

**Washington's Infant Toddler
Early Intervention Program Study:
December 1, 1999**

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

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ACRONYMS

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
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
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

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, who were enrolled in Washington State public services for children with developmental delays or disabilities on December 1, 1999. 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.

Eligibility criteria differ between agencies. Infants and toddlers with special health care needs enrolled in early intervention services may not have developmental delays or disabilities that meet eligibility criteria for the Infant Toddler Early Intervention Program. These children may be at risk of delays and are included in this report to serve as a reference for possible future funding and services, and to portray a more complete picture of the population of children receiving public early intervention services in Washington State.

Summary of Findings: December 1, 1999 Unduplicated Enrollment Count

- In Washington State, 2,781 infants and toddlers under three years of age (1.2% of the estimated population of children under three) and their families were receiving services with completed Individualized Family Service Plans on December 1, 1999. This number has grown from 113 children reported on December 1, 1993.
- A total of 5,557 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, 1999. Over the last six years the *number* of children served has increased by 37% from 4,055 to 5,557, and the *proportion* of children enrolled has risen from 1.6% to 2.3%.
- The 1999 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 (1.4%). The proportion of enrolled children who were Medicaid-eligible (69%) was significantly greater than that for all children in Washington (47%). These patterns are similar among children in the National Health Interview Survey with reported limitations.
- The enrollment rate for children of mothers with no prenatal care (4.7%) was over two 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 (10.6%), preterm birth (5.9%), and Apgar score less than 8 (9.6%). Male children had a higher enrollment rate than female children (2.7% versus 2.0%).
- Children of mothers with diagnosed substance abuse had an enrollment rate of more than three times that for all other Medicaid children in Washington (9.5% versus 3.0%).

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 on December 1, 1999. 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.

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

A consensus about the importance of intervening in the first months and years of life has been emerging in the field of early intervention for children with established disabilities or developmental delays and those at risk biologically or environmentally (Guralnick, 1998; Ramey and Ramey, 1998; Ramey et al., 1998). 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 (Chugani et al., 1987; Huttenlocher, 1990). 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) and lays the foundation for the child's future development. 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, 1986; Shonkoff and Hauser-Cram, 1987), preschoolers *environmentally at-risk* (Lazar and Darlington, 1982; Ramey et al., 2000; Wasik et al., 1990) and preschoolers at *biological risk* due to low birthweight and prematurity (Blair et al., 1995; McCarton et al., 1997; Ramey et al., 1992).

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 Department of Social and Health Services 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 county health and

human service agencies, developmental centers, neurodevelopmental centers, school districts, Tribal programs, and other local and state agencies. The IDEA Part C program acts as an umbrella for program standards and provides linkages and enhancement of early intervention services to ensure a statewide system of comprehensive, family centered, multi-disciplinary, coordinated services to infants and toddlers with disabilities and their families. In October 1994, Washington State began full implementation of Part C. At that time, 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

The early intervention enrollment information presented in this report is based on data from a provider survey and three agency databases. Additional information from the First Steps Database allowed analysis of relationships between early intervention program enrollment and characteristics of the population including income level and a range of biological and environmental risk factors. National comparisons are from data collected by the National Health Interview Study.

DATA SOURCES

Provider Surveys for the December 1, 1999 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, 1999. A child was defined as enrolled if the child 1) was determined to be eligible for services, 2) was receiving services, or 3) the child had a completed service plan.

Provider surveys were mailed to 50 child development programs, 4 neurodevelopmental centers, 10 combined child development programs and neurodevelopmental centers, 34 Infant Toddler Early Intervention Program local lead agencies, of which 11 were also child development programs and/or neurodevelopmental centers, and 296 school districts, of which 111 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.

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 1999.

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 State 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 that evaluations and assessments are completed, to facilitate Individualized Family Service Plans (IFSPs), to coordinate services and activities with community and agency resources, and to coordinate transitions out of early intervention services by the child's third birthday. These federally funded services must enhance and may not duplicate existing services.

DDD (DSHS) funds child development 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. In addition, DDD provides case management to assist with referrals and allow access to Family Support, Medicaid Personal Care, and voluntary placement in foster care, as available through state-legislated budget allotments.

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, 1999 count, 111 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 Office of Child Care Policy, Division of Alcohol and Substance Abuse, and Mental Health), Tribal governments and programs, the military, and non-profit service organizations such as the Elks, Shriners, United Way, and others.

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 1998.

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

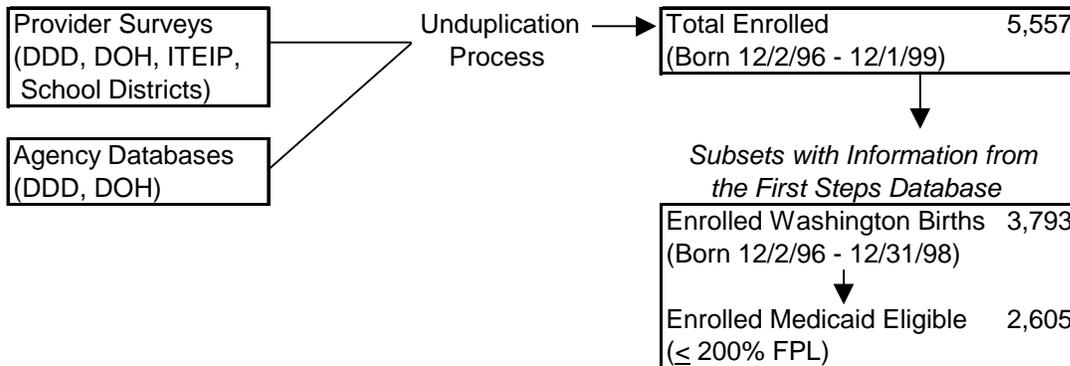
National comparisons are based on child limitations (see page seven) as reported by respondents in the National Health Interview Survey (NHIS). The NHIS is an annual comprehensive survey of health conditions in a sample of households throughout the United States, conducted by the U.S. Bureau of the Census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

ENROLLMENT AND IFSP RATES BY COUNTY

County assignments were estimated based on reported residence zip codes. In cases where there were multiple zip codes reported for the same person (multiple records), precedence was given to the zip code cited most frequently. In a tie, the zip code reported on the provider survey was considered to be the most current.

Zip code boundaries are independent of county boundaries, and zip code boundaries often cross county lines. Zip code to county translations were provided by the GIS specialist for the Department of Social and Health Services, Research and Data Analysis. For zip codes with multiple county associations, records were proportionally distributed stratified by race, age, and gender. Distribution was based on census block, zip code, and county information obtained from Claritas, Inc.

ANALYSIS GROUPS



Enrolled Children. This group contains all 5,557 children from age birth to three identified in the December 1, 1999 count as being enrolled in early intervention services.

Enrolled Washington Births. This group contains the 3,793 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 1998, children born in 1999 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 4,484 enrolled children born before 1999, 85% were matched with the FSDB.

Enrolled Medicaid-Eligible. This group contains only those 2,605 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.

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. Many of these children have special health care needs and may be at risk of developmental delays or disabilities but are not currently eligible for the Infant Toddler Early Intervention Program.

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 received services only through other sources (e.g., private programs and private insurance, military services, Tribal and Indian Health Services, migrant services, 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, 1996, and 1997 (the most recent years for which NHIS data are available).

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.

County Assignments (Enrollment and IFSPs by County)

Zip code boundaries often cross county lines. County assignments presented here are well-informed estimates based on zip codes, and may differ from actual county of residence.

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, 1999 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, 1999

Children Enrolled in Early Intervention Services	5,557
Washington State Population under Three*	238,586
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*

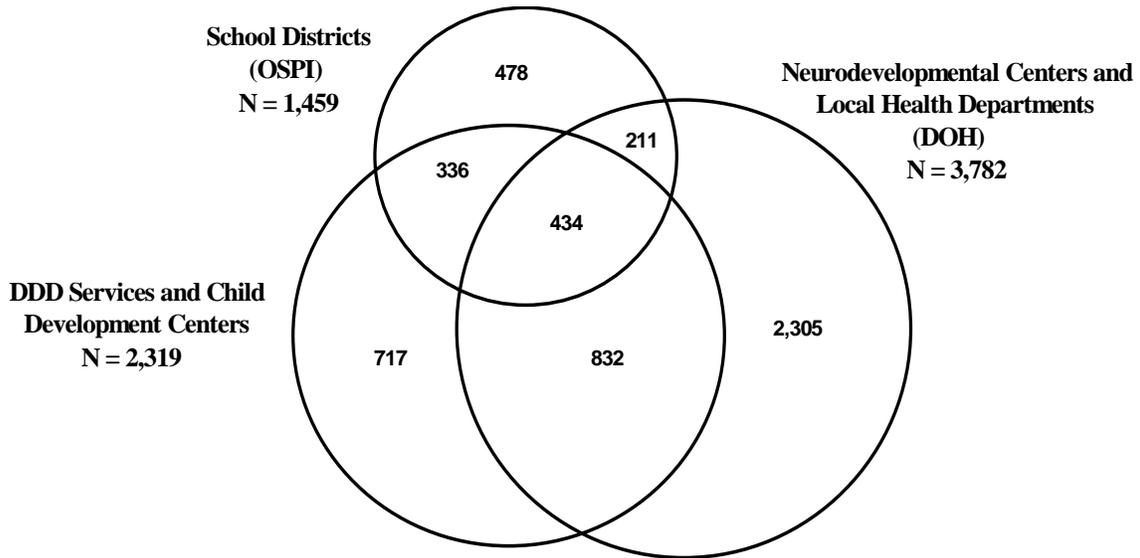
	Dec. 1, <u>1993</u>	Dec. 1, <u>1995</u>	Dec. 2, <u>1996</u>	Dec. 1, <u>1997</u>	Dec. 1, <u>1998</u>	Dec. 1, <u>1999</u>
Enrolled:	4,055	4,138	4,472	5,007	5,332	5,557
Population:	245,182	238,314	234,894	236,042	235,903	238,586
Rate:	1.65%	1.74%	1.90%	2.12%	2.26%	2.33%

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

A total of 5,557 individual children, 2.3% of the Washington State population under three, were reported enrolled in public early intervention services on December 1, 1999. Since 1993—one year before Washington State began full implementation of IDEA Part C—the number of children reported enrolled has increased by 37%.

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



	<u>Number of Children</u>	<u>Percent of Total</u>
Children enrolled with one provider:		
DDD Only	717	12.9%
DOH Only*	2,305	41.5%
OSPI Only	478	8.6%
Children enrolled with two providers:		
DDD and DOH, not OSPI	832	15.0%
DDD and OSPI, not DOH	336	6.0%
DOH and OSPI, not DDD	211	3.8%
Children enrolled with all three providers: DDD, DOH, and OSPI	434	7.8%
Additional children reported :		
ITEIP only	188	3.4%
IFSP only	56	1.0%
Total Children Reported	5,557	100%

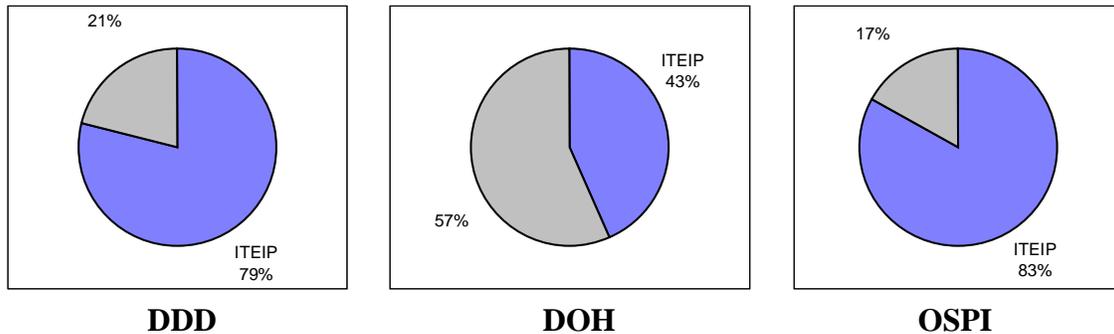
A total of 2,781 children (50.0%) were reported to have an IFSP (Individualized Family Service Plan) in place on December 1, 1999. This represents 1.2% of the estimated Washington State population under age three. A total of 2,843 children (51.2%) were reported to be receiving enhanced services through ITEIP. Distribution of these children by service agency is detailed on the following page.

* Not all DOH enrolled children with medical conditions are eligible for ITEIP services 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

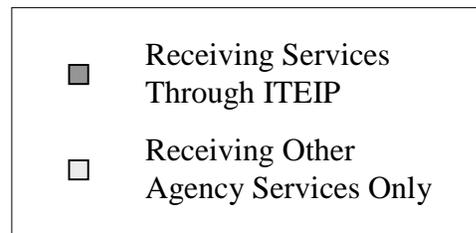
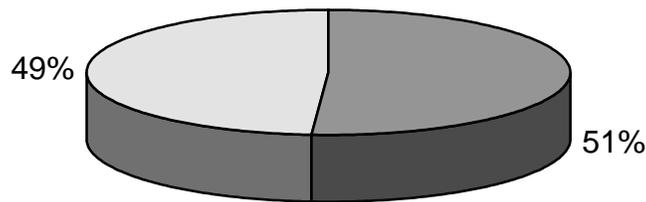


- Seventy-nine percent of those children reported enrolled in DDD programs were reported to be receiving one or more services through ITEIP, including Family Resources Coordination.
- Forty-three percent of those children reported enrolled in DOH programs were reported to be receiving one or more services through ITEIP, including Family Resources Coordination.
- Eighty-three percent of those children reported enrolled in school district programs were reported to be receiving one or more services through ITEIP, including Family Resources Coordination.

		Number of Children	Percent of Total
Children enrolled with ITEIP only:	ITEIP Only	188	3.4%
Children enrolled with ITEIP and one other provider:	ITEIP and DDD	387	7.0%
	ITEIP and DOH	354	6.4%
	ITEIP and OSPI	300	5.4%
Children enrolled with ITEIP and two other providers:	ITEIP, DDD, and DOH	701	12.6%
	ITEIP, DDD, and OSPI	325	5.8%
	ITEIP, DOH, and OSPI	170	3.1%
Children enrolled with all four providers: ITEIP, DDD, DOH, and OSPI		418	7.5%
Total children reported to be receiving services through ITEIP:		2,843	51.2%

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, 1999 unduplicated count, fifty-one 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, 1999



- Among the 5,557 children reported to be enrolled in public early intervention services, 2,843 (51.2%) 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 receiving ITEIP services (2,843 children) were reported to have IFSPs in place. These children were in the process of IFSP development. Not all children reported as having IFSPs (2,781 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.

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, 1996, and 1997 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 5,557 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, caregivers, or others. 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 1998.

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	5,557
Enrolled Washington Births	3,793
Total Washington Births	163,129
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, page 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	1,258	1.6%	1.4%
1 – 2 Years Old	1,880	2.4%	2.5%
2 – 3 Years Old	2,419	3.0%	2.8%
Total	5,557	2.3%	2.3%

**Population estimates for Washington are for April 1, 1999 (Source: OFM). National figures are estimated from a stratified sample of households surveyed in the 1995, 1996, and 1997 NHIS.*

- As children become older, developmental delays may become more evident. For children 2 – 3 years old, the Washington State enrollment rate (3.0%) and the national prevalence rate (2.8%) are higher than the rates for children 0 – 1 years old (1.6% and 1.4%, respectively) and for those 1 – 2 years old (2.4% and 2.5%, 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 = 3,793)	All Washington Births (N=163,129)
Medicaid-Eligible	69%	47%
Not Medicaid-Eligible	31%	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
Below 200% FPL	63%	44%
At or Above 200% FPL	37%	56%

*Data are from the 1995-1997 NHIS.

- Medicaid eligibility was much higher among Washington-born children *enrolled in public early intervention programs* (69%) than among *all* children in Washington State (47%). Similarly, more NHIS children under three *with reported limitations* had family incomes below 200% of the federal poverty level (63%) than did *all* children under three (44%).

DISTRIBUTION OF CHILDREN BY MOTHER'S RACE/ETHNICITY

Mother's Race / Ethnicity	Children Under Three Born to Washington Residents		Children Under Three in the NHIS*	
	Enrolled Children (N = 3,793)	All Washington Births (N = 163,129)	Children with Reported Limitations	All Children
White	71.3%	72.7%	53.2%	63.7%
Hispanic	13.0%	10.9%	19.8%	16.9%
Asian/Pacific Islander	4.0%	6.5%	0.4%	3.2%
African American	3.8%	3.8%	25.4%	14.5%
Native American	4.4%	2.2%	0.5%	0.8%
Other/Unknown	3.6%	4.0%	0.6%	0.9%
Total	100%	100%	100%	100%

*Data are from the 1995-1997 NHIS.

- The proportion of White *enrolled* children (71.3%) was similar to the proportion of White children among *all* children born in Washington State (72.7%).
- The proportion of African American *enrolled* children (3.8%) is the same as the proportion of African American children among *all* children born in Washington State (3.8%).
- The proportion of Asian/Pacific Islander *enrolled* children (4.0%) was lower than the proportion of Asian/Pacific Islander children among *all* children born in Washington State (6.5%).
- The proportions of Hispanic and Native American *enrolled* children (13.0% and 4.4%, respectively) were higher than the proportions for those groups among *all* children born in Washington State (10.9% and 2.2%).

**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 below 200% FPL**

Mother's Race/Ethnicity	Enrolled Children	All Washington Births	Enrollment Rate	% Reported Limitations
White	1,675	47,183	3.6%	2.9%
Hispanic	465	15,200	3.1%	3.0%
Asian/Pacific Islander	95	4,376	2.2%	0.7%
African American	136	4,318	3.1%	4.5%
Native American	152	2,881	5.3%	2.4%
Other/Unknown	82	2,392	3.4%	0.0%
Total	2,605	76,350	3.4%	3.2%

**Data are from the 1995-1997 NHIS.*

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

- The State enrollment rate for White children (3.6%) was slightly higher than the national prevalence rate (2.9%).
- The State enrollment rate for Hispanic children (3.1%) was similar to the national prevalence rate (3.0%).
- The State enrollment rate for African American children (3.1%) was lower than the national prevalence rate (4.5%).
- The State enrollment rates for Asian/Pacific Islander and Native American children (2.2% and 5.3%, respectively) were higher than the national prevalence rates for these groups (0.7% and 2.4%, 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)	1,028	71,346	1.4%	1.3%
Hispanic	28	2,521	1.1%	1.9%
Asian/Pacific Islander	56	6,195	0.9%	0.0%
African American	10	1,926	0.5%	2.8%
Native American	13	700	1.9%	0.0%
Other/Unknown	53	4,091	1.3%	2.7%
Total	1,188	86,779	1.4%	1.5%

**Data are from the 1995-1997 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

ENROLLMENT AND IFSP RATES BY COUNTY

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 the estimated county affiliations for children enrolled in public early intervention programs and for children with Individualized Family Service Plans (IFSPs) for each of the thirty-nine counties in Washington State, showing the extent of geographic variation.

County assignments are estimates, since they are based on residence zip codes, and zip codes often cross county lines. Additionally, *children may or may not be enrolled with providers in their county of residence*. For zip codes with multiple county associations, zip code to county translations were proportionally distributed based on census data, stratified by race, age, and gender.

ENROLLMENT BY COUNTY

In addition to considering each county separately, the table on the following page shows the *estimated* rate of enrollment in public early intervention programs by county, grouped 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.

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.

The information presented in this table is based on the 5,521 unduplicated records (out of the total 5,557 reported this year) for which current residence zip codes were available. 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.

- Among all Washington residents, rural and small urban groups have higher enrollment rates than metropolitan areas.
- Enrollment rates vary widely within the three categories of counties. The enrollment rate for metropolitan counties is 2.2% with a range from 1.7% - 3.2% (-.5 to +1.0). The enrollment rate for small urban counties is 2.6% with a wider range from 1.7% - 3.9% (-.9 to +1.3). As expected, rural counties, with an enrollment rate of 2.3% have the widest range from 0.8% to 8.6% (-1.5 to +6.3). The smaller populations in rural counties result in greater statistical variability, since the status of a single child may considerably influence the enrollment rate.

Enrollment on December 1, 1999 by Estimate of County

County	Estimated Number Enrolled*	Estimate of Population under Three*	Enrollment Rate	Index
Clark	265	15,233	1.7%	0.75
King	1,054	63,877	1.7%	0.71
Pierce	745	31,933	2.3%	1.00
Snohomish	721	25,259	2.9%	1.23
Spokane	543	16,965	3.2%	1.37
Metro Total	3,328	153,266	2.2%	0.93
Kitsap	185	10,726	1.7%	0.74
Thurston	156	8,157	1.9%	0.82
Walla Walla	41	1,999	2.1%	0.88
Whatcom	149	6,318	2.4%	1.01
Cowlitz	98	3,917	2.5%	1.07
Lewis	77	2,839	2.7%	1.16
Skagit	115	4,196	2.7%	1.18
Benton	186	6,324	2.9%	1.26
Yakima	412	11,137	3.7%	1.59
Franklin	106	2,702	3.9%	1.68
S.U. Total	1,525	58,315	2.6%	1.12
Pend Oreille	4	487	0.8%	0.35
Lincoln	4	324	1.2%	0.53
San Juan	5	398	1.3%	0.54
Kittitas	15	1,075	1.4%	0.60
Stevens	21	1,493	1.4%	0.60
Ferry	4	284	1.4%	0.61
Douglas	19	1,261	1.5%	0.65
Whitman	21	1,230	1.7%	0.73
Island	62	3,256	1.9%	0.82
Clallam	43	2,246	1.9%	0.82
Mason	38	1,794	2.1%	0.91
Pacific	16	698	2.3%	0.98
Klickitat	17	735	2.3%	0.99
Chelan	71	3,007	2.4%	1.01
Grant	83	3,458	2.4%	1.03
Grays Harbor	65	2,662	2.4%	1.05
Skamania	10	386	2.6%	1.11
Okanogan	51	1,691	3.0%	1.29
Asotin	25	799	3.1%	1.34
Columbia	5	151	3.3%	1.42
Adams	37	876	4.2%	1.81
Jefferson	38	865	4.4%	1.89
Wahkiakum	7	130	5.4%	2.31
Garfield	7	81	8.6%	3.71
Rural Total	668	29,387	2.3%	0.98
State Total*	5,557	238,586	2.3%	1.00

**Some children could not be assigned a county of residence. As a result, state totals may be slightly higher than the sums of counties. County is assigned based on zip code, and should be treated as best estimate rather than known county of residence. Please note that in counties with low population, a few children can dramatically affect the enrollment rate. County population estimates are derived from OFM figures by county for children under five, while state population is based on OFM estimates for the state as a whole, by single year of age. Index is the ratio of county enrollment rate to state enrollment rate.*

INDIVIDUALIZED FAMILY SERVICE PLANSs (IFSPs) BY COUNTY

An IFSP includes a written plan for providing comprehensive early intervention services to a child eligible under IDEA, Part C and the child's family. The plan must:

- Be developed jointly by the family and appropriate qualified personnel involved in the provision of early intervention services;
- Be based on the multidisciplinary evaluation and assessments of the child;
- Include a family-directed assessment of the concerns, priorities, and resources related to enhancing the development of the child (a family directed assessment is voluntary on the part of the family); and
- Include services necessary to enhance the development of the child and the capacity of the family to meet the special needs of their child.

Among the 5,557 infants and toddlers reported to be enrolled in public early intervention services on December 1, 1999, 2,781 (50%) were reported as having a completed IFSP. The table on the following page portrays the *estimated* county affiliations for children with IFSPs.

Children were identified as having a completed Individualized Family Service Plan by provider report on a provider survey (see page three). Agency database extracts did not include data on IFSPs. If a child was reported through multiple sources and at least one source indicated that the child had a completed IFSP, the child was considered to have an IFSP.

- The estimated proportion of IFSPs among enrolled children at the county level varies widely, from 14% to 96%. Both the highest and the lowest proportion of IFSPs occurred primarily among rural counties, where small populations result in greater variability in rates.

**Estimate of County for Children with Individualized Family Service Plans
December 1, 1999**

Estimate of County:*	Estimated Number Enrolled	Estimated Number with IFSPs	Estimated Proportion with IFSPs:
Adams	37	6	16.2%
Asotin	25	24	96.0%
Benton	186	97	52.2%
Chelan	71	28	39.4%
Clallam	43	33	76.7%
Clark	265	172	64.9%
Columbia	5	3	60.0%
Cowlitz	98	62	63.3%
Douglas	19	11	57.9%
Ferry	4	2	50.0%
Franklin	106	45	42.5%
Garfield	7	1	14.3%
Grant	83	70	84.3%
Grays Harbor	65	33	50.8%
Island	62	53	85.5%
Jefferson	38	19	50.0%
King	1054	554	52.6%
Kitsap	185	121	65.4%
Kittitas	15	5	33.3%
Klickitat	17	16	94.1%
Lewis	77	16	20.8%
Lincoln	4	3	75.0%
Mason	38	21	55.3%
Okanogan	51	40	78.4%
Pacific	16	13	81.3%
Pend Oreille	4	3	75.0%
Pierce	745	282	37.9%
San Juan	5	3	60.0%
Skagit	115	70	60.9%
Skamania	10	5	50.0%
Snohomish	721	407	56.4%
Spokane	543	219	40.3%
Stevens	21	14	66.7%
Thurston	156	62	39.7%
Wahkiakum	7	2	28.6%
Walla Walla	41	31	75.6%
Whatcom	149	88	59.1%
Whitman	21	18	85.7%
Yakima	412	124	30.1%
Not identified:	36	5	13.9%
Total:	5,557	2,781	50.0%

**County is assigned based on zip code, and should be treated as best estimate rather than known county of residence. Please note that in counties with low numbers, the status of a few children can dramatically affect the IFSP 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 1999).

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, 1995). 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, 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, 1991).

- The enrollment rate for very low birthweight infants (26.8%) was fifteen times higher than that for normal birthweight (singleton) infants (1.8%).
- The enrollment rates for medium low birthweight infants (7.1%) and infants from multiple gestations (7.0%) were four times higher than the enrollment rate for normal birthweight (singleton) children (1.8%).
- Low birthweight infants (very low and medium low birthweight combined) had an enrollment rate (10.6%) six times higher than that for normal birthweight (singleton) infants (1.8%).

Infant Characteristics at Birth

Risk Factor	Enrolled Children		All Washington Births		Enrollment Rate
	3,793	(100 %)	(N = 163,129)	(100 %)	(2.3%)
Birthweight					
Very Low (< 3.3 lbs)	344	9.1%	1,284	0.8%	26.8%
Medium Low (3.3 - 5.5 lbs)	416	11.0%	5,865	3.6%	7.1%
Normal (> 5.5 lbs)	2,724	71.8%	151,346	92.8%	1.8%
Mult. Gestation (Twins, etc.)	294	7.8%	4,185	2.6%	7.0%
Unknown Birthweight	15	0.4%	449	0.3%	3.3%
Gestational Age at Birth					
Extreme Preterm (< 28 wks)	189	5.0%	767	0.5%	24.6%
Mod. Preterm (28 - 36 wks)	1,078	28.4%	20,812	12.8%	5.2%
Full Term (37+ wks)	2,476	65.3%	139,669	85.6%	1.8%
Unknown	50	1.3%	1,881	1.2%	2.7%
Apgar Score					
less than 8	534	14.1%	5,548	3.4%	9.6%
8	624	16.5%	14,456	8.9%	4.3%
9	2,411	63.6%	131,151	80.4%	1.8%
10	185	4.9%	11,210	6.9%	1.7%
Unknown	39	1.0%	764	0.5%	5.1%
Gender					
Female	1,563	41.2%	79,438	48.7%	2.0%
Male	2,230	58.8%	83,691	51.3%	2.7%
Unknown	0	0.0%	0	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 (5.9%) over three times that for full term infants (1.8%).
- The enrollment rate for extremely preterm infants (24.6%) was nearly fourteen times higher than that for full term infants (1.8%)

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, 1986).

- The enrollment rate for children with an Apgar score of less than 8 (9.6%) was five times higher than that for children with an Apgar score of 8 or more (2.1%).

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 (2.7%) 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 = 3,793) (100 %)		All Washington Births (N = 163,129) (100 %)		Enrollment Rate (2.3%)
Trimester Prenatal Care Began					
No Prenatal Care	45	1.2%	965	0.6%	4.7%
1st Trimester	2,644	69.7%	123,117	75.5%	2.1%
2nd Trimester	514	13.6%	20,000	12.3%	2.6%
3rd Trimester	126	3.3%	3,737	2.3%	3.4%
Unknown	464	12.2%	15,310	9.4%	3.0%
Mother Smoked During Pregnancy					
Yes	749	19.7%	22,526	13.8%	3.3%
No	2,828	74.6%	132,911	81.5%	2.1%
Unknown	216	5.7%	7,692	4.7%	2.8%

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 (4.7%) was more than twice 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 (3.3%) was more than that for children born to nonsmoking women (2.1%).

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). 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 and Lukashov, 1996).

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

Risk Factor	Enrolled Children (N = 2,258) (100 %)		All Medicaid Births (N = 67,906) (100 %)		Enrollment Rate (3.3%)
Diagnosed Substance Abuse					
<i>Alcohol Only</i>	16	0.7%	220	0.3%	7.3%
<i>Drugs Only</i>	122	5.4%	1,302	1.9%	9.4%
<i>Both Alcohol and Drugs</i>	159	7.0%	1,602	2.4%	9.9%
Any Diagnosed Substance Abuse	297	13.2%	3,124	4.6%	9.5%
No Diagnosed Substance Abuse	1,961	86.8%	64,782	95.4%	3.0%

- For children of Medicaid served mothers, the enrollment rate for those born to women with any diagnosed substance abuse (9.5%) was three 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, unstimulating and non-optimal parent-child interactions, neglect, physical or psychological abuse. Poverty is believed to be one of the major environmental risks in the United States today (Berrick, 1998; 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 and Guralnick, 1991). The individual environmental risk variables most often cited in research studies are poverty (Children's Defense Fund, 1994), maternal education, maternal age, and parent-child interaction or quality of caregiving practices (Kelly and Barnard, 1990; King et al., 1992; Shore, 1997). 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., 1995; Ramey et al., 1998). Bennett and Guralnick (1991) 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., 1992).

- 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 (3.3%) was nearly one and a half times the rate for children of married mothers (2.0%). Thirty percent of unmarried mothers (26% of unmarried mothers with enrolled children) were younger than 20 years of age at the time of the child's birth.

Education

Maternal education is one of the variables most often cited as having a predictive value for poor developmental outcome (King et al., 1992; Ramey et al., 1998).

- Children of parents who completed 8 – 11 years of school had a higher enrollment rate (3.4% and 2.8%, for mothers and fathers) than those whose parents graduated from high school and had no further education (2.3%).
- Enrollment rates decrease further for parents with additional education. The enrollment rate for children of parents who were college graduates (1.6%) was substantially less than the rate for children of parents who completed 8 – 11 years of school (3.4% and 2.8%, 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, exposure to toxic environments, homelessness, and exposure to violent situations (Children’s Defense Fund, 1994). A total of 13.5 million children, or one out of every five, are living in poverty in the United States, with many of these living in extreme poverty (Children’s Defense Fund, 2000).

Maternal Medicaid Eligibility

- The enrollment rate for children of Non-Medicaid women (1.6%) 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 (3.9%) and pre-FS Medicaid Only (3.4%), had higher enrollment rates than all Washington children.

Maternal Demographic Characteristics

	Enrolled Children (N = 3,793) (100 %)		All Washington Births (N = 163,129) (100 %)		Enrollment Rate (2.3%)
Race/Ethnicity					
White	2,703	73.9%	118,529	75.7%	2.3%
Hispanic	493	13.5%	17,721	11.3%	2.8%
Asian/Pacific Islander	151	4.1%	10,571	6.7%	1.4%
African American	146	4.0%	6,244	4.0%	2.3%
Native American	165	4.5%	3,581	2.3%	4.6%
Other/Not Stated	135		6,483		2.1%
Age					
< 15 Years Old	13	0.3%	251	0.2%	5.2%
15 - 19 Years Old	459	12.1%	17,441	10.7%	2.6%
20 - 29 Years Old	1,977	52.1%	85,429	52.4%	2.3%
30 - 39 Years Old	1,222	32.2%	56,121	34.4%	2.2%
40 + Years Old	120	3.2%	3,819	2.3%	3.1%
Not Stated	2		68		2.9%
Marital Status					
Married	2,328	61.6%	118,357	72.7%	2.0%
Single	1,453	38.4%	44,398	27.3%	3.3%
Not Stated	12		374		3.2%
Educational Attainment					
< 8 years	178	5.4%	5,585	3.8%	3.2%
8 - 11 years	702	21.2%	20,755	14.2%	3.4%
12 years	1,068	32.2%	46,112	31.6%	2.3%
13 - 15 years	805	24.3%	38,829	26.6%	2.1%
16+ years	564	17.0%	34,811	23.8%	1.6%
Not Stated	476		17,037		2.8%
Number of Prior Births					
None	1,351	37.1%	65,472	41.4%	2.1%
1 Child	1,136	31.2%	51,698	32.7%	2.2%
2 Children	604	16.6%	24,367	15.4%	2.5%
3 - 5 Children	503	13.8%	14,930	9.4%	3.4%
6 + Children	48	1.3%	1,601	1.0%	3.0%
Not Stated	151		5,061		3.0%
Medicaid Eligibility *					
Grant Recipient	893	23.5%	22,973	14.1%	3.9%
Pre-First Steps Medicaid Only	913	24.1%	27,172	16.7%	3.4%
First Steps Expansion	451	11.9%	17,734	10.9%	2.5%
Served, No Elig. Record	1	0.0%	25	0.0%	4.0%
Non-Medicaid	1,535	40.5%	95,225	58.4%	1.6%

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.

Paternal Demographic Characteristics

	Enrolled Children (N = 3,793)		All Washington Births (N = 163,129)		Enrollment Rate (2.3%)
Race/Ethnicity					
White	2,228	71.4%	105,407	73.0%	2.1%
Hispanic	539	17.3%	20,196	14.0%	2.7%
Asian/Pacific Islander	121	3.9%	8,767	6.1%	1.4%
African American	145	4.6%	7,398	5.1%	2.0%
Native American	87	2.8%	2,592	1.8%	3.4%
Not Stated	673		18,769		3.6%
Age					
< 15 Years Old	2	0.1%	72	0.1%	2.8%
15 - 19 Years Old	131	4.3%	4,997	3.5%	2.6%
20 - 29 Years Old	1,362	44.5%	63,729	44.3%	2.1%
30 - 39 Years Old	1,255	41.0%	62,241	43.3%	2.0%
40 + Years Old	313	10.2%	12,708	8.8%	2.5%
Not Stated	730		19,382		3.8%
Educational Attainment					
< 8 years	168	6.4%	5,227	4.1%	3.2%
8 - 11 years	335	12.8%	12,015	9.4%	2.8%
12 years	966	36.9%	42,717	33.4%	2.3%
13 - 15 years	564	21.5%	31,005	24.2%	1.8%
16+ years	587	22.4%	36,904	28.9%	1.6%
Not Stated	1,173		35,261		3.3%

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

CHAPTER 7

SUMMARY

On December 1, 1999, 5,557 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 37% over the last six years. Both state and national rates have increased slowly over time. The Washington State enrollment rate of 2.3% (2.33%) 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 51.2%. This has increased from 3% in 1993. Fifty percent of enrolled children had an Individualized Family Service Plan in place on December 1, 1999. Many children enrolled in early intervention services have special health care needs and may be at risk of developmental delays or disabilities, but are not currently eligible for the Infant Toddler Early Intervention Program.

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 (1.4%). Similarly, the national prevalence rate of reported limitations for children in lower income families (3.2%) 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 (69%) was significantly greater than the proportion of *all* children in Washington who were Medicaid-eligible (47%).

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 (26.8%) and extremely preterm infants (24.6%). (These two groups may demonstrate considerable overlap.) Enrollment rates between 4.7% and 9.6% 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 2.7% to 3.4%) than the rate for all Washington births (2.3%).

Estimated county enrollment rates vary greatly (from 0.8% to 8.6%), with rural counties exhibiting the widest range. Likewise, the estimated proportion of Individualized Family Service Plans (IFSPs) among enrolled children by county ranges from 14.3% to 96.0%, with the highest and lowest proportions occurring primarily in rural counties. The smaller populations in rural counties result in greater statistical variability, since the status of a single child may considerably influence the enrollment or IFSP rate.

Increasing amounts of research and data continue to demonstrate the importance of intervening in the first months and years of life for children with established disabilities or developmental delays and those at risk biologically or environmentally (Guralnick, 1998; Ramey and Ramey, 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).

The analyses and results presented here provide one perspective on the population of children under three with delaying or disabling conditions in Washington State. The issues and data highlighted in this report are offered and made available for informed planning and discussions at the state and local levels among Washington's early intervention programs for infants and toddlers. While the needs of children with developmental delays, disabilities, and special health care needs are great, 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 as children continue to grow and develop throughout their lives.

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APPENDICES

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 use unique definitions of developmental delay which differ slightly from the Washington State Part C definition. The Washington State Part C definition is an example of state criteria used in determining eligibility for 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 State Lead Agency assures that children, birth to three, shall be eligible for early intervention services under the early intervention section of IDEA, if the multidisciplinary team finds any one of the following criteria exists:

1. Developmental Delay: 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 appropriate evaluation tests or procedures, and administered by qualified personnel. In the case of hearing and vision, the criteria listed within hearing impairment and vision impairment applies:
 - a. Cognitive;
 - b. Physical (vision, hearing, fine or gross motor);
 - (1) Hearing Impairment – a hearing impairment which adversely affects a child’s development is:
 - (a) Unilateral sensorineural hearing loss and/or permanent conductive hearing loss of 45 dB or greater;
 - (b) Bilateral sensorineural hearing loss and/or permanent conductive hearing loss which includes:
 - (i) hearing loss of 20dB or greater in the better ear average of the frequencies 500, 1000, and 2000 Hz;
 - (ii) high frequency loss greater than 25 dB at two or more consecutive frequencies or average of three frequencies between 2000 and 6000 Hz in the better ear;
 - (iii) low frequency hearing loss greater than 30 dB at 250 and 500 Hz in the better ear; or
 - (iv) thresholds greater than 25 dB on Auditory Brainstem Response threshold testing in the better ear; or
 - (c) A six-month history of fluctuating conductive hearing loss or chronic middle ear effusion/infection of three months unresolved past initial evaluation.
 - (2) Vision Impairment – Infants and toddlers with visual impairment/blindness are:

- (a) those children who have a visual impairment which adversely affects the child's development even with correction. Eligibility shall be dependent on documentation of a visual impairment including one or more of the following conditions:
 - (i) legal blindness or visual handicap as they are customarily defined, either in terms of qualifying reduction in visual acuity and/or a qualified reduction in visual fields;
 - (ii) a visual impairment which is progressive in nature and can be expected to lead to blindness within a reasonable period of time;
- (b) If a visual acuity or field cannot be determined:
 - (i) the qualified personnel must identify a diagnosis or medical history which indicates a high probability of visual loss that may adversely affect the child's development;
 - (ii) a functional vision evaluation by a qualified professional is necessary to determine eligibility.

- c. Communication;
- d. Social or Emotional; or
- e. Adaptive.

2. Or a diagnosed physical or mental condition

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:

- a. Chromosomal abnormalities associated with mental retardation, such as Down syndrome;
- b. Congenital central nervous system birth defects or syndromes, such as myelomeningocele, fetal alcohol syndrome, or Cornelia de Lange syndrome;
- c. Deaf, blind, or deaf-blind;
- d. Established central nervous system deficits resulting from hypoxia, trauma, or infection;
- e. Cerebral palsy;
- f. Health impairments such as autism, epilepsy, neurological impairments, or other chronic or acute or degenerative health problems;
- g. Orthopedically impaired, which means impairment of the normal functions of muscles, joints, or bones due to congenital anomaly, disease, or permanent injury; and/or
- h. Microcephaly.

Note: Eligible children will also continue to receive the early intervention service based on their eligibility for other existing State programs. These programs include:

- (1) DSHS Division of Developmental Disabilities, WAC 275-27-026(6)(c) and (d);
- (2) DOH Children with Special Health Care Needs, WAC 246-710-020; and

(3) Public Schools, WAC 392-172-114, 116, 122, 124, 138, 140, 142, and 144.

All children, birth to three, including children at risk of developmental delays, are entitled to participate in the following components with the consent of their parent(s): early identification, multidisciplinary evaluation, and determination of eligibility for early intervention services to at risk infants and toddlers.

The early identification section of IDEA funding shall be used in all cases as the payer of last resort and shall be used to assist the State Lead Agency in assuring that all eligible infants and toddlers and their families receive services.

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

For more information please see *Washington State's Individuals with Disabilities Education Act (IDEA) Early Intervention Section Department of Social and Health Services Infant Toddler Early Intervention Program Application for Federal Assistance to Department of Education Office of Special Education Programs Washington, D.C. 20202-4717 (Federal Fiscal Years 1997-1999 Application)*.

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-97” becomes “010197”.) 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.