest rate, with declining rates for older age groups until rates rise again for children of parents in the group aged forty and older.

Marital Status

- The enrollment rate for children of unmarried mothers (3.4%) was nearly twice the rate for children of married mothers (1.9%).

Education

Maternal education is one of the variables most often cited as having a predictive value for poor developmental outcome (Bee et al., l982; King et al., l992; Kochanek et al., 1987; Ramey et al., l978).

- Children of parents who completed 8 – 11 years of school had a higher enrollment rate (3.7% and 3.1%, for mothers and fathers) than those whose parents graduated from high school and had no further education (2.3% and 2.2%).

- Enrollment rates decrease further for parents with additional education. The enrollment rate for children of parents who were college graduates (1.4%) was less than half the rate for children of parents who completed 8 – 11 years of school (3.7% and 3.1%, for mothers and fathers).

Number of Prior Births

- The enrollment rate for children of mothers with three or more prior births (3.3%) was higher than that for children of mothers with no prior births (2.1%).

Income Status

Poverty is considered a risk factor for learning disabilities and developmental disabilities in children and youth. Poverty is associated with many other risk conditions including poor health and nutrition, learning problems, greater risk of infectious diseases, accidents, and exposure to toxic environments. Other risks associated with living in poverty are homelessness and exposure to violent situations (Children's Defense Fund, l994).

Maternal Medicaid Eligibility

- The enrollment rate for children of Non-Medicaid women (1.5%) was substantially lower than that for all children born in Washington (2.3%). Children of Medicaid women in the lowest income eligibility groups, grant recipients (4.2%) and pre-FS Medicaid Only (3.3%), had higher enrollment rates than all Washington children.

Paternal Demographic Characteristics

	Enrolled Children		**All Washington Births**		**Enrollment Rate**
	(N = 3,682)		(N = 161,139)		(2.3%)
Race/Ethnicity					
White	2,145	72.1%	106,753	75.4%	2.0%
Hispanic	489	16.4%	16,735	11.8%	2.9%
Asian/Pacific Islander	97	3.3%	8,096	5.7%	1.2%
African American	157	5.3%	7,301	5.2%	2.2%
Native American	85	2.9%	2,702	1.9%	3.1%
Not Stated	709		19,552		3.6%
Age					
< 15 Years Old	4	0.1%	99	0.1%	4.0%
15 - 19 Years Old	152	5.2%	4,870	3.5%	3.1%
20 - 29 Years Old	1,279	44.1%	62,379	44.2%	2.1%
30 - 39 Years Old	1,187	40.9%	61,515	43.6%	1.9%
40 + Years Old	277	9.6%	12,143	8.6%	2.3%
Not Stated	783		20,133		3.9%
Educational Attainment					
< 8 years	164	6.6%	5,352	4.2%	3.1%
8 - 11 years	362	14.6%	11,518	9.1%	3.1%
12 years	944	38.1%	42,770	33.7%	2.2%
13 - 15 years	500	20.2%	30,912	24.4%	1.6%
16+ years	505	20.4%	36,188	28.6%	1.4%
Not Stated	1,207		34,399		3.5%

Due to the high number of unstated values for paternal demographics, percentages given are as a proportion of stated values only.

Maternal Demographic Characteristics

	Enrolled Children		All Washington Births		Enrollment Rate
	(N = 3,682)	(100 %)	(N = 161,139)	(100 %)	(2.3%)
Race/Ethnicity					
White	2,596	73.2%	118,036	76.1%	2.2%
Hispanic	474	13.4%	16,873	10.9%	2.8%
Asian/Pacific Islander	136	3.8%	10,358	6.7%	1.3%
African American	171	4.8%	6,191	4.0%	2.8%
Native American	170	4.8%	3,609	2.3%	4.7%
Other/Not Stated	135		6,072		2.2%
Age					
< 15 Years Old	15	0.4%	289	0.2%	5.2%
15 - 19 Years Old	505	13.7%	17,480	10.9%	2.9%
20 - 29 Years Old	1,888	51.3%	84,438	52.4%	2.2%
30 - 39 Years Old	1,168	31.7%	55,246	34.3%	2.1%
40 + Years Old	106	2.9%	3,629	2.3%	2.9%
Not Stated	0		57		0.0%
Marital Status					
Married	2,181	59.5%	117,441	73.1%	1.9%
Single	1,486	40.5%	43,285	26.9%	3.4%
Not Stated	15		413		3.6%
Educational Attainment					
< 8 years	183	5.6%	5,639	3.9%	3.2%
8 - 11 years	762	23.4%	20,799	14.3%	3.7%
12 years	1,071	33.0%	46,656	32.1%	2.3%
13 - 15 years	747	23.0%	38,359	26.4%	1.9%
16+ years	487	15.0%	34,016	23.4%	1.4%
Not Stated	432		15,670		2.8%
Number of Prior Births					
None	1,352	37.9%	65,905	41.9%	2.1%
1 Child	1,093	30.7%	51,096	32.5%	2.1%
2 Children	582	16.3%	23,787	15.1%	2.4%
3 - 5 Children	483	13.5%	14,748	9.4%	3.3%
6 + Children	55	1.5%	1,668	1.1%	3.3%
Not Stated	117		3,935		3.0%
Medicaid Eligibility *					
Grant Recipient	1,082	29.4%	25,635	15.9%	4.2%
Pre-First Steps Medicaid Only	812	22.1%	24,877	15.4%	3.3%
First Steps Expansion	425	11.5%	17,625	10.9%	2.4%
Served, No Elig. Record	2	0.1%	47	0.0%	4.3%
Non-Medicaid	1,361	37.0%	92,955	57.7%	1.5%

Percentages given are as a proportion of stated values only.

** The mother's Medicaid eligibility at time of birth was used as a measure of income. In general, women eligible for cash assistance had family incomes at or below 65% of the Federal Poverty Line (FPL). Pre-First Steps (FS) Medicaid only women had family incomes at or below 90% of FPL. FS Expansion women had family incomes between 90% and 185% of FPL. Some women received Medicaid paid services but did not have a Medicaid eligibility record.*

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CHAPTER 7

MEDICAL CONDITIONS AND MEDICAID EXPENDITURES

This chapter examines the relationship between diagnosed medical conditions, including established risk conditions, and early intervention enrollment rates. Established risk conditions include genetic and biomedical causes of developmental delay and disability, such as chromosomal disorders, inborn errors of metabolism, structural malformations such as neural tube defects, congenital infections, sensory loss and injuries that result in disability and/or developmental delay.

International Classification of Diseases (ICD-9) diagnoses on Medicaid claims were used to categorize by medical condition Medicaid-eligible children born to Washington mothers. ICD-9 diagnoses from an infant's first two years of life, available in Medicaid claims data from the First Steps Database, were reviewed. Diagnoses were grouped into conditions and, in cases of a child with multiple conditions, assignment of conditions was prioritized based on the age at which they are expected to appear. The categorization of ICD-9 codes was developed by Laurie Cawthon, M.D., M.P.H., for the Child Development and Rehabilitation Center in Portland, Oregon. Similar methods were discussed by Palfrey et al. (1987) and First and Palfrey (1994).

Diagnosed medical conditions are not necessarily a basis for early intervention program eligibility. Certain conditions, such as Down syndrome and cerebral palsy, have been defined as qualifying children for services. However, functional assessments of developmental delay are also used to determine eligibility. Developmental delay may be directly related to a diagnosed condition, indirectly associated with a diagnosed condition (e.g., delay caused by prolonged hospitalization), or not related to a diagnosed condition.

Medicaid payment data available in the First Steps Database were used to calculate average first year Medicaid expenditures for various groups. High medical expenditures can indicate severe conditions requiring costly medical treatment and equipment. In addition, medical expenditures reveal part of the financial cost involved in caring for children with developmental delays or disabilities.

The table on page 31 displays enrollment rates by diagnosed medical condition as well as average first year Medicaid expenditures for children who were enrolled in early intervention programs.

- The highest early intervention enrollment rates were reported for the following conditions: cerebral palsy (91.3%), Down syndrome (91.0%), and cleft lip/palate (69.6%).

- Other conditions associated with high levels of early intervention enrollment include: developmental speech and language disorder (57.1%); other developmental disorders or delays (40.8%); congenital musculoskeletal deformities and congenital anomalies of limbs (19.6%); neoplasms, diseases and congenital anomalies of the nervous

- system (18.8%); hearing loss and congenital anomalies of ear, face, and neck (18.7%); and other congenital and chromosomal anomalies (16.8%).

- The average first year Medicaid expenditure for children enrolled in early intervention programs was $15,144.

- The average first year Medicaid expenditure for all other Medicaid-eligible children, not enrolled and with no diagnosis of congenital or acquired medical conditions, was $2,348.

Parents and providers suggest that Medicaid expenditures reflect only part of the medical costs of caring for developmentally delayed or disabled children. They indicate that the true costs can be many times what is paid by Medicaid. Medicaid generally reimburses approximately 60% of billed medical costs. The balance of medical costs may be met through private pay, private insurance, alternative payers (e.g., other state/federal/local programs, the military, Indian Health Service, Tribal Health Service), charitable grants, hospital or physician deferral, forgiveness, or non-recoverable write-offs.

Enrollment and Average First Year Medical Expenditures by Diagnosed Condition
Medicaid-Eligible Children under Three Born to Washington Residents
December 1995 to December 1997

		Enrolled Children		
Condition	**All Diagnosed (Ages 0 to 3)**	**Enrolled (Ages 0 to 3)**	**Enrollment Rate**	**Avg. 1st Year Medicaid Expend.**
Down Syndrome	67	61	91.0%	$ 18,172
Cleft Lip/Palate	112	78	69.6%	$ 18,500
Other Congenital & Chromosomal Anomalies	779	131	16.8%	$ 50,285
Congenital Musculoskeletal Deformities, Congenital Anomalies of Limbs	906	178	19.6%	$ 30,034
Cerebral Palsy	46	42	91.3%	$ 23,498
Neoplasms, Diseases & Congenital Anomalies of the Nervous System	1,802	339	18.8%	$ 35,687
Congenital Anomalies of Heart & Circulatory System	711	122	17.2%	$ 28,562
Endocrine, Nutritional & Metabolic Diseases, & Immunity Disorders	540	52	9.6%	$ 9,269
Hemmorhagic Conditions	558	39	7.0%	$ 16,833
Certain Conditions Originating in the Perinatal Period	2,779	234	8.4%	$ 14,063
Hearing Loss, Congenital Anomalies of Ear, Face, and Neck	123	23	18.7%	$ 4,838
Developmental Speech & Language Disorder	14	8	57.1%	$ 2,373
Hyperkinesis	7	1	14.3%	$ 1,690
Other Mental Disorders	35	0	0.0%	$ -
Other Developmental Disorder or Delay	218	89	40.8%	$ 4,465
Specific Learning Disorders or Difficulties	3	0	0.0%	$ -
All Other Medicaid Eligible Enrolled Children		1,220		$ 2,967
Average for All Medicaid Eligible Enrolled Children		**2,617**		**$ 15,144**
Average for Non-Enrolled Children without a Designated Condition				**$ 2,348**

Some enrolled Medicaid-eligible children were not categorized with one of the listed medical conditions. Of the conditions listed, only Down syndrome and cerebral palsy automatically qualify a child for ITEIP. Eligibility within other conditions is dependent upon more specific diagnosis and/or extent of delay.

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CHAPTER 8

EXPANDED CHARACTERISTICS OF CHILDREN ENROLLED IN PUBLIC EARLY INTERVENTION PROGRAMS

This chapter describes additional characteristics of enrolled children in order to portray a broader view of the characteristics and needs of enrolled children and their use of publicly-funded services other than early intervention. This represents a first step in understanding how children enrolled in early intervention use services across DSHS and other state agencies.

Chapter 8 presents expanded characteristics of infants and toddlers with developmental delays or disabilities born in 1992 through 1997, who were reported to be enrolled in public early intervention programs at one or more times during the first three years of life. Washington State child counts were done at seven different timepoints beginning in 1993. Children are grouped by birth cohort (the year in which they were born) and are classified as enrolled if they were included in one or more of the counts. Each table presents a picture of each individual birth cohort for a number of characteristics at different times during the first three years of life.

The following characteristics are examined by birth cohort:

- Infant and Child Mortality
- Children Affected by Drugs and Alcohol
- Out-of-home Placement
- Medicaid Enrollment and Grant Status
- Managed Care Enrollment
- Supplemental Security Income

It is important to note that these variables do not represent outcomes of early intervention. In some cases, the variable measured may occur before enrollment in publicly-funded early intervention. In other cases, the variable measured may not be an outcome which the program seeks or is able to change. In general these variables were selected to portray a broader view of the range of publicly-funded services which enrolled children receive.

HOW TO READ THE TABLES

This chapter analyzes data on children, birth to three years old, who were matched to the First Steps Database. Where data are available through 1997, the most complete information will be for children born 1994 or earlier, because children born after 1994 are too young to contribute a full three years of data.

In most analyses, children enrolled in early intervention programs are compared to all other children born in the same year (birth cohort). In some cases, where relevant, the analysis is controlled for poverty, using various definitions of Medicaid eligibility.
For each table, the year of the child's birth (birth cohort) is a column heading. The analyses look at certain characteristics during specific times during the child's life – the first year (365 days) of the child's life, the second year and the third year of the child's life, determined by the child's birthdate. These are duplicated counts, that is, children may appear in all three rows (years of life). ***Bold, italic*** notes which appear in the template below are for explanatory purposes, and are not in the final tables.

Explanatory Example of Table Formats:

Birth Cohort (year of child's birth)

Year of the Child's Life	1992	1993	1994	1995	1996	1997
First Year of Child's Life ***(up to 1 yr old)***						
Second Year of Child's Life ***(age 1 to 2)***						
Third Year of Child's Life ***(age 2 to 3)***						
Eligibility Rate ***(unduplicated count)***						

INFANT AND CHILD MORTALITY

Approximately two-thirds of the 900 to 1,000 childhood deaths in Washington each year occur to children less than four years old. Birth defects, perinatal and other disease conditions account for seven of every ten deaths among children less than one year old, and nearly one-half of the deaths among children age one to four. In contrast, the leading cause of childhood death for older children is unintentional injuries (DOH, 1995).

Infant mortality is defined as the death of a child under one year of age. The incidence of childhood death is highest during this first year of life (DOH, 1995). The infant mortality rate is measured as the number of deaths per 1000 live births. Infant deaths are divided into two groups: neonatal mortality (death within the first 27 days of life) and postneonatal mortality (death of an infant between 28-364 days of age). Postneonatal rates exclude neonatal deaths. *Child mortality, typically presented in rates per 100,000 children, is presented here as the deaths among children during their first to third years of life (age 1 to 3) per 1,000 children for simplification.*

Many risk factors for developmental delay are also risk factors for early death. Prematurity, a leading cause of death among children during their first year of life, may cause organ development problems and later developmental difficulties (Guralnick, 1997). Low birthweight children experience a greater incidence of neurodevelopmental disabilities and significantly higher death rates compared to children with normal birthweight. Darlow et al. (1998) found that 64% of liveborn infants less than 28 weeks gestation survived to age seven or eight.

Developmental delay and death are both linked with similar environmental risks, including prenatal exposure to substance abuse (Jones and Lopez, 1990), and child abuse and neglect (Berrick et al., 1998; Sabotta and Davis, 1992).

Conditions closely tied to eligibility for early intervention services are associated with increased risk of death. For example, among children identified at age 0.5 – 3.5 years with cerebral palsy, those with poor motor and eating skills may be up to eight times more likely to die in a given year than children who can roll and sit, and walk ten feet without assistance (Strauss et al., 1998). Similarly, neurologically disabled children have shown reduced survival rates (Plioplys et al., 1998).

Many children receiving early intervention services have special health care needs. While early intervention programs provide a wide range of services to families that may mitigate environmental risk factors and difficulties related to a child's conditions, the mortality rate for children enrolled in early intervention programs is expected to be higher than the rate for other children.

(MORTALITY TABLE)

- The infant mortality rate for enrolled children (9.5 – 12.2 per 1,000) was approximately twice the infant mortality rate for other children (5.6 – 6.4 per 1,000). Two leading causes of child death are birth defects and perinatal conditions. Both of these conditions are also linked with increased risk for developmental delays.

- The post-neonatal mortality rate for enrolled infants (8.4 – 11.8 per 1,000) was from three to six times higher than the post-neonatal mortality rate for other infants (1.8 – 2.9 per 1,000).

- The mortality rate for enrolled children in their second and third years of life (5.0 – 6.3 per 1,000) was nine to nearly thirteen times higher than the rate for other children born in the same year (0.4 – 0.6 per 1,000).

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CHILDREN AFFECTED BY DRUGS AND ALCOHOL

Each year in Washington State an estimated 800 to 1,000 infants are born with measurable effects of drug and/or alcohol exposure because of prenatal exposure to drugs or alcohol. Many of the harmful effects of infant substance exposure are not readily identifiable at birth. Infants that are drug *exposed* with or without measurable effects at birth represent ten to twelve percent of the approximate 80,000 Washington State births per year (Cawthon, 1997).

This report defines drug-*affected* children as those infants born with measurable effects assumed attributable to the mothers' substance abuse (alcohol or drugs) during pregnancy based on indicators on birth certificate and claims data in the First Steps Database. Identification is limited to children born to Medicaid-eligible women, which is a subset of the whole birth cohort. Children were identified as drug-affected if they met one of the following criteria: (1) medical diagnosis of narcotics, hallucinogens or cocaine affecting the fetus, (2) diagnosed drug withdrawal or fetal alcohol syndrome (FAS), (3) identified substance abuse by the mother <u>and</u> developmental delay or abnormality of the placenta (abruptio placentae).

A recent study by the First Steps Database revealed nearly 2,600 women who gave birth in 1992 to be substance abusers, or approximately 9.3% of all Medicaid women giving birth that year. Of those women, 58% were identified as substance abusers during their pregnancy, and only 38% received treatment prior to the birth of their child (DSHS and DOH, 1999).

Treatment for drug and/or alcohol dependency during pregnancy is associated with a 20% reduction in the rates of poor birth outcomes (Deschamps, 1997). Adverse outcomes associated with abuse of drugs and/or alcohol include low birthweight, admission to neonatal intensive care units, low Apgar scores, small for gestational age, and infant mortality. Children born to substance abusing mothers are also more likely to experience cognitive, sensory and physical developmental delays (DSHS and DOH, 1999; Lester, 1998). These children also show higher rates of behavioral disorders, including aggression, lack of attention, and insensitivity towards peers (Hawley et al., 1995; Ornoy et al., 1996). One would hope to see a high proportion of these children enrolled in early intervention programs.

There is general agreement that early intervention is one of the key services needed for infants and children exposed to drugs. "Children have the best opportunity to recover from effects of prenatal drug exposure when child development services are combined with drug treatment in a family context" (Zuckerman and Bresnahan, 1991). Research indicates that early intervention programs designed to serve both children and parents simultaneously can help alleviate physical and cognitive symptoms of drug-affected infants, increase the quality of parent-child interactions, and increase the quality of the home environment (DSHS and DOH, 1999).

(DAC TABLE)

- The proportion of Medicaid-eligible children identified as drug affected at birth was much greater among those enrolled in early intervention programs (5% to 9.4%) compared to those not enrolled (0.5% to 1.3%).

- From 1992 to 1997 the proportion of Medicaid-eligible children not enrolled in early intervention programs who were identified as drug affected decreased by 62%. The proportion of enrolled children identified as drug affected decreased by 6%.

A number of possibilities exist for this overall decrease in children identified as affected by drugs. The decrease may be due to earlier identification and treatment of mothers, or to lower prevalence of substance abuse among pregnant women. On the other hand, the downward trend may reflect changes in reporting. Reporting changes could result from differences in provider screening, cohort changes in self-reporting, or the lack of data from Medicaid claims, since managed care plans do not submit claims with specific diagnoses to Medicaid.

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OUT-OF-HOME PLACEMENT

Over 500,000 children in the United States live in out-of-home care—foster care, kinship care, or residential care (Child Welfare League of America, 1998a). Infants and toddlers are entering the foster care system in extraordinarily high numbers (Berrick et al., 1998; Carnegie Corporation, 1994; Wulczyn and Goerge, 1992). Nationally from 1987 to 1991, the number of young children under three years of age in foster care increased by more than 50%—from 300,000 in 1987 to 460,000 in 1991 (Carnegie Corporation, 1994).

The number of infants entering the foster care system due to prenatal drug exposure has increased dramatically (Barth et al 1992; Berrick et al., 1998; U.S. GAO, 1994; Velsor-Friedrich, 1992). Nationally, alcohol and drug abuse are factors in the placement of more than 75% of the young children who are entering care (Child Welfare League of America, 1998b). In Washington State low-income children affected by drugs demonstrate high rates of out-of-home placement in foster care and high rates of accepted referrals to Child Protective Services (during the first three years of life) for child abuse or neglect (DSHS and DOH, 1999).

Children in out-of-home placement have a high prevalence of both acute and chronic medical conditions, developmental delays, and mental health disorders (Barth et al., 1992; Chernoff et al., 1994; Halfon et al., 1995; Silver et al., 1999; Simms, 1991). These findings on the developmental status of children in foster care are confirmed by a preliminary report from a longitudinal, controlled study on the efficacy of mental health and developmental intervention among children in foster care, birth to three years of age. This research study at the Center for the Vulnerable Child in Oakland, California reports that in its initial assessment of 125 young foster children, birth to three, one half rated below normal (mildly or significantly delayed) on mental and psychomotor development and two-thirds rated below normal on emotional regulation and motor quality (Klee et al., 1997).

Simms et al. (1999) note that recent changes in welfare and health care reform are likely to result in an increased number of children entering out-of-home care, most of whom will be poor and have significant health problems. Berick et al. (1998) point out the necessity of changes in policy and practice to reflect developmentally sensitive child welfare services for this large influx of infants and toddlers. A newborn or six-month old in placement has very different needs during his/her critical first months of life compared to a nine-year old. Foster parents, biological parents and other adult caregivers play critical roles in the child’s development during these early months and years (Carnegie Task Force on Meeting the Needs of Young Children, 1994; Shonkoff et al., 1992). As with biological parents, foster parents need training and knowledge of states, stages, behaviors, and cues of these often fragile infants to enhance development and the foster parent/caregiver–child interaction.

A child’s entry into foster care has been consistently associated with poverty; exit from foster care is associated with providing services to families and children to ensure that families can effectively resume responsibility for meeting their children’s needs (Lindsey, 1994; Pelton, 1989; Simms, 1999).

(OUT-OF-HOME PLACEMENT TABLE)

- During their first year of life, infants in early intervention programs born in 1992 through 1996 were reported to be in out-of-home placement at rates ranging from 8.3% to 10.8%, at least eleven times the rates (0.6% - 0.8%) for all other infants.

- From 1992 to 1996 the out-of-home placement rate for infants, (i.e., less than one year old), increased by at least 30% in Washington State. For infants enrolled in early intervention programs, out-of-home placement increased 30%, from a rate of 8.3% in 1992 to 10.8% in 1996. Among all other infants the out-of-home placement rate increased 33%, from 0.6% in 1992 to 0.8% in 1996.

- For each complete birth cohort year, the numbers of children in foster care decreased at 1 to 2 years. At 2 to 3 years the numbers in foster care increased. This increase at 2 to 3 years exceeded the numbers in foster care at birth to 1 year, with only one exception, non-enrolled children born in 1994.

- Children born in 1992 through 1994 who were enrolled in early intervention programs spent an average of at least six months longer in foster care compared to all other children.

- A high percentage of children in this age group who have been placed out of the home are known to have been enrolled in early intervention programs. Children enrolled in early intervention programs at some point during their first three years of life range from 20% to 31% of children in out-of-home placement.[1] This is a conservative estimate, as early intervention enrollment is determined by status at single points in time (annual or semi-annual enrollment counts), rather than by cumulative records. By comparison, children enrolled in public early intervention programs currently total an estimated 2.3% of the overall state population under three. Therefore, children placed in out-of-home care were much more likely than the state population at large to need early intervention services.

Placement rates are consistently much higher for children born to low income families than for higher income children (DSHS and DOH, 1999). For this reason, an additional analysis was performed looking at out-of-home placement while controlling for poverty. Examining out-of-home placement among children who are Medicaid-eligible limits the population to those who are low income, thereby controlling for poverty.

- Among all children, the proportion of those enrolled in early intervention programs who were in out-of-home placement was at least eight times higher *across all age groups* than for children not known to be enrolled in early intervention. Controlling for poverty reduces the extent of this disparity: among Medicaid-eligible children, the proportion of enrolled children in out-of-home placement was at least five times higher across all age groups than for all other Medicaid-eligible children.

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[1] This data is prior to 1998, when the Division of Developmental Disabilities (DSHS) took on the responsibility for voluntary out-of-home placements due solely to the child's disability. Children in this program have no current issue of abuse or neglect, and families retain custody of the children.

- Among all children, the three year placement rate of those enrolled in early intervention programs was at least ten times higher than for all other children. After controlling for poverty, this difference was not as great. Among Medicaid-eligible children, the three year placement rate for those enrolled in early intervention programs was six times higher.

MEDICAID ENROLLMENT AND GRANT STATUS

Nationally children represent a large share (40%) of the poor population, although they account for only about one-fourth of the total population (US Department of Commerce – Census Bureau, 1998). In the United States, one in four infants and toddlers under the age of three lives in a family with income below the federal poverty level (Carnegie, 1994).

Poverty is considered a risk factor for learning and developmental disabilities for children and youth. The prevalence of reported limitations is higher among children from low income families compared to families with incomes greater than 200% of the federal poverty level (FPL) (see Chapter 4). Poverty is associated with many other health problems, including poor health and nutrition, greater risk of infectious disease, accidents and exposure to violent situations (Children's Defense Fund, 1994).

In Washington, children in families with incomes less than 200% of FPL are eligible to receive Medicaid, a state-federal health insurance program for low income persons. Children born to women covered by Medicaid during their pregnancy, over 40 percent of all births, are eligible to receive well-baby medical coverage during their first year of life. Children with special health care needs may also become eligible for Medicaid coverage when their family resources are depleted due to high cost medical needs or long term disabilities.

Cash assistance, or grants, are available to some low-income families through federal programs such as Temporary Assistance for Needy Families (TANF). Grant eligibility is determined primarily based on income resources and family size compared to the federal poverty level. Children in families receiving cash assistance are considered among the poorest in the nation.

(MEDICAID ENROLLMENT TABLE)

Medicaid Enrollment

- Among children enrolled in early intervention programs, the proportion eligible for Medicaid during the first year of life rose 39%, from 42.0% to 58.3%, over five years' time (1992 to 1997). In contrast, for the same time period, the proportion of children receiving cash assistance declined slightly (11%).

- Greater proportions of children in early intervention programs were eligible for Medicaid, compared to all other children born in the same years. Over one-half of children enrolled in early intervention programs received Medicaid coverage at some point during the first three years of life; in 1995, this rate was 64 percent. In contrast, less than 40 percent of other children born in 1995 received medical assistance.

- Children enrolled in early intervention programs received an average of 20 months' Medicaid coverage. This was greater than the average months of Medicaid coverage for other children born in the same year. The average number of months for other children gradually increased to almost 19 months in 1995.

Cash Assistance

- Approximately 4 of every 10 (42%) enrolled children born from 1992 to 1997 received cash assistance at some point during the first three years of life. Less than one-fourth (24%) of all other children born during the same years received cash assistance.

- Grant eligibility declined for all children as they became older. This decline was more prominent for children enrolled in early intervention programs. More than one-third (37%) of enrolled children born in 1995 received cash assistance in the first year of life compared to one-fourth (26%) during the third year of life. In contrast, approximately 20% of other children born in 1995 received cash assistance in the first year of life and 16% in the third year of life.

Medicaid and Grant Eligibility information was also determined for those children who gained eligibility after their first year of life. This additional information did not change the data greatly; therefore it has not been presented.

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MEDICAID MANAGED CARE ENROLLMENT

During the late 1980s and early 1990s, many states, including Washington, experimented with alternatives to the way Medicaid providers were reimbursed. Several states found managed care plans effective in reducing hospitalization costs and costly emergency room visits by improving access to primary care and coordinating specialty care. By 1997, nearly one-half of the total Medicaid population enrolled in managed care; Washington's Medicaid managed care enrollment rate was among the highest in the nation (Health Care Financing Administration, 1998).

In 1993, Washington implemented its capitated managed care program known as Healthy Options. Under this plan, health plans are paid a contracted monthly premium for each Medicaid-eligible person enrolled in that health plan, regardless of the number of services provided. Primary care providers, assigned or chosen for each enrollee, coordinate patient care. In contrast, under traditional fee-for-service care, providers submit claims, and for each service provided receive compensation based on established reimbursement rates for covered services.

Managed care’s emphasis on preventive treatment of high-cost illness raised concerns that managed care companies would not be able to sustain the high costs associated with long term disabilities or chronic illness. Some researchers point out that emphasis on costs might lead to receipt of inappropriate services, or limited access to or choice of specialists (American Academy of Pediatrics, 1998; Newacheck et al., 1996). Neff and Anderson (1995) note that children with chronic illness are especially vulnerable “because of the higher ongoing costs associated with treating their illnesses and the inherent pressures to reduce services to manage within these capitated rates.” The inability to adequately monitor the types of services most needed by these children, such as Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), presents another issue (Hughes et al., 1995).

These concerns led most states to exclude the disabled population from enrolling in managed care. Washington tested managed care’s ability to provide cost-effective health care services to low income, disabled persons in a demonstration project between 1995 and 1997. This project emphasized the need for, and utilization of, specialty services by many in this population, but it was found to be more costly than under fee-for-service. Consequently, since 1998, persons with SSI benefits now receive Medicaid-covered services from providers reimbursed under the traditional fee-for-service system.

Healthy Options was implemented on a county-by-county basis from 1993 to 1996. Families receiving federal cash assistance (i.e., Aid to Families with Dependent Children (AFDC), now Temporary Assistance for Needy Families (TANF)) were the first group required to enroll with one of several health plans. Nearly all other Medicaid-eligible groups were required to enroll by late 1996, when Healthy Options plans were available in most counties.

(MANAGED CARE TABLE)

- Managed care enrollment rates for low-income children in early intervention programs resembled those for other low-income children over time. Most low-income children born after 1993 were enrolled in a Medicaid managed care plan at some point during their first year of life. Approximately nine of every 10 low-income children born in 1996 enrolled in a Medicaid managed care plan before their first birthday.

- Low income children in early intervention programs who were born in 1994 received, on average, 14.3 months in managed care before age two. This is comparable to the managed care received by other low-income children. Children of Medicaid-eligible women were eligible for Medicaid managed care coverage in their first year of life without meeting other income requirements.

- Medicaid managed care enrollment for children less than one year old nearly doubled between 1993 and 1994. This coincides with the first year of Healthy Options implementation, and children born to Medicaid-eligible women were likely assigned to managed care plans.

- After 1993, managed care enrollment rates were higher for infants than for children ages one to two years old. For children born in 1995 who were enrolled in early intervention programs, 85.9 percent were enrolled in managed care as infants and 66.3 percent were enrolled in managed care between age one and two.

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SUPPLEMENTAL SECURITY INCOME

The Supplemental Security Income (SSI) Program provides cash benefits to financially needy individuals who are aged, blind or disabled. In most states, including Washington, Medicaid enrollment is automatically provided to SSI children younger than 18 years. Children on SSI in the state of Washington are covered under fee-for-service. In 1995, implementation of managed care for SSI children instead of fee-for-service began on a pilot basis; however, it was discontinued in January 1998.

Several policy changes in the early 1990s contributed to rapid growth in the SSI program for children and adolescents, from 275,000 nationwide at the end of 1989 to almost one million in 1996 (Kuhlthau et al., 1998; Social Security Administration, 1996). With the passage of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (the Welfare Reform Act), Public Law 104-193, a new and stricter definition of disability specifically for SSI children was established. It is expected that this change will slow growth in the SSI population, particularly for those with less severe disabilities (Kuhlthau et al., 1998).

Under the new standard, a child’s impairment, or combination of impairments, is disabling if it causes “marked and severe functional limitations” (Social Security Administration, 1997). A child’s impairment generally must result in “marked” limitations in two areas of functioning, such as social functioning and personal functioning, or an extreme limitation in one area of functioning, such as an inability to walk. Previously, children could be determined eligible if their impairment resulted in one marked and one moderate limitation, or three moderate limitations.

According to a factsheet from the Social Security Administration (SSA) (Social Security Administration, 1997), this new definition of disability will mainly affect those with certain mental impairments, such as less severe learning disabilities or behavioral disorders such as attention deficit hyperactivity disorder.

The SSA estimated that about 288,000 children, out of the approximately one million children receiving benefits, would require redetermination of their eligibility under the new more restrictive law and that about 100,000 children will be determined ineligible for SSI benefits (U.S. General Accounting Office, 1998). Benefits were to be stopped July 1, 1997, or one month after their case was reviewed, whichever was later. However the passage of the Balanced Budget Act of 1997, H.R. 2015, extended the time to complete eligibility redeterminations for SSI children under the new standards, with review of cases expected to be completed early in fiscal year 1999. Changes in SSI eligibility rates would not be expected to occur until late 1999.

(SSI TABLE)

- The proportion of infants and toddlers enrolled in early intervention programs who were eligible for Supplemental Security Income was substantially higher (16.3% – 19.3%) than for all other children (0.12% – 0.13%).

- For those enrolled in SSI, the average number of months eligible for Supplemental Security Income was similar for children enrolled in early intervention programs (20.4 – 21.7 months) and for all other children (15.7 – 21.4 months).

Supplemental Security Income eligibility information was also determined for those children who gained eligibility after their first year of life. This additional information did not change the data greatly; therefore, it has not been presented.

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CHAPTER 9

SUMMARY

This report presents two views of infants and toddlers, under the age of three, with developmental delays or disabilities who were enrolled in Washington State public early intervention services. The first view looks at a single child count on December 1, 1998 and details the following measures: unduplicated enrollment count, state enrollment rates and patterns compared to national prevalence rates and patterns, county enrollment rates compared to state enrollment rates, and the relationship of risk factors to enrollment in early intervention. The second view looks at a broader range of characteristics of children born in 1992 through 1997 reported to be enrolled in early intervention services in one or more of seven child counts.

December 1, 1998 Unduplicated Child Count

On December 1, 1998, 5,332 infants and toddlers under three years of age were found to be enrolled in public early intervention services for developmental delays or disabilities. The number of children reported enrolled has increased by 31% over the last five years. Both state and national rates have increased slowly over time. The Washington State enrollment rate of 2.3% is slightly higher than in past years, and similar to the national prevalence rate of 2.3% (2.1% when adjusted for Washington's poverty profile).

With continued implementation of the Individuals with Disabilities Education Act, Part C, the proportion of children enrolled in early intervention services who are receiving services through the Infant Toddler Early Intervention Program is currently 48.4%. This has increased from 3% in 1993. Forty-six percent of enrolled children had an Individualized Family Service Plan in place on December 1, 1998.

The enrollment rate (3.4%) for Medicaid-eligible children, with family incomes up to 200% of the FPL, was greater than that for non-Medicaid children (1.3%). Similarly, the national prevalence rate of reported limitations for children in lower income families (3.4%) was greater than that for children in families with incomes greater than 200% of the FPL (1.5%). The proportion of *enrolled* children who were Medicaid-eligible (71%) was significantly greater than the proportion of *all* children in Washington who were Medicaid-eligible (47%).

For all Washington births, rural counties as a group have a slightly higher enrollment rate (2.7%) than small urban counties (2.6%) and substantially higher enrollment rates than metropolitan counties (2.1%). When Medicaid-eligible children are considered separately from higher income children, the differences in enrollment rates are small. This suggests that differing levels of poverty in different regions of Washington contribute to the higher enrollment rates for rural and small urban county groups.

A number of risk factors associated with enrollment in publicly-funded early intervention programs were described. The highest enrollment rates occurred among very low birthweight infants (25.5%) and extremely preterm infants (27.4%). (These two groups may demonstrate considerable overlap.) Enrollment rates between 5.2% and 11.6% were found for medium low birthweight infants, moderately preterm infants, infants from a multiple gestation, infants with Apgar scores of less than 8, and infants born to mothers who received no prenatal care or who had been identified as substance abusers or who were less than 15 years old. Enrollment rates for male infants and for infants born to mothers who smoked, were single, had low educational attainment, or had three or more prior births, were somewhat higher (from 2.6% to 3.7%) than the rate for all Washington births (2.3%).

Enrollment rates for specific medical conditions were also studied for Medicaid-eligible children. Enrollment rates were highest for Medicaid-eligible children with cerebral palsy (91.3%) and Down syndrome (91.0%). Both of these conditions are included on Washington State's list of conditions with a high probability of resulting in developmental delay and each is sufficient to qualify a child for early intervention services. Medicaid-eligible children diagnosed with other conditions associated with developmental delay also had high enrollment rates: cleft lip and/or palate (69.6%); developmental speech and language disorder (57.1%); other developmental disorders or delays (40.8%); congenital musculoskeletal deformities and congenital anomalies of limbs (19.6%); neoplasms, diseases and congenital anomalies of the nervous system (18.8%); hearing loss and congenital anomalies of ear, face, and neck (18.7%); and other congenital and chromosomal anomalies (16.8%).

The average Medicaid expenditure for all Washington born children enrolled in early intervention programs ($15,144) was more than six times the average expenditure for Medicaid children not enrolled ($2,348). While Medicaid expenditures reflect only a portion of the costs of serving developmentally delayed children or those with disabilities, the difference in expenditures does indicate a high prevalence of expensive medical services among enrolled children.

Expanded Characteristics of Enrolled Children

This view of expanded characteristics of enrolled children is a first step in ascertaining the characteristics and needs of infants and toddlers with developmental delays or disabilities. Analysis of the use of selected publicly-funded services other than early intervention indicates that a high proportion of young children enrolled in early intervention have multiple risk factors, both biological and environmental, and use multiple publicly-funded services.

Environmental factors such as substance abuse (Jones and Lopez, 1990), neglect (Eckenrode et al., 1993; Howing, et al., 1993) and poverty (Berrick et al., 1998) are considered markers for probable deleterious effects in the areas of cognitive, social, and emotional functioning.

The proportion of children enrolled in publicly-funded early intervention who receive other publicly-funded services is much higher than that for all other children. The differences in service use rates for enrolled versus all other children are related to similarities and differences in program eligibility and children's needs. For example, rates of SSI enrollment for children enrolled in early intervention were more than 100 times greater than for children not known to be enrolled in early intervention. This was the largest difference in rates observed between enrolled children and all other children and is consistent with the overlap in eligibility for SSI and early intervention. SSI eligibility requirements are generally stricter than those for early intervention, so the majority of SSI children also receive early intervention.

The difference in rates of children affected by drugs, out-of-home placement, and mortality were moderate. Rates of drug-affected children, out-of-home placement, and mortality between ages one and three for early intervention enrolled children were generally around ten times greater than those for all other children. Different mechanisms may explain the association between early intervention enrollment and each of these measures. Increased mortality rates for enrolled children are most likely explained by the high prevalence of conditions tied to early intervention eligibility (including cerebral palsy, low birthweight, prematurity, and environmental risk factors) which are also strongly associated with increased risk of death.

Many children affected by drugs demonstrate developmental delays or behavioral problems which are likely to resolve with early intervention. Early intervention services are appropriately targeted to this group of children. Possible explanations for the increased rate of out-of-home placement among enrolled children are less clear cut. Financial and emotional resources of families with enrolled children may be exhausted by their child's needs, and the family may seek relief by voluntarily placing their child in foster care of one type or another. On the other hand, one of the reasons young children may be removed from the parents' home is neglect, a known predictor of developmental delay. Thus, young children who are in foster care may need early intervention services because of consequences of abuse or neglect which brought them into foster care.

Nationally, numerous professionals, including the medical and child welfare communities, have called for a strong commitment to providing the kinds of services the vulnerable, young children in foster care and their caregivers so clearly need—comprehensive assessment for children in foster care and greater attention to their multiple needs (American Academy of Pediatrics, 1987; Child Welfare League of America, 1988; Klee et al., 1997). Virtually all of the newborns placed in foster care are reported for neglect (Berrick, 1998). The out-of-home placement rate for infants (less than one year old) has shown an increase of 30% in Washington from 1992 to 1996. The importance of providing foster parent training has been emphasized to give the caregiver knowledge of infant states, behaviors and cues of these often fragile infants. This same training is important for any individual, parent, family, and/or childcare provider who plays an active role in raising a child.

Poverty has consistently been shown to be associated with increased rates of enrollment in early intervention. While the proportion of children eligible for medical assistance during the first year of life has shown continuing increases from 1992 to 1997, the rate of increase has been smaller for enrolled children than for all other children. The proportion of enrolled children who were Medicaid-eligible during the first year of life has increased from 42.0% for children born in 1992 to 55.4% for children born in 1995. This represents an increase of 32%. For all other children, the Medicaid-eligible proportion increased from 22.2% in 1992 to 33.3% in 1995. This represents an increase of 50%.

Since 10 to 15% of enrolled children were SSI eligible, the finding that managed care enrollment among Medicaid-eligible children was quite similar for enrolled and all other children was unexpected. However, the study period is prior to 1998 at which point SSI clients were exempted from mandatory enrollment in Medicaid's managed care plan, Healthy Options. In future years, managed care enrollment rates may diverge for enrolled and all other Medicaid children. In general, these findings are encouraging in that they suggest the majority of enrolled children, some of whom have great needs for specialized medical care, are able to have those needs met through Medicaid's managed care system.

The analyses and results presented in this report provide a partial picture of the population of children under three with developmental delays or disabilities in Washington State. This report highlights the multiple and complex needs of these children and points to the necessity of effective services and responsive policies to help give young children in Washington State the very best start. Research supports the role of early intervention in this endeavor.

A new consensus about the importance of intervening in the first months and years of life is emerging in the field of early intervention for children with established disabilities or developmental delays and those at risk biologically or environmentally (Guralnick, 1998). A general decline in the intellectual development of children with established disabilities and those at risk occurs in the absence of early intervention. Unequivocal evidence now exists that this decline can be substantially reduced by interventions implemented during the first five years of life (Guralnick, 1998).

While the needs of children with developmental delays, disabilities, and special health care needs in Washington State are great and service use rates are high, early intervention offers the opportunity to reach highest potential, improve quality of life for children, families, and communities, and reduce the extent of subsequent services and their related public expenditures.

REFERENCES

American Academy of Pediatrics, Committee on Children With Disabilities. (1998) Managed Care and Children With Special Health Care Needs: A Subject Review. *Pediatrics* 102(3): 657-660.

Andrews H, Goldberg D, Wellen N, Pittman B, Struening E. (1995) Prediction of Special Education Placement from Birth Certificate Data. Research Linkages Between Academia and Practice. *American Journal of Preventive Medicine* 11(3)(Supplement): 55-61.

Barth RP, Berrick JD, Courtney M, Albert V. (1992) *Pathways Through Child Welfare Services*. Final report, School of Social Welfare, Family Welfare Research Group, University of California, Berkeley.

Bee HL, Barnard KE, Eyres SJ, Gray CA, Hammond MA, Spietz AL, Snyder C, Clark B. (1982) Prediction of IQ and Language Skill from Perinatal Status, Child Performance, Family Characteristics, and Mother-infant Interaction. *Child Development* 53: 1134-1156.

Bennett FC and Guralnick MJ. (1991) Effectiveness of Developmental Intervention in the First Five Years of Life. *Pediatric Clinics of North America* 38(6): 1513-1528.

Berrick JD, Needell B, Barth RP, Jonson-Reid M. (1998) *The Tender Years Toward Developmentally Sensitive Child Welfare Services for Very Young Children*. New York: Oxford University Press.

Blair C, Ramey CT, Hardin JM. (1995) Early Intervention for Low Birthweight, Premature Infants: Participation and Intellectual Development. *American Journal on Mental Retardation* 99(5): 542-554.

Breitmayer BJ and Ramey CT. (1986) Biological Nonoptimality and Quality of Postnatal Environment as Codeterminants of Intellectual Development. *Child Development* 57: 1151-1165.

Carnegie Corporation of New York. (1994) *Starting Points: Meeting the Needs of Our Youngest Children*. New York: Author.

Casto GC and Mastropieri MA. (1986) The Efficacy of Early Intervention Programs: A Meta-Analysis. *Exceptional Children* 52(5): 417-424.

Casto GC and White KR. (1984) The Efficacy of Early Intervention Programs with Environmentally At-risk Infants. *Journal of Children in Contemporary Society* 17(1): 37-50.

Cawthon L. (1997) *Substance Use During Pregnancy: Prevalence, Effects, and Costs*. Washington State Department Of Social and Health Services, Research and Data Analysis, Olympia, Washington State.

Chamberlain P, Moreland S, Kathleen Reid. (1992) Enhanced Services and Stipends for Foster Parents: Effects on Retention Rates and Outcomes for Children. *Child Welfare* 71(5): 387-401.

Chernoff R, Combs-Orme T, Risley-Curtiss C, Heisler A. (1994) Assessing the Health Status of Children Entering Foster Care. *Pediatrics* 93(4): 594-601.

Child Welfare League of America. (1998a) *State Agency Survey*. Washington, DC: Author.

Child Welfare League of America. (1998b) *Family Foster Care Fact Sheet*. Washington, DC. Extracted from web site www.cwla.org/cwla/fostercr/ familyfcfacts98.html

Children's Defense Fund. (1994) *The State of America's Children: Yearbook 1994*. Washington, DC: Children's Defense Fund.

Chugani HT, Phelps ME, Mazziotta JC. (1987) Positron Emission Tomography Study of Human Brain Functional Development. *Annals of Neurology* 22(4): 487-497.

Darlow, BA. (1998) Survival and Disability at 7-8 Years of Age in New Zealand Infants Less than 28 Weeks Gestation. *New Zealand Medical Journal,* 111: 264-267.

Department of Social and Health Services and Department of Health. (1999) *Report to the Legislature: A Comprehensive Program For Alcohol and Drug Abusing Mothers and Their Young Children, Response to RCW 13.34.803*. Olympia, Washington.

Department of Health. (1995) *A Strategy to Answer, "Why Do Children Die?"* Division of Community and Family Health. Olympia, Washington.

Deschamps E, Cawthon L, Apodaca K. (1997) *Yakima First Steps Mobilization Project Evaluation*. Unpublished report by the Department of Social and Health Services, Research and Data Analysis, Olympia, Washington.

Eckenrode J, Laird M, Doris J. (1993) School Performance and Disciplinary Problems Among Abused and Neglected Children. *Developmental Psychology* 29(1): 53-62.

First LR and Palfrey JS. (1994) The Infant or Young Child With Developmental Delays. *The New England Journal of Medicine* 330(7): 478-483.

Fowler EJ and Anderson GF. (1996) Capitation Adjustment for Pediatric Populations. *Pediatrics* 98(1): 10-17.

Greenough WT and Black JE. (1992) Induction of Brain Structure by Experience: Substrates for Cognitive Development. *Minnesota Symposia on Child Psychology* 24: 155-200.

Griffith DR, Azuma SD, Chasnoff IJ. (1994) Three-Year Outcome of Children Exposed Prenatally to Drugs, *Journal of the American Academy of Child and Adolescent Psychiatry* 33(1), 20-27.

Guralnick MJ (Ed.). (1997) *The Effectiveness of Early Intervention.* Baltimore: Paul H. Brookes Publishing Co.

Halfon N and Klee L. (1991) Health and Development Services for Children with Multiple Needs: The Child in Foster Care. *Yale Law and Policy Review* 9: 71-96.

Halfon N, Mendonca A, Berkowitz G. (1995) Health Status of Children in Foster Care: The Experience of the Center for the Vulnerable Child. *Archives of Pediatric Adolescent Medicine* 149: 386-392.

Hanson MJ and Lynch EW. (1995) *Early Intervention Implementing Child and Family Services for Infants and Toddlers Who Are At-Risk or Disabled.* Austin, Texas: pro-ed.

Hawley TL, Halle TG, Drasin RE, Thomas NG. (1995) Children of Addicted Mothers: Effects of the “Crack Epidemic” on the Caregiving Environment and the Development of Preschoolers. *American Journal of Orthopsychiatrics*, 63(3) 364-379.

Health Care Financing Administration. (1998, February) *National Summary of Medicaid Managed Care Plans, June 30, 1997.* [On-line]. Available at http://www.hcfa.gov/medicaid.

Howing PT, Wodarski JS Kurtz PD, Gaudin JM. (1993) *Maltreatment And The School-Age Child: Developmental Outcomes and System Issues*. Binghamton, NY: The Haworth Press.

Hughes DC, Newacheck PW, Stoddard JJ, Halfon N. (1995) Medicaid Managed Care: Can It Work for Children? Commentary. *Pediatrics* 95(4): 591-594.

Huttenlocher PR. (1990) Morphometric Study of Human Cerebral Cortex Development. *Neuropsychologia* 28(6): 517-527.

Ireys HT, Anderson GF, Shaffer TJ, Neff JM. (1997) Expenditures for Care of Children with Chronic Illnesses Enrolled in the Washington State Medicaid Program, Fiscal Year 1993. *Pediatrics* 100(2):197-204.

Jones CL and Lopez RE. (1990) Drug Abuse and Pregnancy. In Merkatz IR and Thompson JE (Eds.), *New Perspectives on Prenatal Care*, New York: Elsevier, pp. 273-318.

Kerner JF, Dusenbury L, Mandelblatt JS. (1993) Poverty and Cultural Diversity: Challenges for Health Promotion Among the Medically Underserved. *Annual Review of Public Health* 14: 355-377.

King EH, Logsdon DA, Schroeder, SR. (1992) Risk Factors for Developmental Delay Among Infants and Toddlers. *Children's Health Care* 21(1): 39-52.

Klee L, Kronstadt D, Zlotnick C. (1997) Foster Care's Youngest: A Preliminary Report. *American Journal of Orthopsychiatry* 67(2): 290-299.

Kochanek TT, Kabacoff RI, Lipsitt LP. (1987) Early Detection of Handicapping Conditions in Infancy and Early Childhood: Toward a Multivariate Model. *Journal of Developmental Psychology* 8: 411-420.

Kotelchuck M. (1994) An Evaluation of the Kessner Adequacy of Prenatal Care Index and a Proposed Adequacy of Prenatal Care Utilization Index. *American Journal of Public Health* 84(9): 1414-1420.

Kuhlthau K, Perrin JM, Ettner SL, McLaughlin TJ, Gortmaker SL. (1998) High-expenditure Children With Supplemental Security Income. *Pediatrics* 102(3 pt 1): 610-615.

Lazar I and Darlington R. (1982) Lasting Effects of Early Intervention: A Report from the Consortium for Longitudinal Studies. *Monographs of the Society for Research in Child Development* 47 (Serial No. l95).

Lester BM, LaGasse LL, Seifer R. (1998) Cocaine Exposure and Children: The Meaning of Subtle Effects. *Science* 282: 633-634.

Lindsey D. Factors Affecting the Foster Care Placement Decision: An Analysis of National Survey Data. *American Journal of Orthopsychiatry* 61(2): 272-281.

McCarton CM, Brooks-Gunn J, Wallace IF, Bauer CR, Bennett FC, Bembaum JC, Broyles RS, Casey PH, McCormick MC, Scott DT, Tyson J, Tonascia J, Meinert CL. (1997) Results at Age 8 Years of Early Intervention for Low-Birth-Weight Premature Infants. *Journal of the American Medical Association* 277: 126-32.

Mullen P. (1990) Smoking Cessation Counseling in Prenatal Care. In Merkatz IR and Thompson JE (Eds.), *New Perspectives on Prenatal Care*, New York: Elsevier, pp. 161-176.

National Center for Health Statistics. (1998) *Deaths and Death Rates for the Ten Leading Causes of Death*. National Vital Statistics Report, National Center for Health Statistics, Vol. 47(4).

National Center for Health Statistics (1998). Data File Documentation, National Health Interview Survey, 1996 (machine readable data file and documentation, CD-ROM Series 10, No. 11A), National Center for Health Statistics, Hyattsville, Maryland.

National Center for Health Statistics (1998). Data File Documentation, National Health Interview Survey, 1995 (machine readable data file and documentation, CD-ROM Series 10, No. 10C), National Center for Health Statistics, Hyattsville, Maryland.

Neff JM and Anderson G. (1995) Protecting Children With Chronic Illness in a Competitive Marketplace. *Journal American Medical Association* 274(23): 1866-1869.

Newacheck PW, Stein REK, Walker DK, Gortmaker SL, Kuhlthau K, Perrin JM. (1996) Monitoring and Evaluating Managed Care for Children With Chronic Illnesses and Disabilities. *Pediatrics* 98(5): 952-958.

Ornoy AMV and Lukashov I. (1996). The Developmental Outcome of Children Born to Heroin-Dependent Mothers, Raised at Home or Adopted. *Child Abuse and Neglect,* 20(5): 385-396.

Palfrey JS, Singer JD, Walker DK, Butler JA. (1987) Early Identification of Children's Special Needs: A Study in Five Metropolitan Communities. *Journal of Pediatrics* 11(5): 111-659.

Plioplys AV, Kasnicka I, Lewis S, Moller D. (1998) Survival Rates Among Children With Severe Neurological Disabilities. *Southern Medical Journal* 91(2): 161-172.

Ramey CT, Bryant DM, Wasik BH, Sparling JJ, Fendt KH, LaVange LM. (1992) Infant Health and Development Program for Low Birth Weight, Premature Infants: Program Elements, Family Participation, and Child Intelligence. *Pediatrics* 3: 454-465.

Ramey CT and Campbell PA. (1992) Poverty, Early Childhood Education, and Academic Competence: The Abecedarian Experiment. In Huston A (Ed.), *Children In Poverty*. New York: Cambridge University Press, pp. 190-221.

Ramey CT, Stedman DJ, Borders-Patterson A, Mengel W. (1978) Predicting School Failure from Information Avaliable at Birth. *American Journal of Mental Deficiency* 82(6): 525-534.

Rauh VA, Achenbach TM, Nurcombe B, Howell CT, Teti DM. (1988) Minimizing Adverse Effects of Low Birthweight: Four-Year Results of an Early Intervention Program. *Child Development* 59: 544-553.

Richardson GA. (1998) Prenatal Cocaine Exposure: A Longitudinal Study of Development. *Annals of the New York Academy of Sciences,* 846, 144-152.

Rojahn J, Aman MG, Marshburn E, Moeschberger ML, King EH, Logsdon DA, Schroeder SR. (1995) Biological and Environmental Risk for Poor Developmental Outcome of Young Children. *American Journal on Mental Retardation* 97(6): 702-708, 1993.

Sabotta EE and Davis RL (1992) Fatality After Report to a Child Abuse Registry in Washington State, 1973-1986. *Child Abuse and Neglect* 16: 627-635.

Sameroff AJ and Chandler MJ. (1975) Reproductive Risk and the Continuum of Caretaking Casualty. In Horowitz (Ed.), *Review of Child Development Research*, Chicago: University of Chicago Press 4: 187-244.

Scarr-Salapatek S and Williams ML. (1973) The Effects of Early Stimulation on Low-birth-weight Infants. *Child Development* 44: 94-101.

Shonkoff JP and Hauser-Cram P. (1987) Early Intervention for Disabled Infants and Their Families: A Quantitative Analysis. *Pediatrics* 80(5): 650-658.

Shonkoff JP, Hauser-Cram P, Krauss MW, Upshur CC. (1992) *Development of Infants with Disabilities and Their Families: Implications for Theory and Service Delivery*. Monographs of the Society for Research in Child Development, Serial No. 230, 57, No. 6.

Silver J, DiLorenzo P, Zukoski M, Ross PE, Amster BJ, Schlegel D. (1999) Starting Young: Improving the Health and Developmental Outcomes of Infants and Toddlers in the Child Welfare System. *Child Welfare* 78(1): 148-165.

Simms MD. (1991) Foster Children and the Foster Care System, Part II: Impact on the Child. *Current Problems in Pediatrics* 21: 345-370.

Simms MD, Freundlich M, Battistelli ES, Kaufman ND. (1999) Delivering Health and Mental Health Care Services to Children in Family Foster Care After Welfare and Health Care Reform. *Child Welfare* 78(1): 166-183.

Social Security Administration. (1996) *Children Receiving SSI*. Baltimore, MD: Social Security Administration.

Social Security Administration. (1997, February) Welfare Reform and SSI Childhood Disability. [On-line]. Available at http://www.ssa.gov/pubs/wrchild.html.

Strauss DJ, Shavelle RM, Anderson TW. (1998) Life Expectancy of Children With Cerebral Palsy. *Pediatric Neurology* 18(2): 143-149.

Takayama JI, Bergman AB, Connell FA. (1994) Children in Foster Care in the State of Washington: Health Care Utilization and Expenditures. *Journal American Medical Association* 271(23): 1850-1855.

Tjossem TD. (1976) Early Intervention: Issues and Approaches. In Tjossem TD (Ed.), *Intervention Strategies for High Risk Infants and Young Children*. Baltimore: University Park Press, pp. 3-33.

US Bureau of Labor Statistics and US Bureau of the Census. *Current Population Survey*, Detailed Poverty Tables: 1996 P60 Package (Released September 1997) and Detailed Poverty Tables: 1995 P60 Package (Released September 1996) [Online]. Available at http://www.bls.census.gov/cps/pub/pubpov.htm.

US General Accounting Office. (1994) *Foster Care: Parental Drug Abuse Has Alarming Impact on Young Children*. Washington, DC: GAO/HEHS-94-89.

US General Accounting Office. (1998) *Supplemental Security Income: SSA Needs a Uniform Standard for Assessing Childhood Disability*. *Report to the Honorable E. Clay Shaw, House of Representatives*. Washington, DC: GAO/HEHS-98-123.

US Department of Commerce. (1998) Current Population Reports *Poverty in the United States: 1997.* Current Population Reports, Series P60-201, Bureau of the Census, Washington, DC: GAO.

US Public Health Service. (1991) *Healthy People 2000*: *National Health Promotion and Disease Prevention Objectives.*   Washington, DC: US Public Health Service, DSHS Publication Number (PHS) 91-50212.

Velsor-Friedrich B. (1992) Family Foster Care: A Service Under Siege. *Journal of Pediatric Nursing* Jun 7(3): 216-217.

Wasik BH, Ramey CT, Bryant DM, Sparling JJ. (1990) A Longitudinal Study of Two Early Intervention Strategies: Project CARE. *Child Development* 61: 1682-1696.

Weiler IJ, Hawrylak N, Greenough WT. (1995) Morphogenesis in Memory Formation: Synaptic and Cellular Mechanisms. *Behavioral Brain Research* 66: 1-6.

Wulczyn F and Goerge R. (1992) Foster Care in New York and Illinois: The Challenge of Rapid Change. *Social Service Review* 66: 278-294.

Zuckerman B and Bresnahan K. (1991) Developmental and Behavioral Consequences of Prenatal Drug and Alcohol Exposure. *Pediatric Clinics of North America* 38 (6): 1387-1406.

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APPENDICES

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APPENDIX A

STATE DEFINITIONS OF DEVELOPMENTAL DELAY FOR CHILDREN BIRTH TO THREE WITH DISABILITIES

As a participant in IDEA Part C, Washington State is required to define *developmental delay*. Children meeting this definition of developmental delay are eligible to receive Part C services. (Federal Register, July 30, 1993, Dept. of Ed. 34 CFR 303.300)

State agencies may use definitions of developmental delay which differ slightly from the Washington State Part C definition. The Washington State Part C definition is an example of criteria used in determining eligibility for state funded early intervention programs.

The following eligibility policy is taken from the approved Washington State application for federal assistance under IDEA Part C, submitted to the Department of Education Office of Special Education Programs:

The lead agency assures that children, birth to three, shall be eligible for early intervention services under IDEA Part C, if:

A. The multidisciplinary team finds any one of the following criteria exists:

1. Developmental delay:

    a. A child shall be eligible if he or she demonstrates a delay of 1.5 standard deviations or 25% of chronological age delay in one or more of the following developmental areas as measured by qualified personnel:

        i. Cognitive;
        ii. Physical (vision, hearing, fine or gross motor);
        iii. Communication;
        iv. Social or Emotional; or
        v. Adaptive.

    b. A child shall be eligible if he or she has a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay including, but not limited to:

        i. Chromosomal abnormalities associated with mental retardation, such as Down syndrome;
        ii. Congenital central nervous system birth defects or syndromes, such as myelomeningocele, fetal alcohol syndrome, or Cornelia de Lange syndrome;
        iii. Deaf, blind, or deaf-blind;
        iv. Established central nervous system deficits resulting from hypoxia, trauma, or infection;
        v. Cerebral palsy;

        vi. Health impairments such as autism, epilepsy, neurological impairments, or other chronic or acute or degenerative health problems.
        vii. Orthopedically impaired, which means impairment of the normal functions of muscles, joints, or bones due to congenital anomaly, disease, or permanent injury; and/or
        viii. Inborn errors of metabolism; or
        ix. Microcephaly.

2. Eligible children will continue to receive the early intervention service based on their needs that they receive under other existing state program criteria. These programs include:

    a. DSHS Division of Developmental Disabilities, WAC 275-27-026(6)(c) and (d);

    b. DOH Children with Special Health Care Needs, WAC 246-710-020; and

    c. Public Schools, WAC 392-172-114.

B. The multidisciplinary team (consisting of at least two qualified personnel) shall determine eligibility for Part C, based on the results of the evaluation; including the use of informed clinical opinion agreed upon by the multidisciplinary team. The informed clinical opinion shall be substantiated and documented in a written narrative and may include information provided by parent report and/or interview.

APPENDIX B

IDEA PART C EARLY INTERVENTION SERVICES

Early intervention services which must be available to all eligible children and their families in accordance with the Individuals with Disabilities Education Act (IDEA), Part C, include (Federal Register, July 30, 1993, Dept. of Ed. 34 CFR Part 303):

- Early identification, evaluation and assessment
- Assistive technology devices and services
- Audiology
- Family training, counseling, and home visits
- Health services necessary to enable the infant or toddler to benefit from the other early intervention services
- Medical services only for diagnostic or evaluation purposes
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Family resources coordination
- Social work services
- Special instruction
- Speech-language pathology
- Transportation and related costs
- Vision services

APPENDIX C

UNDUPLICATION AND MATCH PROCEDURE

Analyses appearing in this report are based on listings of children enrolled in early intervention programs. These lists have been unduplicated to obtain a count of enrolled children with only one entry per child. These unique records have been matched with the First Steps Database, which holds information from birth certificates, infant death certificates, Medicaid claim records for maternal and infant services, and Medicaid eligibility histories.

MATCHING CLIENT RECORDS

The process of unduplication and matching identifies and links records which refer to the same individual. There may be multiple references to the same child within a single source file, and/or matching records across different sources. Records may contain differing pieces of information about a single child.

The first step in matching is to standardize records received in data collection so they can be compared against one another. For example, dates of birth from different source files may be in different formats. These are translated into a six digit month-day-year format. (e.g., “1-JAN-94” becomes “010194”.) Names are translated into all uppercase letters, non-letter symbols are removed, and common prefixes, such as “MC” and “DELA” are combined into the name. (e.g., “MC MAHAN” becomes “MCMAHAN”.)

The process of matching combines computer processing with analyst evaluation of potential matches. This combination is designed to efficiently identify records which belong to a single child while avoiding acceptance of invalid matches.

Computer Processing

Computer processing identifies potential matches in a three-step operation. First, candidate matches are found. In general, two records are considered a candidate match if they share a same first name, last name, or date of birth. Name identifiers must have the same spelling for records to be flagged as candidate matches.

Second, candidate matches are scored based on the amount of information which the two records have in common. For example, a candidate match that shares a first name and five digits of a date of birth would score higher than a candidate match that shared a first name only.

Third, two data sets are output. Candidate matches which share all three identifiers—first name, last name, and date of birth—are output to a data set of perfect matches which do not require further review. Candidate matches which share many pieces of information, but not all three identifiers, are output to a data set of potential matches for evaluation by an analyst. For example, a potential match may be a pair of records that share the same last name and date of birth, but in which only the first letter of the first name is the same. Candidate matches with a minimum of shared information, for example, a first name only, are discarded.

Analyst Evaluation

An analyst evaluates potential matches by visually comparing record information. In many cases, records for the same child have a dissimilar piece of information, such as different spellings of a name, which prevent them from being perfect matches. In these cases, an analyst can judge if records are sufficiently the same to confirm a legitimate match.

UNDUPLICATION AND MATCH WITH THE FIRST STEPS DATABASE

Internal Unduplication

Receipt of more than one record from provider surveys and agency databases for a single child is common. As a first step in internal unduplication, these records are checked against each other for matches.

After matches are identified, duplicate records are compressed. All of the information is taken from one record in each matched set, and different pieces of information from records to which it is matched are added (for example alternate spelling of a name or a second last name). Records without matches are unchanged. This results in an unduplicated data set in which identified duplicate records have been combined into single records.

Match with the First Steps Database

In order to analyze enrollment using information in the First Steps Database (FSDB), the unduplicated records must be matched with records in the FSDB. When matching records are found, an identifier is added to the early intervention enrollment records linking that record to its match in the FSDB. The process of matching with the FSDB improves the accuracy and completeness of internal unduplication. Additional information contained in birth certificates (for example, a mother’s maiden name or indicators of multiple births) reveal new cases of duplicate early intervention records as well as early intervention records which had been improperly unduplicated.

The unduplication and match process uses available information to identify records as belonging to the same individual. New information increases the accuracy and completeness of an unduplication and match. This change in the underlying data can lead to revisions of previously reported figures.

The figures in this report may be revised as birth certificates become available to the First Steps Database and as additional counts are conducted.

APPENDIX D

DETAILED METHODS FOR CHAPTER 8 TABLES

Chapter eight of this report analyzes data on children aged birth to three years old who were matched to the First Steps Database. Where data are available through 1997, the most complete information will be for children born 1994 or earlier, because children born after 1994 are too young to contribute a full three years of data.

In most analyses, children enrolled in early intervention programs in any one of seven enrollment counts from December 1993 to December 1998 are compared to all other children born alive in the same year (birth cohort). In a few cases, where it is relevant, the analysis is controlled for poverty, using various definitions of Medicaid eligibility. Data are presented in two tables: "enrolled" versus "all other" children born that year.

DEATH TABLES

The FSDB death tables were updated for 1997 deaths obtained from the Department of Health Center for Health Statistics; therefore, the most complete child death (age birth to 3) information available would be for children born in 1994.

Total Liveborn: The total number of infants born alive. Liveborn infants include infants who may subsequently die within minutes or hours of their birth.

Infant deaths: Deaths occurring to infants who were born alive but died before their first birthday. Fetal deaths are not included in this number. Neonatal deaths refer to the number of infants who died within the first 27 days of birth. Postneonatal deaths refer to the number of infants who died from 28 to 364 days after birth.

Child Deaths: Deaths of children between one and three years old, including the first birthday but excluding the child’s third birthday.

Infant Mortality Rate: The number of infant deaths (neonatal and postneonatal) divided by the total number of liveborn children. The infant mortality rate is expressed as deaths per 1,000 liveborn children. Postneonatal rates exclude neonatal deaths.

Age-Specific Mortality Rates for Children: Ratios of the number of child deaths divided by the number of children born during a given birth year. Mortality rates in this table are expressed as deaths per 1,000 children.

CHILDREN AFFECTED BY DRUGS

Drug Affected Children: The number of infants born to low income women with measurable effects assumed attributable to the mothers’ substance abuse (alcohol or drugs) during pregnancy based on indicators on birth certificate and claims data in the First Steps Database. Identification is limited to children born to Medicaid-eligible women. Children identified as drug affected include those with a diagnosis of narcotics, hallucinogens or cocaine affecting the fetus, drug withdrawal, fetal alcohol syndrome

(FAS), or, in the presence of identified substance abuse by the mother, developmental delay or an abnormality of the placenta (abruptio placentae). Data on mother's substance abuse treatment (TARGET-matched data from DASA) are not available after 1995. Additionally, diagnosis codes from claims data are not collected in Medicaid managed care (Healthy Options), implemented in 1993. A likely reason for the decline in the proportion of identified drug affected children is the increasing lack of claims data (1993 on) for children and mothers in Medicaid managed care.

OUT-OF-HOME PLACEMENT

Out-of-home Placements: The number of children referred to Child Protective Services that result in a temporary or permanent removal of the child into an alternative home. Children may be placed in a group foster home, with foster parents, or with other family members. Out-of-home placements were measured using birth cohorts from the First Steps Database with linkage to CAMIS. Observations with missing start or end dates were not included; nor were those with a placement type of ‘BA’ (Birth/Adoptive Parent (custodial)), ‘BN’ (Birth/Adoptive Parent (non-custodial) or Step Parent (not licensed)), or ‘OR’ (on the run).

ELIGIBILTY

The OFM eligibility history file was used for grant, medical and SSI eligibility. Analyses were run separately for grant eligibility and Medicaid eligibility. In this way, children receiving grants were not excluded from the Medicaid – medical assistance eligibility analyses, since children in Medicaid (medical assistance) also could have been receiving grants. In both cases, Medicaid eligibility for children enrolled in early intervention programs was compared to all other Medicaid-eligible children. The analyses look at eligibility at three age intervals: from birth to one year, one year to just before two years old, and from two to three years old.

Grant-eligible records had match codes of ‘1’, ‘2’, and ‘U’; persons without these codes who had eligibility segments were defined as other Medicaid-eligible. Children aged birth to three years old were classified as grant-eligible if they were (1) eligible for A, B or P grant programs or had a needy relative in the AFDC grant program, (2) were dependents in AFDC or TANF grant programs, or (3) were eligible under GA-C. Grant-eligible children enrolled in early intervention programs were compared with all other Medicaid-eligible, non-Grant eligible children.

MANAGED CARE ENROLLMENT TABLES

Medicaid-eligible children aged birth to three years were identified as managed care enrollees if Medical Assistance Administration paid a capitation fee between age 0 to 2, determined by procedure code ‘0350M’, ‘0352M’, ‘0356M’, ‘0357M’, ‘0355M’, ‘0365M’, ‘0366M’, ‘0367M’, or ‘0368M’ (fees must have been for the child, not the mother). The tabulation is restricted to Medicaid-eligible children (those with Medicaid charges over $100 from birth to age two, or whose mothers had Medicaid claims for prenatal or delivery services), and picks up services for children received anytime between age 0 and 2 years old.

SSI ELIGIBILITY

Children aged birth to three years of age were identified as eligible to receive Supplemental Security Income benefits if they met three conditions: (1) their program eligibility history included the general category of assistance ('A', 'B', 'P', 'X'); (2) their match codes, which give greater detail on assistance, were in ('1', '2', 'C', 'I', 'J', 'N', 'S', 'U'); and (3) they were eligible to receive services under regular medical care (Medelig=’0’) versus a specified medical plan. These eligibility codes were provided to FSDB/ITEIP project staff by the Medical Assistance Administration. Eligibility was obtained from real-time eligibility files, current through 1999.

The following are descriptions of the program and match codes. Programs ‘A’, ‘B’, ‘P’, ‘X’ are for the aged, blind, disabled, or presumptive SSI. This definition does not include persons eligible as medically indigent, other children not eligible for AFDC, food stamps, AFDC regular or unknown. The following lists those eligible under match codes ‘1’, ‘2’, ‘C’, ‘I’, ‘J’, ‘N’, ‘S’, ‘U’: eligible for ‘A’, ‘B’ or ‘P’ grant program or a needy relative in AFDC Grant program; dependent adult in ‘A’, ‘B’, ‘P’ grant program or dependent in AFDC grant program; Medical assistance (categorically needy); Title IV-E foster care cases; institutionalized medical assistance, categorically needy (categorically related to SSI but not eligible for cash assistance if not institutionalized – income under the fed cap 300% of SSI benefit standard but above the categorically needy income level grant standard); institutionalized medical assistance (categorically needy) at or below categorically needy income level grant standard including SSI beneficiaries in a nursing home; medical assistance, categorically needy, ‘A’, ‘B’, ‘P’, and ‘C’ programs; eligible for ‘GA-C’. These match codes exclude the following groups: the medically needy limited casualty program with or without spend down programs; the qualified Medical beneficiary dependent eligible for AFDC under other criteria except for age; Medical assistance categorically needy H program independent; children’s health program other than undocumented aliens; limited casualty institutionalized medically indigent; and adopting support program or undocumented aliens.

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APPENDIX E

RESPITE CARE

Respite care is a part of the Family Support Program funded by the Division of Developmental Disabilities (DDD) of DSHS. The program is designed to support families in their role of caring for their children who have developmental disabilities. The program is most important when families are not able to use other types of childcare, such as relatives, childcare programs or babysitters. Respite is also available for adults who live with their families.

The respite care for the child provides a break for the family. Respite care providers must be licensed foster or daycare homes if the care is delivered in the provider's home. Care may also be delivered in the home of the child by a contracted provider.

The Family Support program makes available an amount of money to families. The family can choose how to spend their benefit from a number of options. Respite is the most popular service funded through the program.

The Family Support program has a long waiting list. In the past, a family might wait several years for services, making it unlikely a young child would get respite or another service. Waiting lists are currently in the six to twelve month range.

The birth cohorts in this table are a subset of the total cohorts presented in the other tables in Chapter 8. Only children eligible for DDD services are included.

Trends and Patterns Database

The Trends and Patterns Database, developed by the Division of Developmental Disabilities (DDD) and Research and Data Analysis, contains information about DDD caseloads, services, expenditures, and staffing. This database served as the direct source for data concerning DDD respite care services, without linkage to *Birth to Three Study* data.

(RESPITE TABLE)

- For each complete birth cohort year the numbers of children receiving respite services increased with age; i.e., more 2 to 3 year olds were receiving respite care than 1 to 2 year olds, and more 1 to 2 year olds than infants.

- From 1992 to 1995 the three year respite rate increased 46%, from a rate of 4.3% in 1992 to 6.3% in 1995.

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APPENDIX F

MEDICAID EXPENDITURES

Recent studies, one national and one from Washington State, indicate that a small proportion of children with Supplemental Security Income (approximately 10%) account for the largest proportion of children's Medicaid expenditures (approximately 70%) (Ireys et al., 1993; Kuhlthau et al., 1998). High medical expenses can indicate severe and chronic health conditions. Approximately 15% of Washington's children enrolled in Medicaid have a chronic health condition (Ireys et al., 1993). For some conditions, durable equipment, home nursing, and medication-related services account for a large proportion of total expenditures. For others, high expenditures are related to inpatient hospital care.

- Average or <u>mean</u> Medicaid expenditure for the first year of a child's life for children enrolled in early intervention programs was $19,390 (birth year 1992 – pre-managed care), more than eight times that for all other Washington Medicaid-eligible children, whose average expenditure was $2,367.

- The <u>median</u> expenditure for the first year of life for children born in 1992 and enrolled in early intervention was $2,828, just slightly more than two times that for other low income children ($1,212). For children born in 1995 the median expenditure was $2,186 versus $1,470, one and a half times greater.

- The <u>mean</u> expenditure for the second year of life for children enrolled in early intervention programs was $6,502, slightly more than seven times that for all other Medicaid-eligible children born in 1992 ($902).

- The <u>median</u> expenditure for the second year of life for children enrolled in early intervention programs was $1,270, a little more than two times that for other low-income children born in 1992 ($622).

- Differences in <u>mean</u> and <u>median</u> are greatest for early intervention children, since individual high expenditures drive up the average, or mean, to be significantly greater than the median (the middle figure in a range of values). <u>Mean</u> and <u>median</u> are less different for all other Medicaid-eligible children.

In the first year of life, the largest proportion of Washington State Medicaid expenditures for children enrolled in early intervention programs was for inpatient hospital expenditures.

Specific costs for services covered under managed care plans are not known. Implementation of managed care for Medicaid-eligible groups occurred in 1993; thus expenditures prior to 1994 represent a more complete picture of the expenses incurred by the children in this study.

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(COST BRTHYR OTHER TABLE- YR 2)

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(MED EXPEND TABLE-ITEIP YR 2, PAGE 1)

(MED EXPEND TABLE-ITEIP YR 2, PAGE 2)

(MED EXPEND TABLE-OTHER YR 2, PAGE 1)

(MED EXPEND TABLE-OTHER YR 2, PAGE 2)

MEDICAID EXPENDITURES METHODS

This analysis identifies Medicaid costs for the first and second year of life, comparing data for children enrolled in early intervention and matched to the First Steps Database (FSDB) with data for all other Medicaid-eligible children born 1992 through 1997 (see Appendix D). Children are defined as Medicaid-eligible if their mothers had Medicaid claims for prenatal or delivery services, or if the child had Medicaid charges over $100 from birth to age two. Charges which appear under the mother's ID but which are actually for the child are included. Medicaid expenditures for eleven specific categories are identified from provider specialty codes and categories of services as listed in the table on the following page.

Remaining expenditures that did not fall into these categories were classified as either inpatient or outpatient using service class definitions. Services information in the First Steps Database is updated through 1997 services. The average cost per child is calculated by the total expenditures divided by the total number of children receiving services.

The overall average (mean) expenditure per child born was calculated by dividing total Medicaid expenditures in each year of the child's life by the total number of Medicaid-eligible children born in a given year. This data is presented in a separate table. It provides an understanding of how financial resources were allocated. Not all children enrolled in early intervention programs received services. Some children with expenditures could not be matched to the FSDB. Higher income children who were out of their home environment (i.e. hospitalized) for over a month might have also had Medicaid expenditures for that period. Specific expenditures for services covered under managed care plans are not known; thus expenditures prior to 1994 represent a more complete picture of expenses.

The following table lists type of service with the accompanying provider specialty categories and categories of services by which the service type is defined:

Type of Service	Provider Specialty	Category of Services
Assistive Tech (Devices and Svcs.)	‘51’ Medical Supply/Prosth/Ortho	‘74’ Durable Medical Equipment
Audiology	‘04’ Otology – Laryngology – Rhinology; ‘64’ Audiology	‘82’ Hearing Aids
EPSTD		‘63’ EPSDT
Home Health		‘62’ Home Health Agencies
Nutrition	‘68’ Dietician	
Occupational Therapy	‘66’ Occupational Therapy	
Physical Therapy	‘65’ Physical Therapy	
Psychology Services	‘35’ Pediatric Psychiatry; ‘36’ Psychiatry; ‘62’ Psychology	
Speech and Language Services	‘76’ Speech Pathology (neuromuscular center)	
Transportation	‘37’ Transportation Ambulance Only ; ‘59’ Medical Transportation;	‘76’ Medically Required Ambulance and Air Ambulance; ‘77’ Medically Required Ambulance; ‘78’ Medically Required Taxi; ‘79’ Other Medically Required Transportation
Vision Services	‘18’ Ophthalmology; ‘88’ Optician/Optometry	‘70’ Optometrist/Optician; ‘71’ Eye Glasses

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