

Washington's Infant Toddler Early Intervention Program Study

Enrollment of Washington Children with Disabilities
and Special Health Care Needs
in Washington State Public Programs
on December 2, 1996

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ACRONYMS

CCDB	Common Client Database
CFH	Community 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
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

EXECUTIVE SUMMARY

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

This report presents information on infants and toddlers, birth to three with delaying or disabling conditions who were enrolled in Washington State public services on December 2, 1996. 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

- In Washington State, 4,472 infants and toddlers under three years of age were found to be enrolled in public early intervention services for delaying or disabling conditions as of December 2, 1996.
- The rate of enrollment in services in Washington (1.9%) was somewhat lower than the rate found in the National Health Interview Survey (NHIS) for children with limitations in some daily activity (2.2%).
- The proportion of enrolled children in Washington who were Medicaid eligible with family incomes at or below 200% of the Federal Poverty Level (FPL) (74%) was greater than the proportion of NHIS children with reported limitations who are at or below 200% of the FPL (63%).
- The enrollment rate for children of mothers with no prenatal care (5.4%) was over three times higher than that for children of mothers who received first trimester prenatal care (1.7%).
- Characteristics of infants at birth that were associated with high enrollment rates include low birthweight (9%), preterm birth (5.1%), and Apgar score less than 8 (8.3%). Male children had a higher enrollment rate than female children (2.2% versus 1.6%).
- Among children who were Medicaid eligible with diagnosed medical conditions, enrollment rates were highest for those with Down Syndrome (85.1%) and cerebral palsy (84.8%). High rates were also evident among children with cleft lip and/or palate (55.2%), other developmental disorders or delays (31.7%), developmental speech and language disorder (26.7%), congenital and chromosomal anomalies other than Down Syndrome and cleft lip and/or palate (25.7%), and hearing loss and congenital anomalies of the ear, face, and neck (22.8%).
- Children of mothers with diagnosed substance abuse had an enrollment rate over two and one half times that for all other Medicaid children in Washington (7.9% versus 2.7%).

CHAPTER 1

INTRODUCTION

This report presents information on infants and toddlers, birth to three, with delaying or disabling conditions who were enrolled in Washington State public services on December 2, 1996. The following measures are examined in this report: unduplicated enrollment count, state enrollment rates and patterns versus national prevalence rates and patterns, county enrollment rates versus state enrollment rates, and the relationship of risk factors to the enrollment of children in early intervention programs.

The analyses and results presented in this report provide baseline data for planning and implementing services, for discussion at the state and local levels, and to facilitate decision making and priority setting for Washington's early intervention programs for infants and toddlers with delaying or disabling conditions.

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

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, 1990; Chugani et al., 1987). This is a period of great potential, for it is sensory experience that 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, 1986; Shonkoff and Hauser-Cram, 1987), preschoolers *environmentally at-risk* (Casto and White, 1984; Lazar and Darlington, 1982; Ramey and Campbell, 1992; 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; Rauh et al., 1988; Scarr-Salapatek and Williams, 1973).

Policy makers at the federal level, recognizing the importance of early referral and intervention for infants and toddlers under the age of three, passed the 1986 amendments to the Individuals with Disabilities Education Act (IDEA), establishing Part H of IDEA. The Infant Toddler Early Intervention Program (ITEIP) administers the Part H program in Washington State.

In Washington State, public early intervention services for infants and toddlers birth to three with delaying or disabling conditions were provided by school districts, neuro-developmental centers, developmental centers, tribal programs, and other local and state

agencies. The IDEA, Part H 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 H. 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, risk factors, and medical diagnoses. National prevalence estimates for disabilities among children under three were generated using data from the National Health Interview Survey.

DATA SOURCES

Provider Surveys

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 2, 1996. 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; i.e., an Individualized Education Plan (IEP), an Individualized Service Plan (ISP), or an Individualized Family Service Plan (IFSP).

These surveys were mailed to 37 child development programs, 5 neurodevelopmental centers, 9 combined child development programs and neurodevelopmental centers, 33 Infant Toddler Early Intervention Program contractors, of which 10 were also child development programs and/or neurodevelopmental centers, and 296 school districts, of which 119 reported they were providing services either directly or through a contract with another provider. An additional 61 school districts reported that no children were identified as eligible at this time, but that if children were identified, they would be served by the school district either directly or through a contract. Completed surveys were received from 100% of all service providers contacted. The types of service providers are listed in the table on page 4.

Agency Databases

The DDD/DSHS Common Client Data Base (CCDB) provided a list of clients known to DDD who were under the age of three as of December 2, 1996. The County Human Resource Information System (CHRIS) provided information about the disability-related service(s) in which these individuals were enrolled.

The DOH Community Family Health (CFH) database included data from the Child Health Intake Form (CHIF) and the providers' Health Services Authorization Form (Children with Special Health Care Needs (CSHCN)) for children under three years old who were enrolled in at least one disability-related CFH/DOH service as of December 2, 1996.

Service Providers

Existing public services are provided and/or funded through 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 the Superintendent of Public Instruction (OSPI) Special Education (SE).

ITEIP (DSHS) is responsible for the coordination of 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 H. Program implementation occurs through local contracts with a variety of local contractors and a state interagency agreement. Specific contractors are determined in coordination with County Interagency Coordinating Councils, Indian Tribes, and the Washington Migrant Council.

FRCs are professional and paraprofessional community workers trained by ITEIP and employed by provider agencies or parent advocacy organizations through contracts with the state. 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 2, 1996, count, 119 school districts reported they were providing services to children with disabilities ages birth to three, either directly or by contract with a child developmental center (DDD) or neurodevelopmental center (DOH).

Additionally, birth-to-three early intervention services are available through private service providers (pediatricians or therapists) and are funded by private organizations, private insurance, DSHS Medical Assistance programs, other DSHS programs (e.g., Mental Health and Children and Family Services), Tribal authorities, the military and non-profit service organizations such as the Elks, Shriners, United Way, and others.

UNDUPLICATION AND MATCH

A single child may need services from more than one provider and may be reported on multiple submissions. Survey and database records were therefore unduplicated to obtain a count of enrolled children with only one entry per child. After unduplication, enrollment records were matched to the First Steps Database using reported information including name, date of birth, gender, and family residence zip code.

The First Steps Database (FSDB) is a single repository for information taken from birth certificates, infant death certificates, Medicaid claim 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 demographic characteristics for all births to Washington State residents. 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 RDA. It is currently updated to include births from mid-1988 (a year prior to the implementation of First Steps) through 1995.

NATIONAL PREVALENCE RATES

National comparisons are based on child limitations as reported by respondents in the National Health Interview Survey (NHIS), 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

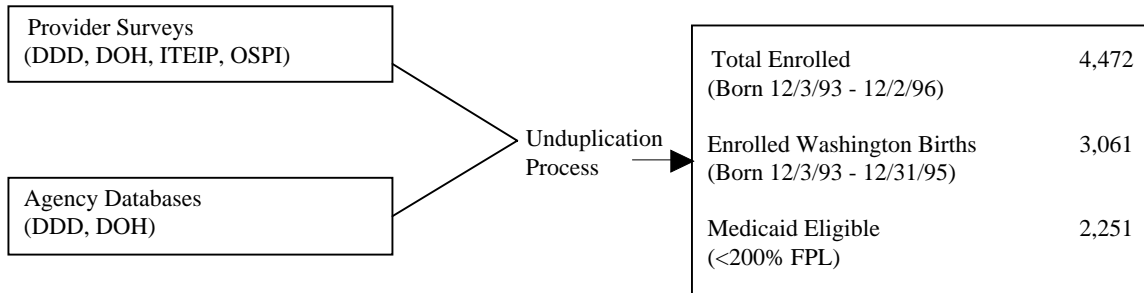
Enrolled Children. This group contains all children from age birth to three identified in the December 2, 1996, count as being enrolled in early intervention services. A total of 4,472 children were identified.

Enrolled Washington Births. This group contains the 3,061 enrolled children whose mothers were residents of Washington at the time of the child's birth. These children were matched with the First Steps Database. Since birth certificate information is available only through 1995, children born in 1996 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 3,584 enrolled children born before 1996, 85% were matched with the FSDB.

Enrolled Medicaid Eligible. This group contains only those 2,251 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 DDD/DSHS, ITEIP/DSHS, DOH, and OSPI. Being enrolled does not imply that the child is receiving any or all of the services needed; children may be in various stages of the programs such as screening, evaluation and/or assessment, or determination of eligibility related to a particular service or set of services from local or non-local providers.

This count of children enrolled in public early intervention programs was limited to all children enrolled as of December 2, 1996. Because this count is based on a single point in time, some children who had received and completed services prior to December 2, 1996 were not included; nor were those who enrolled after December 2, 1996.

These numbers do not include all children under three years of age experiencing disabilities and special health care needs in Washington. They reflect only those children and families needing, requesting, and found eligible for services provided through DDD/DSHS, ITEIP/DSHS, DOH, and OSPI. These numbers do not include those who may have been potentially 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 delaying or disabling conditions in public law and program policies. National comparison values used in this report are for 1992 through 1994 (the most recent year for which NHIS data are available).

CHAPTER 3

WASHINGTON STATE UNDUPLICATED COUNT

This chapter presents the Washington State unduplicated count of infants and toddlers under the age of three with delaying or disabling conditions who were enrolled on December 2, 1996 in early intervention services through ITEIP/DSHS, or in early intervention, education, or health services provided through DDD/DSHS, DOH, or OSPI.

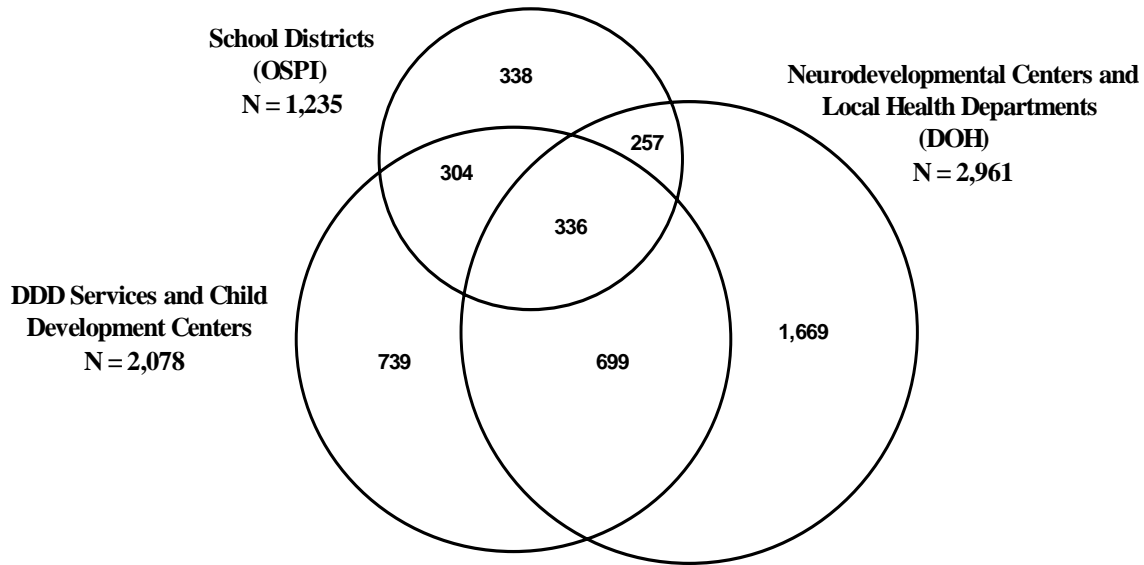
**Washington State Children under Three
Enrolled in Public Early Intervention Services
December 2, 1996**

Children Enrolled in Early Intervention Services	4,472
Washington State Population under Three	234,894
Washington State Enrollment Rate	1.9%

A total of 4,472 individual children, 1.9% of the Washington State population under three, were reported enrolled in public early intervention services on December 2, 1996. These children represent a range of complexity of needs and severity of disabling conditions 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 diagram and table on the following page portray the distribution of enrolled children by service provider.

DISTRIBUTION OF ENROLLED CHILDREN BY SERVICE PROVIDER



	<u>Number of Children</u>	<u>Percent of Total</u>
Children enrolled with one provider:		
DDD Only	739	16.5%
DOH Only	1,669	37.3%
OSPI Only	338	7.6%
Children enrolled with two providers:		
DDD and DOH, not OSPI	699	15.6%
DDD and OSPI, not DOH	304	6.8%
DOH and OSPI, not DDD	257	5.7%
Children enrolled with all three providers: DDD, DOH, and OSPI	336	7.5%
Additional children reported by:		
ITEIP only*	128	2.9%
Other Provider, with IFSPs	2	0.0%
Total Children Reported	4,472	100.0%

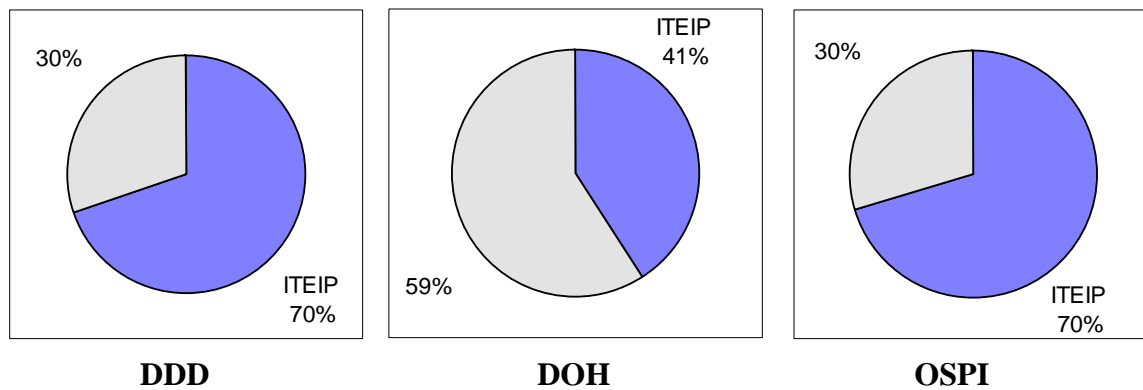
* A total of 2086 children (46.6%) were reported to be receiving one service or more through ITEIP. Distribution of these children by service provider is detailed on the following page.

- A total of 2,195 children (49%) were reported to have an IFSP (Individualized Family Service Plan) in place at the time of the Count.

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

The Infant Toddler Early Intervention Program (ITEIP), the IDEA Part H 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



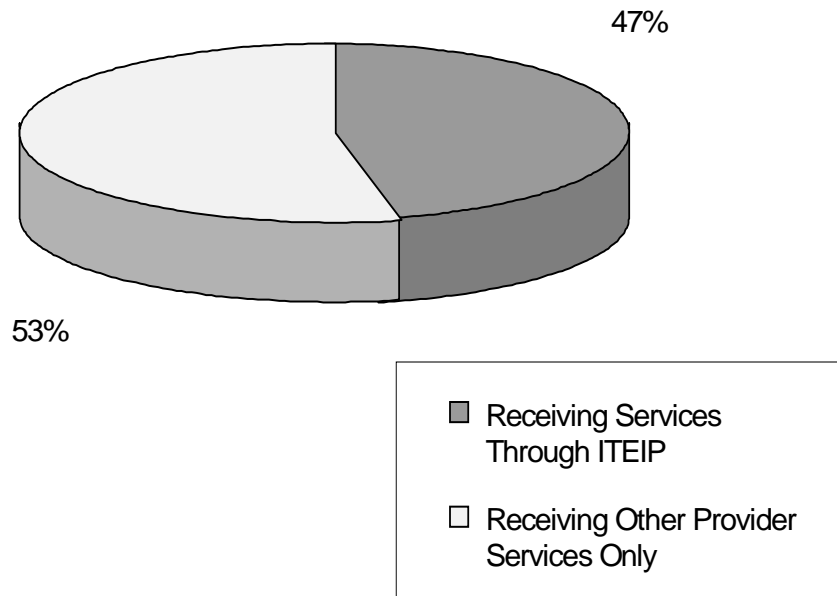
- Seventy percent of those children reported enrolled in DDD programs were reported to be receiving one service or more through ITEIP.
- Forty-one percent of those children reported enrolled in DOH programs were reported to be receiving one service or more through ITEIP.
- Seventy percent of those children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

		Number of Children	Percent of Total
Children enrolled with ITEIP only:	ITEIP Only	128	2.9%
Children enrolled with ITEIP and one other provider:	ITEIP and DDD	385	8.6%
	ITEIP and DOH	167	3.7%
	ITEIP and OSPI	140	3.1%
Children enrolled with ITEIP and two other providers:	ITEIP, DDD, and DOH	539	12.1%
	ITEIP, DDD, and OSPI	223	5.0%
	ITEIP, DOH, and OSPI	202	4.5%
Children enrolled with all four providers: ITEIP, DDD, DOH, and OSPI		302	6.8%

Total children reported to be receiving services through ITEIP: 2086 46.6%

Washington State began full implementation of Part H in October 1994. The proportion of the unduplicated count receiving services through ITEIP rose from 3% in December 1993 to 47% in December 1996. This rising trend is expected to continue. The chart below depicts the proportion of the December 2, 1996 unduplicated count that is receiving one or more services through ITEIP.

**RECEIPT OF SERVICES THROUGH ITEIP
December 2, 1996**



- Among the 4,472 children reported to be enrolled in public early intervention services, 2,086 (47%) were reported to be receiving services funded by IDEA, Part H, coordinated and administered through ITEIP.

Note: Not all children reported as having IFSPs (2,195 children) were reported to be receiving services funded through ITEIP (2,086 children). 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 presents a comparison of 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 that has delaying or disabling conditions. In this report, national prevalence rates are estimated using information from the 1992 through 1994 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 NHIS reported to have limitations in major or minor activities. These limitations may only partially correspond to defined delaying or disabling conditions 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	1.9%
National Prevalence Rate	2.2%
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.*

- The 4,472 children enrolled in Washington State constitute an enrollment rate of 1.9%. This rate is slightly higher than the state enrollment rates in previous years, but still below the estimated national prevalence rate of 2.2% (2.1% when adjusted for Washington's poverty profile). Slight increases over time are also evident in the national prevalence rates.

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 which are the source of NHIS information. 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 (FSDB) for all children born to Washington mothers between July 1988 and December 1995.

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

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

Enrolled Children	4,472
Enrolled Washington Births	3,061
Total Washington Births	159,792
Enrollment Rate	1.9%

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, please see Enrolled Washington Births, p. 5.

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*

	Number	Rate
0 – 1 Years Old		
Washington State	994	1.3%
National Prevalence	167,920 (est.)	1.4%
1 – 2 Years Old		
Washington State	1,468	1.9%
National Prevalence	272,134 (est.)	2.3%
2 – 3 Years Old		
Washington State	2,010	2.5%
National Prevalence	365,978 (est.)	3.0%

*Population estimates for Washington are for April 1, 1996 (Source: OFM). National figures are estimated from a stratified sample of households surveyed in the 1992-1994 NHIS.

- As children become older, developmental delays may increase or become more evident. Enrollment rates are therefore higher for older children. The current enrollment rate for children 2 – 3 years old (2.5%) is equivalent to the estimated prevalence rate used by ITEIP for planning purposes.

DISTRIBUTION OF CHILDREN BY FAMILY INCOME

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

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

	Enrolled Washington Births (N = 3061)	All Washington Births (N=159,792)		Children Under Three with Limitations	All Children Under Three
Medicaid Eligible	74%	46%	At or Below 200% FPL	63%	47%
Not Medicaid Eligible	26%	54%	Above 200% FPL	37%	53%

*Data are from the 1992-1994 NHIS

- Medicaid eligibility was much higher among *enrolled* children born in Washington (74%) than among *all* children in Washington State (46%). Similarly, more NHIS children under three *with reported limitations* had family incomes at or below 200% of the federal poverty level (63%) than did *all* children under three (47%).

DISTRIBUTION OF CHILDREN BY MOTHER'S RACE/ETHNICITY

Race/Ethnicity Among All Children And Enrolled Children Under Three Born to Washington Mothers

Race/Ethnicity Among All Children and Children with Reported Limitations Under Three in the NHIS*

Mother's Race / Ethnicity	Enrolled Children (N = 3061)	All Washington Births (N = 159,792)	Children with Reported Limitations	All Children
White (Non-Hispanic)	71.2%	75.0%	54.6%	62.3%
Hispanic	11.4%	9.8%	15.1%	15.5%
Asian/Pacific Islander	3.8%	6.2%	2.9%	5.1%
African American	5.2%	3.8%	25.9%	15.9%
Native American	4.9%	2.1%	1.4%	1.0%
Other/Unknown	3.5%	3.1%	0.0%	0.1%
Total	100%	100%	100%	100%

**Data are from the 1992-1994 NHIS.*

- The proportion of White children (71.2%) was similar, though slightly lower, among enrolled children compared to all children born in Washington State (75%).
- The proportion of Asian/Pacific Islander children (3.8%) was lower among enrolled children compared to all children born in Washington State (6.2%).
- The proportion of African American, Hispanic, and Native American children (5.2%, 11.4%, and 4.9%, respectively) was higher among enrolled children compared to all children born in Washington State (3.8%, 9.8%, and 2.1%).
- The national pattern of limitations by race/ethnicity is similar to the state enrollment pattern by race/ethnicity, with the exception of the Hispanic 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 Mothers
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 (Non-Hispanic)	1,488	47,353	3.1%	2.9%
Hispanic	325	13,582	2.4%	2.1%
Asian/Pacific Islander	79	4,369	1.8%	2.0%
African American	141	4,114	3.4%	4.2%
Native American	139	2,674	5.2%	3.4%
Other/Unknown	79	1,939	4.1%	0.0%
Total	2,251	74,031	3.0%	3.0%

**Data are from the 1992-1994 NHIS*

For Medicaid Eligible Children and those with Incomes at or below 200% FPL:

- Enrollment rates for White and Asian/Pacific Islander children (3.1% and 1.8%, respectively) were similar to the national prevalence rates for these ethnic groups (2.9% and 2.0%, respectively).
- The enrollment rate for Hispanic children (2.4%) was slightly higher than the national prevalence rate (2.1%).
- The enrollment rate for African American children (3.4%) was lower than the national prevalence rate (4.2%).
- The enrollment rate for Native American children (5.2%) was substantially higher than the national prevalence rate (3.4%).

**Enrollment Rates by Mother's Race/Ethnicity
 Non-Medicaid Eligible Children Under Three Born to Washington Mothers
 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)	692	72,510	1.0%	1.4%
Hispanic	23	2,153	1.1%	2.3%
Asian/Pacific Islander	37	5,460	0.7%	2.6%
African American	19	1,941	1.0%	2.0%
Native American	10	713	1.4%	0.0%
Other/Unknown	29	2,984	1.0%	0.0%
Total	810	85,761	0.9%	1.6%

**Data are from the 1992-1994 NHIS*

- Among Non-Medicaid Eligible Washington children and NHIS children with family incomes above 200% FPL, Washington State enrollment rates were lower than the national prevalence rates, with the exception of Native American children.
- The enrollment rates for Medicaid-Eligible children were greater than the enrollment rates for Non-Medicaid Eligible children. Similarly, the national prevalence rate of reported limitations for children in lower income families was greater than the rate for children with family incomes above 200% FPL.

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 39 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 FSDB, analysis of enrollment by county was limited to children born in 1995 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 mothers and for Medicaid eligible children born to Washington mothers. 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 40% (40,469÷101,609) of children born in metropolitan counties are Medicaid eligible, while 55% (21,606÷39,119) of children from small urban and 63% (11,955÷19,060) 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 2, 1996, by County of Residence
All Children and Medicaid Eligible Children
Born to Washington Mothers December 3, 1993, to December 31, 1995**

County	Medicaid				All Births			
	Enrolled Births	WA Births	Enroll. Rate	Index	Enrolled Births	WA Births	Enroll. Rate	Index
Clark	74	3,737	2.0%	0.65	130	9,240	1.4%	0.73
King	495	16,800	2.9%	0.97	696	45,308	1.5%	0.80
Pierce	234	8,483	2.8%	0.91	335	19,842	1.7%	0.88
Snohomish	180	5,878	3.1%	1.01	292	15,981	1.8%	0.95
Spokane	213	5,571	3.8%	1.26	291	11,238	2.6%	1.35
Metro Total	1,196	40,469	3.0%	0.97	1,744	101,609	1.7%	0.90
Benton	52	1,898	2.7%	0.90	72	4,084	1.8%	0.92
Cowlitz	61	1,393	4.4%	1.44	69	2,458	2.8%	1.47
Franklin	64	1,542	4.2%	1.37	72	2,090	3.4%	1.80
Kitsap	85	2,362	3.6%	1.18	134	6,827	2.0%	1.02
Lewis	44	1,189	3.7%	1.22	52	1,832	2.8%	1.48
Skagit	41	1,461	2.8%	0.92	54	2,687	2.0%	1.05
Thurston	62	2,186	2.8%	0.93	87	5,022	1.7%	0.90
Walla Walla	39	940	4.1%	1.36	46	1,437	3.2%	1.67
Whatcom	78	1,849	4.2%	1.39	107	3,872	2.8%	1.44
Yakima	166	6,786	2.4%	0.80	181	8,810	2.1%	1.07
S.U. Total	692	21,606	3.2%	1.05	874	39,119	2.2%	1.17
Adams	12	478	2.5%	0.83	12	617	1.9%	1.02
Asotin	15	330	4.5%	1.49	16	513	3.1%	1.63
Chelan	40	1,417	2.8%	0.93	43	2,027	2.1%	1.11
Clallam	27	852	3.2%	1.04	31	1,310	2.4%	1.24
Columbia	3	55	5.5%	1.79	3	93	3.2%	1.68
Douglas	19	614	3.1%	1.02	21	929	2.3%	1.18
Ferry	0	133	0.0%	0.00	2	178	1.1%	0.59
Garfield	0	27	0.0%	0.00	1	39	2.6%	1.34
Grant	53	1,806	2.9%	0.97	63	2,562	2.5%	1.28
Grays Harbor	46	1,219	3.8%	1.24	56	1,760	3.2%	1.66
Island	19	631	3.0%	0.99	33	2,037	1.6%	0.85
Jefferson	12	295	4.1%	1.34	16	442	3.6%	1.89
Kittitas	3	345	0.9%	0.29	6	636	0.9%	0.49
Klickitat	2	320	0.6%	0.21	6	467	1.3%	0.67
Lincoln	3	87	3.4%	1.13	4	215	1.9%	0.97
Mason	24	663	3.6%	1.19	34	1,102	3.1%	1.61
Okanogan	29	951	3.0%	1.00	32	1,166	2.7%	1.43
Pacific	11	303	3.6%	1.19	11	456	2.4%	1.26
Pend Oreille	8	208	3.8%	1.26	9	288	3.1%	1.63
San Juan	3	116	2.6%	0.85	5	214	2.3%	1.22
Skamania	3	96	3.1%	1.03	3	171	1.8%	0.92
Stevens	18	576	3.1%	1.03	24	882	2.7%	1.42
Wahkiakum	2	46	4.3%	1.43	2	80	2.5%	1.31
Whitman	9	387	2.3%	0.76	10	876	1.1%	0.60
Rural Total	363	11,955	3.0%	1.00	443	19,060	2.3%	1.21
State Total*	2,251	74,031	3.0%	1.00	3,061	159,792	1.9%	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.

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 delaying or disabling conditions in public early intervention programs. Information in this chapter is for *Enrolled Washington Births* (enrolled children with Washington State birth certificates prior to 1996). 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, 1995). The following tables present analyses which 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 (*Healthy People 2000*, 1991).

- The enrollment rate for very low birthweight infants (21.2%) was over fourteen times higher than that for normal birthweight (singleton) infants (1.5%).
- The enrollment rates for medium low birthweight infants (6.8%) and infants from multiple gestations (6.4%) were more than four times higher than the enrollment rate for normal birthweight (singleton) children (1.5%).
- Low birthweight infants (very low and medium low birthweight combined) had an enrollment rate (9.0%) six times higher than that for normal birthweight (singleton) infants (1.5%).

Infant Characteristics at Birth

Risk Factor	Enrolled Children		All Washington Births		Enrollment Rate (1.9%)
	(N = 3,061)	(100 %)	(N = 159,792)	(100 %)	
Birthweight					
Very Low (< 3.3 lbs)	218	7.1%	1,028	0.6%	21.2%
Medium Low (3.3 - 5.5 lbs)	390	12.7%	5,736	3.6%	6.8%
Normal (> 5.5 lbs)	2,202	71.9%	149,021	93.3%	1.5%
Mult. Gestation (Twins, etc.)	239	7.8%	3,733	2.3%	6.4%
Unknown Birthweight	12	0.4%	274	0.2%	4.4%
Gestational Age at Birth					
Extreme Preterm (< 28 wks)	122	4.0%	608	0.4%	20.1%
Mod. Preterm (28 - 36 wks)	874	28.6%	18,907	11.8%	4.6%
Full Term (37+ wks)	2,033	66.4%	138,724	86.8%	1.5%
Unknown	32	1.0%	1,553	1.0%	2.1%
Apgar Score					
less than 8	411	13.4%	4,970	3.1%	8.3%
8	502	16.4%	14,216	8.9%	3.5%
9	1,952	63.8%	127,347	79.7%	1.5%
10	161	5.3%	12,567	7.9%	1.3%
Unknown	35	1.1%	692	0.4%	5.1%
Gender					
Female	1,267	41.4%	78,298	49.0%	1.6%
Male	1,794	58.6%	81,493	51.0%	2.2%
Unknown	0	0.0%	1	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 (5.1%) over three times that for full term infants (1.5%).
- The enrollment rate for extremely preterm infants (20.1%) was over thirteen times higher than that for full term infants (1.5%)

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 this poor cognitive performance (Breitmayer and Ramey, 1986).

- The enrollment rate for children with an Apgar score of less than 8 (8.3%) was almost five times higher than that for children with an Apgar score of 8 or more (1.7%).

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 (2.2%) than females (1.6%).

Prenatal Care and Maternal Behaviors

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

Prenatal Care and Smoking Status

Risk Factor	Enrolled Children		All Washington Births		Enrollment Rate (1.9%)
	(N = 3,061)	(100 %)	(N = 159,792)	(100 %)	
Trimester Prenatal Care Began					
No Prenatal Care	67	2.2%	1,245	0.8%	5.4%
1st Trimester	2,122	69.3%	123,656	77.4%	1.7%
2nd Trimester	514	16.8%	20,932	13.1%	2.5%
3rd Trimester	97	3.2%	3,831	2.4%	2.5%
Unknown	261	8.5%	10,128	6.3%	2.6%
Adequacy of Prenatal Care					
Adequate Plus	1,036	33.8%	46,483	29.1%	2.2%
Adequate	821	26.8%	57,898	36.2%	1.4%
Intermediate	450	14.7%	30,423	19.0%	1.5%
Inadequate	140	4.6%	5,722	3.6%	2.4%
Unknown	614	20.1%	19,266	12.1%	3.2%
Mother Smoked During Pregnancy					
Yes	804	26.3%	25,773	16.1%	3.1%
No	2,160	70.6%	130,066	81.4%	1.7%
Unknown	97	3.2%	3,953	2.5%	2.5%

Prenatal Care

Prenatal care is measured in terms of both timing (the trimester in which prenatal care began) and adequacy (the frequency of prenatal care visits). This report uses Kotelchuck's Adequacy of Received Services Index (Kotelchuck, 1994), which compares the frequency of prenatal visits to recommendations by the American College of Obstetricians and Gynecologists, as a measure of the adequacy of prenatal care. Prenatal care is considered inadequate if the mother has fewer than 50% of the recommended number of prenatal care visits during the period between the first visit and delivery.

- The enrollment rate for children of mothers who did not receive prenatal care (5.4%) was over three times higher than that for children of mothers who received prenatal care in the first trimester (1.7%).
- The enrollment rate for children of mothers with inadequate prenatal care (2.4%) was nearly twice that for children of mothers who received adequate prenatal care (1.4%). (Note: adequate plus prenatal care had a high enrollment rate (2.2%), as relatively high risk pregnancies (e.g., multiple gestation, premature birth) tend to receive a greater amount of care.)

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 (3.1%) was nearly twice that for children born to nonsmoking women (1.7%).

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% FPL, which is a subgroup of the children equal to or less than 200% FPL.

Diagnosed Maternal Substance Abuse among Medicaid Served Women

Risk Factor	Enrolled Children		All Medicaid Births		Enrollment Rate (3.0%)
	(N = 1,949)	(100%)	(N = 64,686)	(100%)	
Diagnosed Substance Abuse					
<i>Alcohol Only</i>	7	0.4%	78	0.1%	9.0%
<i>Drugs Only</i>	100	5.1%	1,375	2.1%	7.3%
<i>Both Alcohol and Drugs</i>	176	9.0%	2,122	3.3%	8.3%
Any Substance Abuse	283	14.5%	3,575	5.5%	7.9%
No Substance Abuse	1,666	85.5%	61,111	94.5%	2.7%

- For Medicaid served mothers, the enrollment rate for children born to women with any diagnosed substance abuse (7.9%) was almost three times higher than that for children born to women without diagnosed substance abuse (2.7%).

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, 1994), maternal education, maternal age, and caregiving practices (King et al., 1992). 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). 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 maternal age, marital status, maternal education, number of prior births, income status, and race/ethnicity by income status.

Maternal 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 (6.0%) more than three times that of all children born in Washington (1.9%).

Marital Status

- The enrollment rate for children of unmarried mothers (3.0%) was twice the rate for children of married mothers (1.5%).

Maternal Education

Maternal education is one of the variables most often cited as having a predictive value for poor developmental outcome (Bee et al., 1982; King et al., 1992; Kochanek et al., 1987; Ramey et al., 1978).

- Children of mothers who completed 8 – 11 years of school had a higher enrollment rate (3.2%) than those whose mothers graduated from high school and had no further education (2.0%).
- The enrollment rate for children of mothers who completed 8 – 11 years of school (3.2%) was nearly three times the rate for children of mothers who were college graduates (1.1%).

Maternal Demographic Characteristics

Risk Factor	Enrolled Children		All Washington Births		Enrollment Rate (1.9%)
	(N = 3,061)	(100 %)	(N = 159,792)	(100 %)	
Age					
< 15 Years Old	20	0.7%	333	0.2%	6.0%
15 - 19 Years Old	436	14.2%	17,596	11.0%	2.5%
20 - 29 Years Old	1,605	52.4%	83,955	52.5%	1.9%
30 - 39 Years Old	915	29.9%	54,413	34.1%	1.7%
40 + Years Old	81	2.6%	3,337	2.1%	2.4%
Unknown	4	0.1%	158	0.1%	2.5%
Marital Status					
Married	1,819	59.4%	117,874	73.8%	1.5%
Single	1,234	40.3%	41,604	26.0%	3.0%
Unknown	8	0.3%	314	0.2%	2.5%
Educational Attainment					
< 8 years	157	5.1%	5,880	3.7%	2.7%
8 - 11 years	666	21.8%	20,902	13.1%	3.2%
12 years	930	30.4%	47,597	29.8%	2.0%
13 - 15 years	618	20.2%	37,959	23.8%	1.6%
16+ years	342	11.2%	32,087	20.1%	1.1%
Unknown	348	11.4%	15,367	9.6%	2.3%
Number of Prior Births					
None	1,074	35.1%	65,293	40.9%	1.6%
1 Child	912	29.8%	49,969	31.3%	1.8%
2 Children	509	16.6%	23,711	14.8%	2.1%
3 - 5 Children	416	13.6%	14,616	9.1%	2.8%
6 + Children	42	1.4%	1,503	0.9%	2.8%
Unknown	108	3.5%	4,700	2.9%	2.3%
Medicaid Eligibility *					
Grant Recipient	908	29.7%	25,389	15.9%	3.6%
Pre-First Steps Medicaid Only	547	17.9%	18,241	11.4%	3.0%
First Steps Expansion	482	15.7%	20,781	13.0%	2.3%
Served, No Elig. Record	12	0.4%	275	0.2%	4.4%
Non-Medicaid	1,112	36.3%	95,106	59.5%	1.2%

* 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.

Number of Prior Births

- The enrollment rate for children of mothers with three or more prior births (2.8%) was higher than that for children of mothers with no prior births (1.6%).

Income Status

Poverty is considered a risk factor for learning disabilities and developmental disabilities in children and youth (Children’s Defense Fund, 1994). 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 (Children’s Defense Fund, 1994). Other risks associated with living in poverty are homelessness and exposure to violent situations (Children’s Defense Fund, 1994).

Maternal Medicaid Eligibility

- The enrollment rate for children of Non-Medicaid women (1.2%) was substantially lower than that for all children born in Washington (1.9%). Children of Medicaid women in the lowest income eligibility groups, grant recipients (3.6%) and pre-FS Medicaid Only (3.0%), had higher enrollment rates than all Washington children.

Race/Ethnicity and Income Level

Poverty and ethnic/racial group membership are linked determinants of health status. A conceptual change has recently occurred in health promotion from a minority population focus to a poverty focus (Kerner et al., 1993). The first table below depicts enrollment rates with a focus on race/ethnicity only. The two tables on the following page depict enrollment rates by race/ethnicity stratified by income level.

Race/Ethnicity for all Washington Births

Risk Factor	Enrolled Children		All Washington Births		Enrollment Rate (1.9%)
	(N = 3,061)	(100 %)	(N = 159,792)	(100 %)	
Race/Ethnicity					
White (Non-Hispanic)	2,180	71.2%	119,863	75.0%	1.8%
Hispanic	348	11.4%	15,735	9.8%	2.2%
Asian/Pacific Islander	116	3.8%	9,829	6.2%	1.2%
African American	160	5.2%	6,055	3.8%	2.6%
Native American	149	4.9%	3,387	2.1%	4.4%
Other/Unknown	108	3.5%	4,923	3.1%	2.2%

Race/Ethnicity for Medicaid Births (\leq 200% FPL)

Risk Factor	Enrolled Children		All Washington Births		Enrollment Rate (3.0%)
	(N = 2,251)	(100 %)	(N = 74,031)	(100 %)	
Race/Ethnicity					
White (Non-Hispanic)	1,488	66.1%	47,353	64.0%	3.1%
Hispanic	325	14.4%	13,582	18.3%	2.4%
Asian/Pacific Islander	79	3.5%	4,369	5.9%	1.8%
African American	141	6.3%	4,114	5.6%	3.4%
Native American	139	6.2%	2,674	3.6%	5.2%
Other/Unknown	79	3.5%	1,939	2.6%	4.1%

Race/Ethnicity for Non-Medicaid Births ($>$ 200% FPL)

Risk Factor	Enrolled Children		All Washington Births		Enrollment Rate (0.9%)
	(N = 810)	(100 %)	(N = 85,761)	(100 %)	
Race/Ethnicity					
White (Non-Hispanic)	692	85.4%	72,510	84.5%	1.0%
Hispanic	23	2.8%	2,153	2.5%	1.1%
Asian/Pacific Islander	37	4.6%	5,460	6.4%	0.7%
African American	19	2.3%	1,941	2.3%	1.0%
Native American	10	1.2%	713	0.8%	1.4%
Other/Unknown	29	3.6%	2,984	3.5%	1.0%

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 rate for all Washington births is 1.9% with a range from 1.2% – 4.4% (-0.7 to +2.5) for the different race/ethnicity groups. Considering Medicaid and Non-Medicaid births separately shows different patterns in the range of enrollment rates. For Non-Medicaid births the enrollment rate is 0.9% with a narrow range from 0.7% to 1.4% (-0.2 to +0.5); the range of variation across racial/ethnic groups is less than for Medicaid. For Medicaid births, the enrollment rate is 3.0% with a wider range from 1.8% – 5.2% (-1.2 to +2.2); the rates are consistently higher for all race/ethnicity groups than for the same Non-Medicaid racial/ethnic groups.

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, congenital malformations, 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 FSDB, 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 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 FSDB 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 delaying or disabling conditions.

The table on the following page 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: Down syndrome (85.1%), cerebral palsy (84.8%), and cleft lip/palate (55.2%).
- Other conditions associated with high levels of early intervention enrollment include: other developmental disorders or delays (31.7%); developmental speech and language disorder (26.7%); congenital and chromosomal anomalies other than Down syndrome and cleft lip/ palate (25.7%); and hearing loss and congenital anomalies of ear, face, and neck (22.8%).

- The average first year Medicaid expenditure for children enrolled in early intervention programs was \$18,874.
- 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 \$1,562.

**Enrollment and Average First Year Medical Expenditures by Diagnosed Conditions
Medicaid Eligible Children under Three Born to Washington Mothers
December 1993 to December 1995**

Condition	All Diagnosed (Ages 0 to 3)	Enrolled Children		
		Enrolled (Ages 0 to 3)	Enrollment Rate	Avg. 1st Year Medicaid Expend.
Down Syndrome	94	80	85.1%	\$ 25,544
Cleft Lip/Palate	96	53	55.2%	\$ 23,415
Other Congenital & Chromosomal Anomalies	303	78	25.7%	\$ 57,924
Congenital Musculoskeletal Deformities, Congenital Anomalies of Limbs	1,534	204	13.3%	\$ 40,919
Cerebral Palsy	46	39	84.8%	\$ 48,313
Neoplasms, Diseases & Congenital Anomalies of the Nervous System	6,019	404	6.7%	\$ 34,980
Congenital Anomalies of Heart & Circulatory System	880	97	11.0%	\$ 39,934
Endocrine, Nutritional & Metabolic Diseases, & Immunity Disorders	1,270	57	4.5%	\$ 11,795
Certain Conditions Originating in the Perinatal Period	6,473	248	3.8%	\$ 12,044
Hearing Loss, Congenital Anomalies of Ear, Face, and Neck	127	29	22.8%	\$ 5,589
Developmental Speech & Language Disorder	15	4	26.7%	\$ 1,874
Other Mental Disorders	215	25	11.6%	\$ 4,026
Other Developmental Disorder or Delay	164	52	31.7%	\$ 2,780
All Other Medicaid Eligible Enrolled Children		880		\$ 2,693
Average for All Medicaid Eligible Enrolled Children		2,251		\$ 18,874
Average for Non-Enrolled Children without a Designated Condition				\$ 1,562

**Some enrolled Medicaid eligible children were not categorized with one of the listed medical conditions.*

Parents and providers suggest that Medicaid expenditures reflect only part of the 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.

CHAPTER 8

SUMMARY

This report has presented data for children enrolled in publicly-funded early intervention programs in Washington State on December 2, 1996. The Washington State enrollment rate of 1.9% is slightly higher than in past years, but still below the national prevalence rate of 2.2% (2.1% when adjusted for Washington's poverty profile). Both state and national rates have increased slowly over time. Explanations for the difference between state enrollment and national prevalence rates may include the observation that not all eligible children in Washington are enrolled in publicly funded early intervention programs.

With continued implementation of IDEA, Part H, and increased and more coordinated child find, the proportion of enrolled children receiving services through ITEIP has increased from 3% in 1993 to 47% in 1996. Forty-nine percent of enrolled children had an IFSP in place on December 2, 1996.

The enrollment rate (3.0%) for Medicaid eligible children, with family incomes up to 200% of the FPL, was greater than that for non-Medicaid children (0.9%). Similarly, the national prevalence rate of reported limitations for children in lower income families (3.0%) was greater than that for children in families with incomes greater than 200% of the FPL (1.6%). The proportion of enrolled children who were Medicaid eligible (74%) was significantly greater than that for all children in Washington (46%).

For all Washington births, rural counties as a group have a slightly higher enrollment rate (2.3%) than small urban counties (2.2%) and substantially higher enrollment rates than metropolitan counties (1.7%). When Medicaid eligible children were considered separately from higher income children, the differences in enrollment rates were 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 (21.2%) and extremely preterm infants (20.1%). (These two groups may demonstrate considerable overlap.) Enrollment rates between 4.6% and 8.3% 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 2.2% to 3.2%) than the rate for all Washington births (1.9%).

Enrollment rates for specific medical conditions were also studied for Medicaid eligible children. Enrollment rates were highest for Medicaid eligible children with Down syndrome (85.1%) and cerebral palsy (84.8%). 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 (55.2%), developmental speech and language disorder (26.7%), and other developmental disorder or delay (31.7%).

The average Medicaid expenditure for all Washington born children enrolled in early intervention programs (\$18,874) was over twelve times the average expenditure for Medicaid children not enrolled (\$1,562). While Medicaid expenditures reflect only a portion of the costs of caring for developmentally delayed or disabled children, the difference in expenditures does indicate a high prevalence of expensive medical treatments among enrolled children.

The analyses and results presented here enhance planning and discussion at the state and local levels, and facilitate decision making and priority setting for Washington's early intervention programs for infants and toddlers. This report addresses only some of the many research directions which could be helpful for program planning. Issues that have not been addressed include, among others, appropriateness of services received, long-term outcomes of early intervention, and family program satisfaction.

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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 H, Washington State is required to define *developmental delay*. Children meeting this definition of developmental delay are eligible to receive Part H 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 H definition. The Washington State Part H 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 FFY 1994 – 1996 Washington State application for federal assistance under IDEA Part H, submitted to the Department of Education Office of Special Education Programs:

The lead agency assures that children birth to three shall be eligible for Year 6 early intervention services under IDEA, Part H, 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 1.5 standard deviation or twenty-five percent of chronological 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. Significant hearing or vision impairments, including 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 which adversely affect developmental performance;
 - vii. Orthopedically impaired, which means impairment of the normal functions of muscles, joints, or bones due to congenital anomaly, disease, or permanent injury which adversely affects developmental performance;
 - 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 392-171-381, 382, 383, 396, 401, 436, 441, 446, and 451.
- B. The multidisciplinary team (consisting of at least two qualified personnel) shall determine eligibility for Part H, 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 H 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 H, 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
- Medical services for diagnostic or evaluation purposes
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Service 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 a listing of children enrolled in early intervention programs on December 2, 1996. This list has 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 (FSDB), 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. Records may contain differing pieces of information about a single child. There may be multiple references to the same child within a single source file, and/or matching records across different sources.

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”.)

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 had the same spelling to have caused records to be flagged as candidate matches.

Second, candidate matches are scored based on the amount of information which is in agreement between the two records. 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 were output. Candidate matches which shared all three identifiers—first name, last name, and date of birth—were output to a data set of perfect matches which did not require further review. Candidate matches which shared many pieces of information, but not all three identifiers, were output to a data set of potential matches for

evaluation by an analyst. An example of a potential match is 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 FSDB

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 any different pieces of information that appear in its matches, for example alternate spelling of a name or a second last name, are added. 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 FSDB

In order to analyze enrollment using information in the 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 FSDB and as additional counts are conducted.