Washington's Infant Toddler Early Intervention Program Study: December 1, 2000

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 may 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. Families, local communities, and state agencies share a common vision for a service system of coordinated, comprehensive, family-centered and culturally competent 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, 2000. 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 Part C 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, 2000 Unduplicated Enrollment Count

- In Washington State, 2,900 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, 2000. This number has increased 51% from 1,923 children reported on December 1, 1995, one year after full implementation of Part C.
- A total of 5,520 infants and toddlers under three years of age were found to be enrolled in public early intervention services for developmental delays, disabilities, or special health care needs as of December 1, 2000.
- The 2000 rate of enrollment in services in Washington (2.3%) exceeded the rate found in the National Health Interview Survey (NHIS) for children with limitations in some daily activity (2.0%).
- The enrollment rate (3.5%) 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 (70%) 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 (7.7%) was over three times higher than that for children of mothers who received first trimester prenatal care (2.3%).

- Characteristics of infants at birth that were associated with high enrollment rates include low birthweight (10.7%), preterm birth (6.1%), and Apgar score less than 8 (9.7%). Male children had a higher enrollment rate than female children (2.8% versus 2.0%).
- Children of mothers with diagnosed substance abuse had an enrollment rate of three times that for all other Medicaid children in Washington (9.3% versus 3.1%).

CHAPTER 1

INTRODUCTION

This report presents information on infants and toddlers, ages birth to three, with developmental delays, disabilities or special health care needs who were enrolled in Washington State public early intervention services on December 1, 2000. The following measures are examined: unduplicated enrollment count, state enrollment rates and patterns compared to national prevalence rates and patterns, enrollment and Individualized Family Service Plan (IFSP) rates by county, 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, disabilities or special health care needs 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

Research has shown evidence of the nature of the human brain with its rapid growth period in the early years of life and its continuing plasticity throughout life. During infancy and early childhood there is a burst of synapse formation, or connections between neurons in the brain, followed by a refining or pruning of those synapses extending into adolescence (Chugani et al., 1987; Huttenlocher, 1990). The early years of life are a period of great potential, as sensory experience during this time helps determine the developmental pattern of wiring between neurons (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 early years of life.

The National Academies, established under congressional charter to advise the government in scientific and technical matters, recently reaffirmed the importance of early child development. The National Research Council and Institute of Medicine (2000) emphasize the importance of early experiences and relationships as the foundation for development, and note that well-designed early intervention programs can influence the developmental trajectories of children who live in high-risk environments and those with developmental disabilities. This report supports the importance of family centered services and nurturing environments for infants and toddlers.

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 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, multidisciplinary, 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, 2000 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, 2000. 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 41 child development programs, 4 neuorodevelopmental centers, 10 combined child development programs and neurodevelopmental centers, 36 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 105 reported they were providing services either directly or through a contract with another provider. An additional 55 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 further 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 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 2000.

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 including families and community members, 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 resources, 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 DDD 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, 2000 count, 105 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 55 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, 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 1999.

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

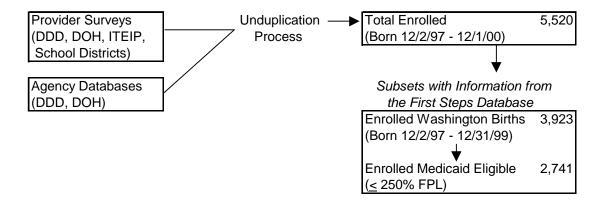
National comparisons are based on child limitations (see page seven) as reported by respondents in the National Health Interview Survey (NHIS). The NHIS is an annual comprehensive survey of health conditions in a sample of households throughout the United States, conducted by the U.S. Bureau of the Census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



<u>Enrolled Children.</u> This group contains all 5,520 children from birth to age three identified in the December 1, 2000 count as being enrolled in early intervention services.

Enrolled Washington Births. This group contains the 3,923 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 1999, children born in 2000 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 4,553 enrolled children born before 2000, 86% were matched with the FSDB.

Enrolled Medicaid-Eligible. This group contains only those 2,741 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 federal counts require an annual, unduplicated count of children enrolled in services on a single day, some children who had received and completed services prior to the count date for that year were not included; nor were those who enrolled after the count date 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. Eligibility of children not receiving services through the Infant Toddler Early Intervention Program is discussed in greater detail in *Washington's Infant Toddler Early Intervention Study: Part C Eligibility* (Baker et al., 2001).

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 the 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 some sources such as 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 1996, 1997, and 1998 (the most recent years for which NHIS data are available). These include populations beyond the definition of the ITEIP/Part C eligibility definition by addressing children with broader special health care needs.

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 calculated 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, disabilities or special health care needs who were enrolled on December 1, 2000 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, 2000

| Children Enrolled in Early Intervention Services | 5,520 |
|--|---------|
| | |
| Washington State Population under Three* | 237,635 |
| | |
| Washington State Enrollment Rate | 2.3% |

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

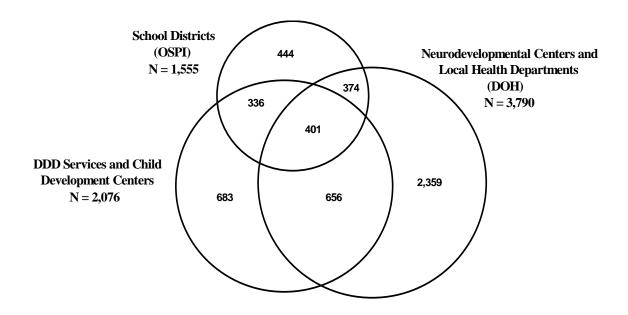
| | Dec. 1, 1993 | Dec. 1, 1995 | Dec. 2, 1996 | Dec. 1, 1997 | Dec. 1, 1998 | Dec. 1, 1999 | Dec. 1, 2000 |
|------------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Enrolled: | 4,055 | 4,138 | 4,472 | 5,007 | 5,332 | 5,557 | 5,520 |
| Population: | 245,182 | 238,314 | 234,894 | 236,042 | 235,903 | 238,586 | 237,635 |
| Rate: | 1.65% | 1.74% | 1.90% | 2.12% | 2.26% | 2.33% | 2.32% |

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

A total of 5,520 individual children, 2.3% of the Washington State population under three, were reported enrolled in public early intervention services on December 1, 2000. Since 1993—one year before Washington State began full implementation of IDEA Part C—the number of children reported enrolled has increased by 36%.

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

DISTRIBUTION OF ENROLLED CHILDREN BY SERVICE AGENCY



| |] | Number of <u>Children</u> | Percent of Total |
|---------------------------------------|-------------------------|------------------------------|------------------|
| Children enrolled with one provider: | DDD Only | 683 | 12.4% |
| - | DOH Only* | 2,359 | 42.7% |
| | OSPI Only | 444 | 8.0% |
| Children enrolled with two providers | : DDD and DOH, not OSI | PI 656 | 11.9% |
| | DDD and OSPI, not DO | Н 336 | 6.1% |
| | DOH and OSPI, not DD | D 374 | 6.8% |
| Children enrolled with all three prov | iders: DDD, DOH, and OS | SPI 401 | 7.3% |
| Additional children reported : | ITEIP only | 267 | 4.8% |
| | Total Children Reporte | ed 5,520 | 100% |

A total of 2,900 children (52.5%) were reported to have an IFSP (Individualized Family Service Plan) in place on December 1, 2000. This represents 1.2% of the estimated Washington State population under age three. A total of 3,046 children (55.2%) were reported to be receiving enhanced services through ITEIP. Distribution of these children by service agency is detailed on the following page.

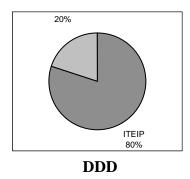
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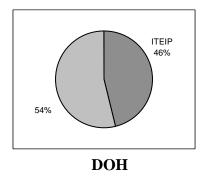
^{*} Not all DOH enrolled children with medical conditions are eligible for ITEIP services because they may not demonstrate developmental delays or developmental disabilities.

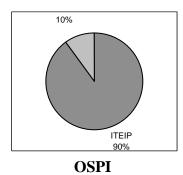
DISTRIBUTION OF ENROLLED CHILDREN RECEIVING SERVICES THROUGH THE INFANT TODDLER EARLY INTERVENTION PROGRAM

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





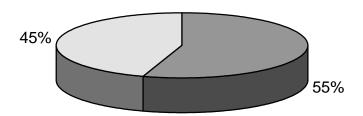


- The proportion of children reported enrolled in DDD programs and also receiving one or more services through ITEIP has increased from 70% in 1996 to 80% in 2000.
- The proportion of children reported enrolled in DOH programs and also receiving one or more services through ITEIP has increased from 41% in 1996 to 46% in 2000.
- The proportion of children reported enrolled in school district programs and also receiving one or more services through ITEIP has increased from 70% in 1996 to 90% in 2000.

| | | Number of <u>Children</u> | Percent of Total |
|--|---------------------------|------------------------------|------------------|
| Children enrolled with ITEIP only: | ITEIP Only | 267 | 4.8% |
| Children enrolled with ITEIP and one of | other provider: | | |
| | ITEIP and DDD | 367 | 6.6% |
| | ITEIP and DOH | 429 | 7.8% |
| | ITEIP and OSPI | 335 | 6.1% |
| Children enrolled with ITEIP and two | other providers: | | |
| | ITEIP, DDD, and DOH | 587 | 10.6% |
| | ITEIP, DDD, and OSPI | 324 | 5.9% |
| | ITEIP, DOH, and OSPI | 345 | 6.2% |
| Children enrolled with all four provider | rs: ITEIP, DDD, DOH, and | OSPI 392 | 7.1% |
| Total children reported to be receiving | ng services through ITEII | P: 3,046 | 55.2% |

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, 2000 unduplicated count, fifty-five 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, 2000



- Receiving Services
 Through ITEIP
- □ Receiving Other
 Agency Services Only
- Among the 5,520 children reported to be enrolled in public early intervention services, 3,046 (55.2%) were reported to be receiving services funded by IDEA Part C, coordinated and administered through the Infant Toddler Early Intervention Program.

Not all children reported as receiving ITEIP services (3,046 children) were reported to have IFSPs in place. These children were in the process of IFSP development. Not all children reported as having IFSPs (2,900 children) were reported to be receiving services funded through ITEIP. For these 72 children (2.5%), 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, disabilities or special health care needs. In this report, national prevalence rates are estimated using information from the 1996, 1997, and 1998 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 <u>limitations</u> in major or minor activities. These limitations may only partially correspond to defined <u>developmental delays or disabilities</u> 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 | 2.0% |
| 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 5,520 children enrolled in Washington State constitute an enrollment rate of 2.3%. This rate is similar to the state enrollment rate for December 1, 1999. Washington's December 1, 2000 rate (2.3%) is slightly higher than both the estimated national prevalence rate (2.0%), and the estimated national prevalence rate adjusted for Washington's 1990 poverty profile (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. 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 1999.

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 | 5,520 |
|----------------------------|---------|
| Enrolled Washington Births | 3,923 |
| Total Washington Births | 164,178 |
| Enrollment Rate | 2.4% |

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 | 967 | 1.2% | 1.2% |
| 1 – 2 Years Old | 1,799 | 2.3% | 2.3% |
| 2 – 3 Years Old | 2,754 | 3.5% | 2.4% |
| Total | 5,520 | 2.3% | 2.0% |

^{*}Population estimates for Washington are for April 1, 2000 (Source: OFM). National figures are estimated from a stratified sample of households surveyed in the 1996, 1997, and 1998 NHIS.

As children become older, developmental delays may become more evident. For children 2 to 3 years old, the Washington State enrollment rate (3.5%) and the national prevalence rate (2.4%) were higher than the rates for children 0 to 1 years old (1.2%) and for those 1 to 2 years old (2.3%). (Please see Appendix D for distribution of children with an IFSP by age and by race/ethnicity.)

DISTRIBUTION OF CHILDREN BY FAMILY INCOME

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

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

| | Enrolled Washington Births (N = 3,923) | All Washington Births (N=164,178) | | Children Under Three with Limitations | All Children Under Three |
|---------------------------|---|--|-------------------------|--|-----------------------------------|
| Medicaid-Eligible | 70% | 47% | Below 200% FPL | 60% | 43% |
| Not Medicaid- Eligible | 30% | 53% | At or Above 200% FPL | 40% | 57% |

^{*}Data are from the 1996-1998 NHIS.

• Medicaid eligibility was much higher among Washington-born children *enrolled in public early intervention programs* (70%) 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 (60%) than did *all* children under three (43%).

In Washington State the Children's Health Insurance Program (CHIP) was implemented in February of 2000. CHIP is available to children with family incomes greater than 200% and less than or equal to 250% FPL. Only one of the children enrolled in early intervention services on December 1, 2000 and matched to the First Steps Database (the Enrolled Medicaid-Eligible group) was enrolled in CHIP. Therefore, nearly all Enrolled Medicaid-Eligible children met the income criteria of family incomes less than or equal to 200% FPL. Children with family incomes below 200% FPL were thus determined to be the appropriate comparison population for the national data (NHIS).

DISTRIBUTION OF CHILDREN BY MOTHER'S RACE/ETHNICITY

| | Children Under Three Born to Washington Residents | | Children Under Three in the NHIS* | | |
|---------------------------|---|--------------------------|--|--------------|--|
| | Enrolled Children | All Washington Births | Children with Reported Limitations | All Children | |
| Mother's Race / Ethnicity | (N = 3,923) | (N = 164,178) | | | |
| White | 71.0% | 71.2% | 49.0% | 63.6% | |
| Hispanic | 13.5% | 11.5% | 20.8% | 17.1% | |
| Asian/Pacific Islander | 3.6% | 6.6% | 0.8% | 3.2% | |
| African American | 3.3% | 3.9% | 28.1% | 13.7% | |
| Native American | 4.3% | 2.2% | 0.6% | 0.8% | |
| Other/Unknown | 4.3% | 4.6% | 0.8% | 1.6% | |
| Total | 100% | 100% | 100% | 100% | |

^{*}Data are from the 1996-1998 NHIS.

- The proportion of White *enrolled* children (71.0%) was similar to the proportion of White children among *all* children born in Washington State (71.2%).
- The proportion of African American *enrolled* children (3.3%) is similar to the proportion of African American children among *all* children born in Washington State (3.9%).
- The proportion of Asian/Pacific Islander *enrolled* children (3.6%) was lower than the proportion of Asian/Pacific Islander children among *all* children born in Washington State (6.6%).
- The proportions of Hispanic and Native American *enrolled* children (13.5% and 4.3%, respectively) were higher than the proportions for those groups among *all* children born in Washington State (11.5% and 2.2%).

DISTRIBUTION OF CHILDREN WITH IFSPs BY RACE/ETHNICITY

Children Under Three Born To Washington Residents

| | Enrolled Children | Enrolled Children with IFSPs | % With IFSPs |
|---------------------------|-------------------|------------------------------|---------------|
| Mother's Race / Ethnicity | (N = 3,923) | (N = 2,220) | (N = 2,220) |
| White | 2,786 | 1,640 | 58.9% |
| Hispanic | 530 | 243 | 45.8% |
| Asian/Pacific Islander | 141 | 89 | 63.1% |
| African American | 129 | 78 | 60.5% |
| Native American | 168 | 72 | 42.8% |
| Other/Unknown | 169 | 98 | 58.0% |
| Total | 3,923 | 2,220 | 56.6% |

Birth certificate information is only available for children born before 2000.

- Among enrolled children born to Washington residents, the proportion of children with Individualized Family Service Plans (IFSPs) by race/ethnicity ranged from 42.8% to 63.1%.
- Of these differences, only two were significantly (p<0.01) different from the proportion for all other children: among enrolled children born to Washington residents, the proportions of Hispanic children with IFSPs (45.8%) and Native American children with IFSPs (42.8%) were lower than that for all other children.
- While the proportion of enrolled Asian/Pacific Islander children with IFSPs (63.1%) was higher than the proportions of all other race/ethnicity groups, this difference was not statistically significant (that is, 11% of the time, by chance alone we would expect a difference between the two groups at least as large as that observed).

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 | National Prevalence Rate (NHIS) |
|----------------------------|----------------------|--------------------------|-----------------|---------------------------------------|
| White | 1,779 | 46,458 | 3.8% | 2.3% |
| Hispanic | 493 | 16,284 | 3.0% | 2.5% |
| Asian/Pacific Islander | 91 | 4,513 | 2.0% | 1.2% |
| African American | 113 | 4,375 | 2.6% | 4.8% |
| Native American | 155 | 2,973 | 5.2% | 2.4% |
| Other/Unknown | 110 | 2,968 | 3.7% | 0.0% |
| Total | 2,741 | 77,571 | 3.5% | 2.8% |

^{*}Data are from the 1996-1998 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 (3.8%) was higher than the national prevalence rate (2.3%).
- The State enrollment rate for Hispanic children (3.0%) was slightly higher than the national prevalence rate (2.5%).
- The State enrollment rate for Asian/Pacific Islander children (2.0%) was higher than the national prevalence rate (1.2%).
- The State enrollment rate for African American children (2.6%) was lower than the national prevalence rate (4.8%).
- The State enrollment rate for Native American children (5.2%) was higher than the national prevalence rate (2.4%).

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 | National Prevalence Rate (NHIS) |
|----------------------------|----------------------|--------------------------|-----------------|---------------------------------------|
| White (Non-Hispanic) | 1,007 | 70,359 | 1.4% | 1.2% |
| Hispanic | 37 | 2,608 | 1.4% | 2.4% |
| Asian/Pacific Islander | 50 | 6,386 | 0.8% | 0.0% |
| African American | 16 | 1,950 | 0.8% | 2.8% |
| Native American | 13 | 713 | 1.8% | 0.0% |
| Other/Unknown | 59 | 4,591 | 1.3% | 1.8% |
| Total | 1,182 | 86,607 | 1.4% | 1.4% |

^{*}Data are from the 1996-1998 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 calculated 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 5,474 unduplicated records (out of the total 5,520 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 1.9% with a range from 1.4% 3.7% (-.5 to +1.8). The enrollment rate for small urban counties is 2.9% with a slightly smaller range from 1.7% 3.8% (-1.2 to +.9). As expected, rural counties, with an enrollment rate of 2.7% have the widest range from 0.8% to 5.4% (-1.9 to +2.7). 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, 2000 by Estimate of County

| County | Estimated Number Enrolled* | Estimate of Population under Three* | Enrollment Rate | Index |
|--------------|----------------------------------|---|--------------------|-------|
| King | 919 | 63,877 | 1.4% | 0.62 |
| Pierce | 497 | 31,933 | 1.6% | 0.67 |
| Clark | 315 | 15,233 | 2.1% | 0.89 |
| Snohomish | 623 | 25,259 | 2.5% | 1.06 |
| Spokane | 624 | 16,965 | 3.7% | 1.58 |
| Metro Total | 2,978 | 153,266 | 1.9% | 0.84 |
| Kitsap | 184 | 10,726 | 1.7% | 0.74 |
| Thurston | 156 | 8,157 | 1.9% | 0.82 |
| Walla Walla | 61 | 1,999 | 3.1% | 1.31 |
| Whatcom | 194 | 6,318 | 3.1% | 1.32 |
| Skagit | 140 | 4,196 | 3.3% | 1.44 |
| Lewis | 96 | 2,839 | 3.4% | 1.46 |
| Benton | 220 | 6,324 | 3.5% | 1.50 |
| Yakima | 409 | 11,137 | 3.7% | 1.58 |
| Franklin | 101 | 2,702 | 3.7% | 1.61 |
| Cowlitz | 147 | 3,917 | 3.8% | 1.62 |
| S.U. Total | 1,708 | 58,315 | 2.9% | 1.26 |
| San Juan | 3 | 398 | 0.8% | 0.32 |
| Kittitas | 10 | 1,075 | 0.9% | 0.40 |
| Ferry | 3 | 284 | 1.1% | 0.46 |
| Garfield | 1 | 81 | 1.2% | 0.53 |
| Whitman | 16 | 1,230 | 1.3% | 0.56 |
| Stevens | 24 | 1,493 | 1.6% | 0.69 |
| Pend Oreille | 8 | 487 | 1.6% | 0.71 |
| Clallam | 38 | 2,246 | 1.7% | 0.73 |
| Chelan | 61 | 3,007 | 2.0% | 0.87 |
| Grays Harbor | 60 | 2,662 | 2.3% | 0.97 |
| Douglas | 31 | 1,261 | 2.5% | 1.06 |
| Island | 86 | 3,256 | 2.6% | 1.14 |
| Columbia | 4 | 151 | 2.6% | 1.14 |
| Asotin | 22 | 799 | 2.8% | 1.19 |
| Skamania | 11 | 386 | 2.9% | 1.23 |
| Mason | 61 | 1,794 | 3.4% | 1.46 |
| Klickitat | 25 | 735 | 3.4% | 1.46 |
| Jefferson | 31 | 865 | 3.6% | 1.54 |
| Grant | 128 | 3,458 | 3.7% | 1.59 |
| Pacific | 27 | 698 | 3.9% | 1.66 |
| Okanogan | 71 | 1,691 | 4.2% | 1.81 |
| Lincoln | 14 | 324 | 4.3% | 1.86 |
| Adams | 46 | 876 | 5.3% | 2.26 |
| Wahkiakum | 7 | 130 | 5.4% | 2.31 |
| Rural Total | 788 | 29,387 | 2.7% | 1.15 |
| State Total* | 5,520 | 237,635 | 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.

Estimate of County for Children with Individualized Family Service Plans December 1, 2000

| Estimate of County:* | Estimated Number Enrolled | Estimated Number with IFSPs | Estimated Proportion with IFSPs: |
|----------------------|------------------------------|-----------------------------|--|
| Adams | 46 | 4 | 8.7% |
| Asotin | 22 | 19 | 86.4% |
| Benton | 220 | 103 | 46.8% |
| Chelan | 61 | 36 | 59.0% |
| Clallam | 38 | 31 | 81.6% |
| Clark | 315 | 152 | 48.3% |
| Columbia | 4 | 1 | 25.0% |
| Cowlitz | 147 | 76 | 51.7% |
| Douglas | 31 | 18 | 58.1% |
| Ferry | 3 | 2 | 66.7% |
| Franklin | 101 | 44 | 43.6% |
| Garfield | 1 | 1 | 100.0% |
| Grant | 128 | 63 | 49.2% |
| Grays Harbor | 60 | 28 | 46.7% |
| Island | 86 | 51 | 59.3% |
| Jefferson | 31 | 21 | 67.7% |
| King | 919 | 610 | 66.4% |
| Kitsap | 184 | 139 | 75.5% |
| Kittitas | 10 | 3 | 30.0% |
| Klickitat | 25 | 15 | 60.0% |
| Lewis | 96 | 30 | 31.3% |
| Lincoln | 14 | 5 | 35.7% |
| Mason | 61 | 24 | 39.3% |
| Okanogan | 71 | 32 | 45.1% |
| Pacific | 27 | 16 | 59.3% |
| Pend Oreille | 8 | 4 | 50.0% |
| Pierce | 497 | 333 | 67.0% |
| San Juan | 3 | 1 | 33.3% |
| Skagit | 140 | 65 | 46.4% |
| Skamania | 11 | 8 | 72.7% |
| Snohomish | 623 | 371 | 59.6% |
| Spokane | 624 | 225 | 36.1% |
| Stevens | 24 | 16 | 66.7% |
| Thurston | 156 | 47 | 30.1% |
| Wahkiakum | 7 | 0 | 0.0% |
| Walla Walla | 61 | 33 | 54.1% |
| Whatcom | 194 | 96 | 49.5% |
| Whitman | 16 | 14 | 87.5% |
| Yakima | 409 | 151 | 36.9% |
| Not identified: | 46 | 12 | 26.1% |
| Total: | 5,520 | 2,900 | 52.5% |

^{*}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.

INDIVIDUALIZED FAMILY SERVICE PLANS (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 5,520 infants and toddlers reported to be enrolled in public early intervention services on December 1, 2000, 2,900 (52.5%) were reported as having a completed IFSP. The table on the previous 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 0.0% to 100%. Both the highest and the lowest proportion of IFSPs occurred primarily among rural counties, where small populations result in greater variability in rates.

CHAPTER 6

RISK FACTORS

A framework for risk factors that may lead to developmental delay and disability includes three categories of risk: established, biological and environmental (Tjossem, 1976). 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 2000).

BIOLOGICAL RISK FACTORS

Biological risk conditions include prematurity, low birthweight, prenatal drug exposure, toxicant exposure (March of Dimes, 1999), 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 (24.8%) was over thirteen times higher than that for normal birthweight (singleton) infants (1.8%).
- The enrollment rates for medium low birthweight infants (7.8%) and infants from multiple gestations (7.5%) 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 (10.7%) six times higher than that for normal birthweight (singleton) infants (1.8%).

Infant Characteristics at Birth

| | Enrolled | Children | All Washington Births | | Enrollment |
|-------------------------------|----------|----------|-----------------------|--------|-------------------------|
| Risk Factor | 3,923 | (100%) | (N = 164,178) | (100%) | Rate (2.4%) |
| Birthweight | | | - | - | |
| Very Low (< 3.3 lbs) | 304 | 7.7% | 1,228 | 0.7% | 24.8% |
| Medium Low (3.3 - 5.5 lbs) | 460 | 11.7% | 5,904 | 3.6% | 7.8% |
| Normal (> 5.5 lbs) | 2,774 | 70.7% | 151,382 | 92.2% | 1.8% |
| Mult. Gestation (Twins, etc.) | 339 | 8.6% | 4,495 | 2.7% | 7.5% |
| Unknown Birthweight | 46 | 1.2% | 1,169 | 0.7% | 3.9% |
| Gestational Age at Birth | | | | | |
| Extreme Preterm (< 28 wks) | 174 | 4.4% | 745 | 0.5% | 23.4% |
| Mod. Preterm (28 - 36 wks) | 1,177 | 30.0% | 21,520 | 13.1% | 5.5% |
| Full Term (37+ wks) | 2,492 | 63.5% | 139,455 | 84.9% | 1.8% |
| Unknown | 80 | 2.0% | 2,458 | 1.5% | 3.3% |
| Apgar Score | | | | | |
| less than 8 | 545 | 13.9% | 5,628 | 3.4% | 9.7% |
| 8 | 608 | 15.5% | 14,645 | 8.9% | 4.2% |
| 9 | 2,537 | 64.7% | 132,038 | 80.4% | 1.9% |
| 10 | 174 | 4.4% | 10,831 | 6.6% | 1.6% |
| Unknown | 59 | 1.5% | 1,036 | 0.6% | 5.7% |
| Gender | | | | | |
| Female | 1,583 | 40.4% | 80,014 | 48.7% | 2.0% |
| Male | 2,340 | 59.6% | 84,164 | 51.3% | 2.8% |
| 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, based on the number of weeks of gestation. Infants with a gestational age of 37 weeks or greater are considered full-term. Infants with a gestational age of less than 37 weeks are considered premature. Preterm delivery is a major cause of low birthweight.

- Preterm infants had an enrollment rate (6.1%) over three times that for full term infants (1.8%).
- The enrollment rate for extremely preterm infants (23.4%) was thirteen 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 (9.7%) was almost 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 (2.8%) 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

| | Enrolled Children | | All Washington Births | | Enrollment Rate |
|--------------------------------|-------------------|--------|-----------------------|--------|--------------------|
| Risk Factor | (N = 3,923) | (100%) | (N = 164,178) | (100%) | (2.4%) |
| Trimester Prenatal Care Began | | | | | |
| No Prenatal Care | 55 | 1.4% | 715 | 0.4% | 7.7% |
| 1st Trimester | 2,774 | 70.7% | 123,191 | 75.0% | 2.3% |
| 2nd Trimester | 520 | 13.3% | 20,625 | 12.6% | 2.5% |
| 3rd Trimester | 126 | 3.2% | 3,821 | 2.3% | 3.3% |
| Unknown | 448 | 11.4% | 15,826 | 9.6% | 2.8% |
| Mother Smoked During Pregnancy | , | | | | |
| Yes | 771 | 19.7% | 21,280 | 13.0% | 3.6% |
| No | 2,972 | 75.8% | 137,277 | 83.6% | 2.2% |
| Unknown | 180 | 4.6% | 5,621 | 3.4% | 3.2% |

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 (7.7%) was more than three times that for children of mothers who received prenatal care in the first trimester (2.3%).

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 (3.6%) was more than that for children born to women who did not report smoking during pregnancy (2.2%).

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

| | Enrolled C | Children | All Medicaid Births | | Enrollment Rate | |
|-------------------------------|-------------------------|----------|---------------------|----------|--------------------|--|
| Risk Factor | (N = 2,265) (100 %) | | (N = 67,352) | (3.4%) | | |
| Diagnosed Substance Abuse | | | | | | |
| Alcohol Only | 25 | 1.1% | 235 | 0.3% | 10.6% | |
| Drugs Only | 119 | 5.3% | 1,390 | 2.1% | 8.6% | |
| Both Alcohol and Drugs | 133 | 5.9% | 1,348 | 2.0% | 9.9% | |
| Any Diagnosed Substance Abuse | 277 | 12.2% | 2,973 | 4.4% | 9.3% | |
| No Diagnosed Substance Abuse | 1,988 | 87.8% | 64,379 | 95.6% | 3.1% | |

• For children of Medicaid served mothers, the enrollment rate for those born to women with any diagnosed substance abuse (9.3%) was three times higher than that for children born to women without diagnosed substance abuse (3.1%).

ENVIRONMENTAL RISK FACTORS

Environmental risks include conditions in the infant or toddler's life that interfere with healthy development, such as unstimulating and non-optimal parent-child interactions, neglect, inadequate nutrition, toxicant exposure (National Research Council, 2000), 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. In the National Academies' report (National Research Council and Institute of Medicine, 2000), the committee noted that one of the most important findings in early childhood development is the importance of nurturing, stable relationships as the key to promoting competence in young children, particularly with regard to school readiness. The report emphasizes that children's social and emotional development is critical to their learning, and just as important as their cognitive and linguistic development.

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 (4.5%) nearly twice the rate for all children born in Washington (2.4%). The enrollment rates for children of women 15 – 19 years old (2.7%) and for children with parents in the group aged forty and older (3.5% and 2.6%, for mothers and fathers) were also higher than for all children born to Washington mothers.

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%). Twenty-nine percent of unmarried mothers (24% 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 (3.5% and 3.1%, for mothers and fathers) than those whose parents graduated from high school and had no further education (2.5% and 2.3%, for mothers and fathers).
- 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 (3.5% and 3.1%, for mothers and fathers).

Number of Prior Births

• The enrollment rate for children of mothers with three or more prior births (3.2%) was higher than that for children of mothers with no prior births (2.2%).

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 (1.7%) was lower than that for all children born in Washington (2.4%). Children of Medicaid women in the lowest income eligibility groups, grant recipients (4.3%) and pre-FS Medicaid Only (3.2%), had higher enrollment rates than all Washington children.

Maternal Demographic Characteristics

| | Enrolled Children | | All Washington Births | | Enrollment Rate |
|-------------------------------|-------------------|----------|-----------------------|--------|--------------------|
| | (N = 3,923) |) (100%) | (N = 164,178) | (100%) | (2.4%) |
| Race/Ethnicity | | | | | |
| White | 2,786 | 74.2% | 116,817 | 74.6% | 2.4% |
| Hispanic | 530 | 14.1% | 18,892 | 12.1% | 2.8% |
| Asian/Pacific Islander | 141 | 3.8% | 10,899 | 7.0% | 1.3% |
| African American | 129 | 3.4% | 6,325 | 4.0% | 2.0% |
| Native American | 168 | 4.5% | 3,686 | 2.4% | 4.6% |
| Other/Not Stated | 169 | | 7,559 | | 2.2% |
| Age | | | | | |
| < 15 Years Old | 11 | 0.3% | 243 | 0.1% | 4.5% |
| 15 - 19 Years Old | 463 | 11.8% | 17,351 | 10.6% | 2.7% |
| 20 - 29 Years Old | 2,095 | 53.4% | 85,673 | 52.2% | 2.4% |
| 30 - 39 Years Old | 1,210 | 30.9% | 56,781 | 34.6% | 2.1% |
| 40 + Years Old | 143 | 3.6% | 4,058 | 2.5% | 3.5% |
| Not Stated | 1 | 21272 | 72 | , | 1.4% |
| Marital Status | | | | | |
| Married | 2,419 | 61.9% | 118,472 | 72.4% | 2.0% |
| Single | 1,487 | 38.1% | 45,222 | 27.6% | 3.3% |
| Not Stated | 17 | | 484 | | 3.5% |
| Educational Attainment | | | | | |
| < 8 years | 169 | 4.9% | 5,412 | 3.7% | 3.1% |
| 8 - 11 years | 722 | 20.9% | 20,908 | 14.2% | 3.5% |
| 12 years | 1,158 | 33.6% | 46,036 | 31.3% | 2.5% |
| 13 - 15 years | 805 | 23.3% | 38,610 | 26.2% | 2.1% |
| 16+ years | 595 | 17.3% | 36,226 | 24.6% | 1.6% |
| Not Stated | 474 | | 16,986 | | 2.8% |
| Number of Prior Births | | | | | |
| None | 1,413 | 37.4% | 65,523 | 41.3% | 2.2% |
| 1 Child | 1,168 | 30.9% | 51,881 | 32.7% | 2.3% |
| 2 Children | 660 | 17.5% | 24,734 | 15.6% | 2.7% |
| 3 - 5 Children | 464 | 12.3% | 14,822 | 9.3% | 3.1% |
| 6 + Children | 71 | 1.9% | 1,597 | 1.0% | 4.4% |
| Not Stated | 147 | | 5,621 | | 2.6% |
| Medicaid Eligibility * | | | | | |
| Grant Recipient | 833 | 21.2% | 19,559 | 11.9% | 4.3% |
| Pre-First Steps Medicaid Only | | 22.8% | 27,652 | 16.8% | 3.2% |
| First Steps Expansion | 537 | 13.7% | 20,117 | 12.3% | 2.7% |
| Served, No Elig. Record | 1 | 0.0% | 24 | 0.0% | 4.2% |
| Non-Medicaid | 1,658 | 42.3% | 96,826 | 59.0% | 1.7% |

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 | All Washingt | on Births | Enrollment Rate |
|------------------------|------------|----------|--------------|-----------|--------------------|
| | (N = 3 | ,923) | (N = 164 | ,178) | (2.4%) |
| Race/Ethnicity | • | | | | |
| White | 2,270 | 70.3% | 103,781 | 71.9% | 2.2% |
| Hispanic | 591 | 18.3% | 21,343 | 14.8% | 2.8% |
| Asian/Pacific Islander | 114 | 3.5% | 9,117 | 6.3% | 1.3% |
| African American | 160 | 5.0% | 7,358 | 5.1% | 2.2% |
| Native American | 94 | 2.9% | 2,667 | 1.8% | 3.5% |
| Not Stated | 694 | | 19,912 | | 3.5% |
| Age | | | | | |
| < 15 Years Old | 0 | 0.0% | 11 | 0.0% | 0.0% |
| 15 - 19 Years Old | 130 | 4.0% | 5,397 | 3.7% | 2.4% |
| 20 - 29 Years Old | 1,494 | 46.0% | 65,086 | 44.3% | 2.3% |
| 30 - 39 Years Old | 1,281 | 39.5% | 63,076 | 43.0% | 2.0% |
| 40 + Years Old | 340 | 10.5% | 13,194 | 9.0% | 2.6% |
| Not Stated | 678 | | 17,414 | | 3.9% |
| Educational Attainment | | | | | |
| < 8 years | 171 | 6.3% | 5,111 | 4.0% | 3.3% |
| 8 - 11 years | 373 | 13.7% | 12,091 | 9.5% | 3.1% |
| 12 years | 984 | 36.0% | 42,426 | 33.2% | 2.3% |
| 13 - 15 years | 605 | 22.1% | 30,347 | 23.7% | 2.0% |
| 16+ years | 599 | 21.9% | 37,872 | 29.6% | 1.6% |
| Not Stated | 1,191 | | 36,331 | | 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, 2000, 5,520 infants and toddlers under three years of age were found to be enrolled in public early intervention services for developmental delays, disabilities, or special health care needs. The number of children reported enrolled has increased by 36% over the last seven years. Both state and national rates have increased slowly over time. The Washington State enrollment rate of 2.3% (2.32%) is similar to last year's rate (2.33%), and higher than the national prevalence rate of 2.0% (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 55.2 %. This has increased from 3% in 1993. A total of 2,900 children (52.5%) had an Individualized Family Service Plan in place on December 1, 2000. 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 (3.5%) 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 (2.8%) was greater than that for children in families with incomes greater than 200% of the FPL (1.4%). The proportion of *enrolled* children who were Medicaid-eligible (70%) 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 (24.8%) and extremely preterm infants (23.4%). (These two groups may demonstrate considerable overlap.) Enrollment rates between 4.5% and 9.7% 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 2.8% to 3.6%) than the rate for all births to Washington residents (2.4%).

Estimated county enrollment rates vary greatly (from 0.8% to 5.4%), with rural counties exhibiting the widest range. Likewise, the estimated proportion of Individualized Family Service Plans (IFSPs) among enrolled children by county ranges from 0.0% to 100%, 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.

REFERENCES

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

Baker B, Lyons D, Lindsay J, Pinard D, Verellen C, Cawthon L. (2001) *Washington's Infant Toddler Early Intervention Study: Part C Eligibility*. Olympia WA: Washington State Department of Social and Health Services, Report Number 7.101.

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

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

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

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

Children's Defense Fund. (2000) *The State of America's Children: Yearbook 2000*. Washington, DC: Children's Defense Fund.

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

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

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

Guralnick MJ. (1998) Effectiveness of Early Intervention for Vulnerable Children: A Developmental Perspective. *American Journal on Mental Retardation*, 102(4): 319-345.

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

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

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

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

Kelly JF and Barnard KE. (1990) Assessment of parent-child interaction and implications for early intervention. In S.J. Meisels and J.P. Shonkoff (Eds.), *Handbook of Early Childhood Intervention*. Cambridge: Cambridge University Press.

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

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

March of Dimes. (1999) *Facts and Figures of Birth Defects* [Online] Available at http://modimes.org/HealthLibrary2/FactsFigures/stats.htm#Birth Defects

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

National Center for Health Statistics. (2001) National Health Interview Survey, 1998. [Online] Available at http://www.cdc.gov/nchs/nhis.htm#1998 NHIS.

National Center for Health Statistics. (2000) Data File Documentation, National Health Interview Survey, 1997 (machine readable data file and documentation, CD-ROM Series 10, No. 12A), National Center for Health Statistics, Hyattsville, Maryland.

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

National Research Council. (2000) Scientific Frontiers in Developmental Toxicology and Risk Assessment. Committee on Developmental Toxicology, Board on Environmental Studies and Toxicology, Commission on Life Science. Washington, D.C.: National Academy Press. [Online] Available at http://www.nap.edu/books/0309070864/html/.

National Research Council and Institute of Medicine. (2000) From Neurons to Neighborhoods: The Science of Early Childhood Development. Committee on Integrating Science of Early Childhood Development. Jack P. Shonkoff and Deborah A.

Phillips, Eds. Board on Children, Youth, and Families, Commission on Behavioral and Social Sciences and Education. Washington, D.C.: National Academy Press. Available online at http://www.nap.edu/books/0309069882/html/.

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

Ramey CT, Campbell FA, Ramey SL. (1998) Early Intervention: Successful Pathways to Improving Intellectual Development. Paper presented at the Conference on Dendritic Mechanisms in Mental Retardation and Developmental Disabilities. National Institute for Child Health and Human Development, Bethesda, MD. May, 1998.

Ramey CT and Ramey SL. (1998) Early Intervention and Early Experience. *American Psychologist* 53: 109-120.

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

Shore R. (1997) *Rethinking the Brain: New Insights into Early Development.* New York: Families and Work Institute.

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

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

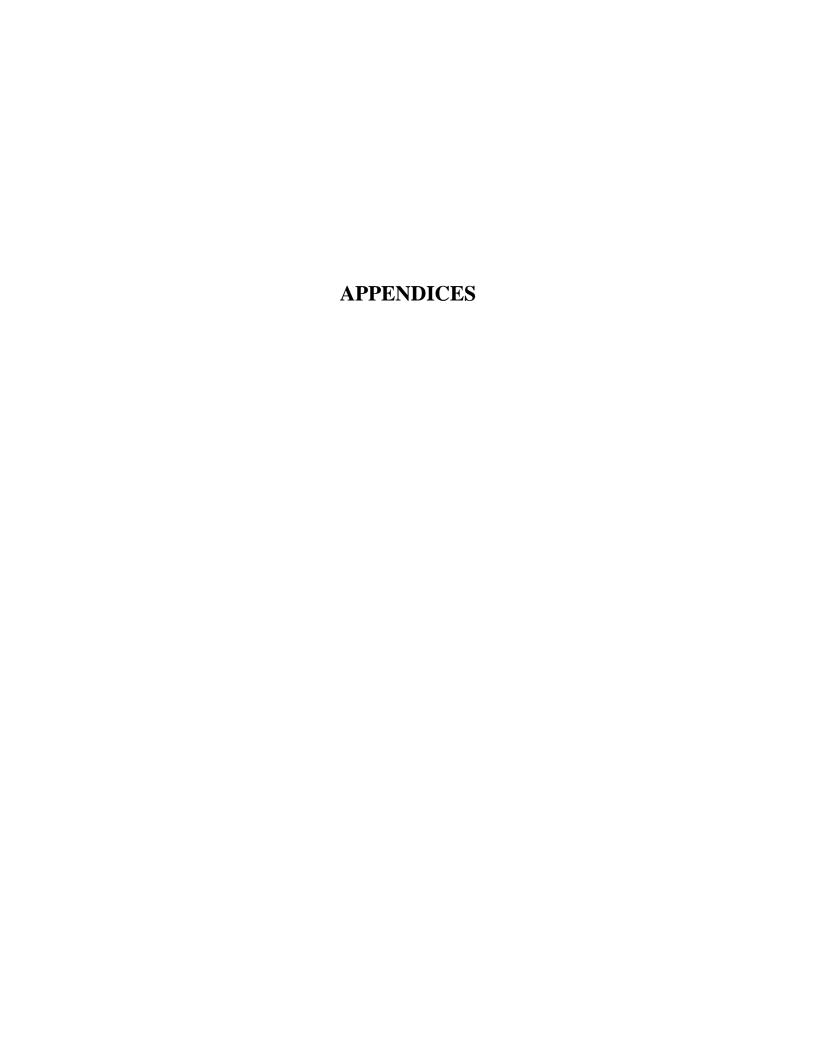
US Bureau of Labor Statistics and US Bureau of the Census. *Current Population Survey*, Detailed Poverty tables: 1996 P60 Package (Released September 1997) and Detailed Poverty Tables: 1995 P60 Package (Released September 1996) [Online]. Available at http://www.bls.census.gov/cps/pub/pubpov.htm.

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

Washington State Office of Financial Planning. (November, 1999) *Forecast of the State Population by Age and Sex: 1990 to 2020.* [Online] Available at http://www.ofm.wa.gov/demographics.htm.

Washington State Office of Financial Planning. (October, 1999) *Intercensal and Postcensal Estimates of County Population by Age and Sex: 1980 to 1999.* [Online] Available at http://www.ofm.wa.gov/demographics.htm.

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



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 imipairment 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 1998-2001 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-98" becomes "010198".) Names are translated into all uppercase letters, non-letter symbols are removed, and common prefixes, such as "MC" and "DELA" are combined into the name. (e.g., "MC MAHAN" becomes "MCMAHAN".)

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

Computer Processing

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

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

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

name is the same. Candidate matches with a minimum of shared information, for example, a first name only, are discarded.

Analyst Evaluation

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

UNDUPLICATION AND MATCH WITH THE FIRST STEPS DATABASE

Internal Unduplication

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

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

Match with the First Steps Database

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

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

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

APPENDIX D

UNDUPLICATED COUNT RESULTS REPORTED TO THE OFFICE OF SPECIAL EDUCATION PROGRAMS

An annual unduplicated count of the number of Part C eligible children and their families with IFSPs is a federal requirement under IDEA. The following tables depict the unduplicated count of children enrolled in Birth to Three services on December 1, 2000 by age and by ethnicity, for the following two populations:

- 1) "Total Unduplicated Count" includes children born after December 1, 1997 and on or before December 1, 2000, who were reported in the DDD MIS; the DOH MIS; or reported on Form B by neurodevelopmental centers (DOH), child development centers (DDD), ITEIP contractors, or school districts.
- 2) "Unduplicated Count of Children with IFSP" includes children born after December 1, 1997 and on or before December 1, 2000, reported on Form B as having a completed IFSP.

TOTAL UNDUPLICATED COUNT BY AGE

| Age (years) on | Unduplicated |
|-------------------------|--------------|
| December 1, 2000 | Children |
| 0 | 967 |
| 1 | 1799 |
| 2 | 2754 |
| Total | 5520 |

UNDUPLICATED COUNT OF CHILDREN WITH IFSP BY AGE

| Age (years) on | Unduplicated |
|-------------------------|--------------|
| December 1, 2000 | Children |
| 0 | 309 |
| 1 | 958 |
| 2 | 1633 |
| Total | 2900 |

TOTAL UNDUPLICATED COUNT BY RACE/ETHNICITY December 1, 2000

| Race/Ethnicity | Unduplicated <u>Children</u> |
|---|------------------------------|
| White (not Hispanic) | 3435 |
| Black or African American (not Hispanic) | 259 |
| American Indian or Alaska Native | 202 |
| Hispanic or Latin American | 938 |
| Asian or Pacific Islander | 167 |
| Other (Multiracial/Cultural, unspecified, etc.) | 519 |
| Total | 5520 |

UNDUPLICATED COUNT OF CHILDREN WITH IFSP BY RACE/ETHNICITY December 1, 2000

| Race/Ethnicity | Unduplicated Children |
|---|-----------------------|
| White (not Hispanic) | 1906 |
| Black or African American (not Hispanic) | 154 |
| American Indian or Alaska Native | 91 |
| Hispanic or Latin American | 470 |
| Asian or Pacific Islander | 104 |
| Other (Multiracial/Cultural, unspecified, etc.) | 175 |
| Total | 2900 |

Determination of Race/ethnicity Categories

When available, race/ethnicity data were taken from the original submissions through ITEIP, DDD, DOH, and school districts. For children reported with no race/ethnicity values, information about the child's race and Hispanic ethnicity was retrieved from birth certificate data, where available.

Children receiving early intervention services may be reported by multiple providers. Sometimes records assumed to represent the same child, but submitted by different

providers, report differing racial categories. Differences in race/ethnicity categories for the same child were reconciled as follows:

- Combinations of 'White' and 'Hispanic,' or 'Black' and 'Hispanic,' were assigned a race/ethnicity category of 'Hispanic,' as the categories 'Black' and 'White' are both specified as 'not Hispanic.'
- Since 'not Hispanic' is notably absent for the categories 'American Indian or Alaska Native' and 'Asian or Pacific Islander,' combinations of these categories with 'Hispanic' were assigned their respective values of 'American Indian or Alaska Native' or 'Asian or Pacific Islander.'
- Combinations of any of the designated categories with 'Other' were assigned the designated category, as the federal request is for reporting within these categories, and the category 'Other' includes records for whom the data was not available.
- Combinations of 'White (not Hispanic),' 'Black or African American (not Hispanic),' 'American Indian or Alaska Native,' and 'Asian or Pacific Islander' were assigned a designation of 'Other,' as representing multiracial/multicultural identification.