Washington's Infant Toddler Early Intervention Program Study

Enrollment of Washington Children with Disabilities and Special Health Care Needs in Washington State Public Programs on December 1, 1995

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EXECUTIVE SUMMARY

State agencies, families, and local communities share a common vision for developing a system of coordinated, comprehensive, family-centered and culturally relevant early intervention services for infants and toddlers with delaying or disabling conditions. These children and their families are eligible to receive an array of publicly funded early intervention services although all may not seek enrollment in state programs.

This report presents information on infants and toddlers, under the age of three, with delaying or disabling conditions enrolled as of December 1, 1995 in Washington State public services provided by child development programs, schools, neurodevelopmental centers, local health jurisdictions and Family Resources Coordinators. A child was defined as enrolled if the child 1) was determined to be eligible for services and/or 2) had an individualized service plan.

Summary of Findings

- In Washington State, 4,197 infants and toddlers under three years of age were found to be enrolled in public early intervention services for delaying or disabling conditions as of December 1, 1995.
- The rate of enrollment in services in Washington (1.8%) was somewhat lower than the rate found in the National Health Interview Survey (NHIS) for children with limitations in some daily activity (2.1%).
- The percentage of enrolled children in Washington who were Medicaid eligible with family incomes at or below 200% of the Federal Poverty Level (FPL) (70%) was greater than the percentage of NHIS children with reported limitations who are at or below 200% of the FPL (61%).
- Analysis of enrollment rates by race/ethnicity shows that White children (1.7%) were enrolled at a slightly lower rate than that for all children in Washington (1.8%). Asian/Pacific Islander children (1.0%) had a substantially lower enrollment rate. African American (2.3%), Hispanic (2.0%) and Native American (3.6%) children were enrolled in early intervention programs at higher rates than all Washington children (1.8%).
- The enrollment rate for children of mothers with no prenatal care (5.4%) was over three times higher than that for children of mothers who received prenatal care in the first trimester (1.6%).
- Characteristics of infants at birth that were associated with high enrollment rates include low birthweight (8.1%), preterm birth (4.6%), and Apgar score less than 8 (8.4%). Male children had a higher enrollment rate than female children (2.0% versus 1.5%).
- Children of mothers with diagnosed substance abuse had an enrollment rate over three times that for all other Medicaid children in Washington (7.4% versus 2.4%).

ENROLLMENT NUMBERS, RATES AND PATTERNS

Methods

Based on identifier information from provider surveys and agency databases, this report presents enrollment numbers, rates, and patterns of infants and toddlers birth to three with disabilities enrolled as of December 1, 1995 in Washington State public services.

Provider Surveys

Surveys requesting a listing of every child under the age of three who was enrolled on December 1, 1995 were mailed to 37 child development programs, 7 neurodevelopmental centers, 7 combined child development/neurodevelopmental centers, and 296 school districts, of which 175 provide services either directly or through contract. A child was defined as enrolled if the child 1) was determined to be eligible for services and/or 2) had a service plan [i.e., Individualized Education Plan (IEP), Individualized Service Plan (ISP), or Individualized Family Service Plan (IFSP)].

Completed surveys were received from 100% of all service providers.

Agency Databases

The DDD/DSHS Common Client Data Base (CCDB) provided a list of clients known to DDD who were under the age of three as of December 1, 1995. The County Human Resource Information System (CHRIS) provided information about the disability-related service(s) in which these individuals were enrolled.

The database of Community Family Health (CFH), DOH included data from the Child Health Intake Form (CHIF) and the providers' Health Services Authorization Form (for CSHCN) for those children, less than three years old, who were enrolled in at least one disability-related DOH/CFH service as of December 1, 1995.

Unduplication and Matching

Since each child could be reported by more than one provider/agency, records were unduplicated to obtain a count of enrolled children with each individual counted only once. After unduplication, enrollment records were matched to the First Steps Database (FSDB) using identifier information including name, date of birth, gender and family residence zip code.

The FSDB provides a single repository for data from different sources (birth certificates, infant death certificates, maternal and infant services paid by Medicaid, and Medicaid eligibility history) which are linked at the individual level. It begins with births in July 1988 (a year prior to the implementation of First Steps) and is currently updated to include births through 1994. The FSDB was created and is maintained by the DSHS Office of Research and Data Analysis (ORDA).

Service Providers

Existing public services are provided and/or funded through the Infant Toddler Early Intervention Program (ITEIP) including Family Resources Coordinators (FRCs); the Department of Health (DOH) Children with Special Health Care Needs (CSHCN); the Department of Social and Health Services (DSHS) Division of Developmental Disabilities (DDD); and the Office of the Superintendent of Public Instruction (OSPI) Special Education (SE).

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

FRCs are professional and paraprofessional community workers trained by ITEIP and employed by provider agencies or parent advocacy organizations through contracts with the state. Their tasks are to support families, to seek and provide information about community organizations, to ensure screenings and assessments, to prepare individualized family service plans (IFSPs), and to refer to community and agency resources.

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.

DDD (**DSHS**) funds early-intervention services for young children from birth to age three through contracts with county governments for most counties in Washington. The county developmental disability branch selects and contracts with service providers for child development services. There are 44 child development programs in the state of Washington. These services, designed to maximize a child's developmental potential, include developmental therapy, parent education and training.

OSPI administers and funds special education programs run by local school districts and educational service districts. At this time 175 school districts provide services to children with disabilities ages birth to three, either directly or by contract with a child developmental center (DDD) or neurodevelopmental center (DOH).

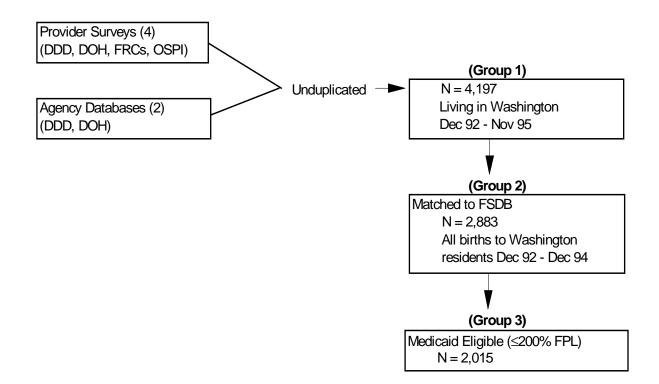
Additionally, birth-to-three early-intervention services are available through private service providers (pediatricians or therapists) and may be funded by private pay, private insurance, DSHS Medical Assistance programs, other DSHS programs (e.g., Mental Health and Children

Analysis Groups

Analyses were based on three overlapping groups of enrolled children. The unduplicated population was comprised of 4,197 enrolled children born from December 1, 1992 to December 1, 1995.

Only children born in 1992 through 1994 could be matched to the FSDB because birth certificates are only available through 1994. Of the 3,456 children whose births occurred in these years, 2,883 (83%) were successfully matched. Some of the reasons for non-matches to the FSDB included adoption, name changes and in-migration. (In-migration refers to the movement of families from out-of-state to Washington. As the mother was not a Washington resident at the time of the child's birth, no record of the birth certificate is available in the FSDB.)

Among the 2,883 children matched to the FSDB, 2,015 (70%) were identified as Medicaid eligible. Medicaid eligible children included (1) those whose mothers were Medicaid eligible during pregnancy, i.e., whose family income was less than or equal to 185% of the Federal Poverty Level (FPL) or (2) those with family incomes less than or equal to 200% FPL who received Medicaid paid services of \$100 or more within two years of birth. The Medicaid claims data provided diagnostic information and expenditure data for these children not otherwise available for non-Medicaid children.



Limitations

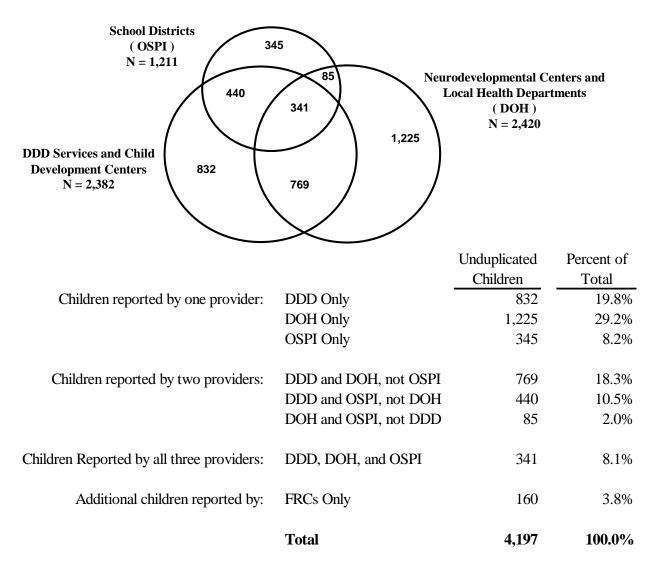
The count of children enrolled in a service plan was limited to all children enrolled as of December 1, 1995. Due to the snapshot nature of this count and different definitions of enrolled (see below), some children who had received and completed services prior to December 1, 1995 were not included; those determined eligible and/or who received a service plan December 2, 1995 or later were also not included.

These numbers do not include all children under three years of age experiencing disabilities and special health care needs in Washington. They reflect only those children and families needing and found eligible for services provided through DDD/DSHS, DOH and OSPI. These numbers do not include those who may have been potentially eligible for services but, for whatever reason, were not enrolled, nor those who received services through other sources (e.g., private pay, military services, Tribal and Indian Health services, migrant services).

"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 <u>and/o</u>r has been provided with a plan of service, defined somewhat differently by DDD/DSHS, DOH, and OSPI. Because each service area relies on somewhat different eligibility criteria and definitions (e.g., disabling conditions, medical issues, learning disabilities), the definitions used by each service area were incorporated as provided. Being enrolled does not imply that the child is receiving any or all of the services needed; children may be in various stages of the programs such as screening, evaluation and/or assessment, determination of eligibility related to a particular service or set of services from local or non-local providers.

An Unduplicated Count of Children Enrolled in a Service Plan

Three state agencies – DOH, DSHS, and OSPI – provide early intervention, education, and health services to children under the age of three with delaying or disabling conditions. The following graph and table display the distribution of children enrolled in early intervention programs on December 1, 1995.



Unduplicated Enrollment by Service Providers

A total of 4,197 children were reported* enrolled in early intervention programs by at least one of the three state agencies. These children experience a range of severity in delaying or disabling conditions and have substantial differences in the type and complexity of needs. Individual children may have their needs met by one provider or may require coordinated service from two or more providers.

*Reported children may not be receiving all or any of the services needed. A reported child may be awaiting approval of eligibility for a particular service or provision of services from local or non-local providers.

Washington State Early Intervention Enrollment Rates and National Limitations Prevalence Rates

A stated goal of the Infant Toddler Early Intervention Program (ITEIP) is to insure that families of children with delaying or disabling conditions have access to early intervention services. To determine the degree of accessibility to state agency services, this report compares a precise Washington State agency count of enrolled children to a national estimate, based on the National Health Interview Survey (NHIS)*.

Computation of the percentage of children enrolled in early intervention programs in Washington, or the Washington State *enrollment rate*, was accomplished by dividing the unduplicated count of children enrolled in a service plan by the Office of Financial Management (OFM) estimate of the Washington population under the age of three.

The *prevalence rate* is the percentage of the general population that have delaying or disabling conditions. This report relied on prevalence rates derived from a national probability sample of households from the NHIS. In the NHIS, parents are asked to identify major or minor <u>limitations</u> in daily activity for every person in their household; these <u>limitations</u> may only partially correspond to what is defined as <u>delaying or disabling conditions</u> in public law and program policies.

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

The NHIS reported rate of limitations for children under three is 2.1%; by contrast, the rate for persons under twenty years of age is 6.2%. Much of this difference over time is due to later recognition of limitations which have been present since early childhood and to limitations appearing after the children have turned three years of age.

For planning purposes, ITEIP estimates that 2.5% of the general population has a delaying or disabling condition. The NHIS-produced national prevalence rate of 2.1% is somewhat lower than that of ITEIP. This may be due to underreported or unidentified limitations in the national survey. As the children become older and enter preschool and their delays increase or are identified, the achieved enrollment rate in Washington is expected to approximate the higher state planning rate.

^{* 1991-1993} NHIS sample: 145,000 households, about 350,000 persons living in these households, of which 5 percent were less than 3 years old (i.e. 17,661).

Early Intervention Enrollment Rates and NHIS National Prevalence Rates

Washington Children under Three Enrolled in Early Intervention Programs Reported Prevalence Rates for Children under Three From NHIS 1991 to 1993

All Living in Washington	Matched to Washington Birth Certificates	NHIS	NHIS Applied to Washington, Controlling for Poverty Status of Washington Residents
1.8% (4,197 / 238,314)	1.8% (2,883 / 161,657)	2.1%	1.9%

- The 4,197 enrolled children in Washington constitute an enrollment rate of 1.8%. Of those children born December 1992 to December 1994 to mothers who were Washington state residents, the enrollment rate was also 1.8%.
- State enrollment rates were somewhat lower than the national prevalence rate for reported limitations (1.8% compared to 2.1%).

Mother's Race/Ethnicity	Enrolled Children	All Washington Births	Enrollment Rate	% Reported Limitations
	(N = 2,883)	(N = 161,657)	(1.8%)	(2.1%)
White (Non-Hispanic)	2,133	122,816	1.7%	1.9%
Hispanic	308	15,043	2.0%	1.8%
Asian/Pacific Islander	100	9,624	1.0%	1.1%
African American	144	6,275	2.3%	3.2%
Native American	121	3,389	3.6%	3.2%
Other/Unknown	77	4,510	1.7%	0.0%

Enrollment and Prevalence Rates by Mother's Race/Ethnicity

- Enrollment rates among White, Hispanic, Asian/Pacific Islander and Native American children in Washington were similar to the national prevalence rates for these ethnic groups with percent differences ranging from 9.1% to 12.5%.
- For African Americans the enrollment rate (2.3%) was substantially lower than the national prevalence rate (3.2%) with a percent difference of 28%, more than twice the percent differences for the other ethnic groups.

* The NHIS prevalence rate was controlled for poverty status based on the income distribution of Washington's population in the 1990 United States Census of the Population.

Distribution of Enrolled Children by Family Income

The costs to parents of caring for a child with a delaying or disabling condition are generally very high. These children often require costly medical treatment and equipment (*see "Enrollment Conditions and First Year Medicaid Costs" below*). In addition, one or both parents are often forced to reduce or curtail employment to care for the child.

Given the cost of caring for children with delaying or disabling conditions, the income levels of families with such children take on a twofold importance. First, the income level gives an indication of the resources available to the family in meeting the challenge of caring for their child. Second, the income level can reveal the impact of reduced or curtailed employment.

This report describes the distributions of enrolled children under the age of three in Washington and children with limitations in the NHIS by relative family income.

Medicaid Eligibility Among All Children and Enrolled Children Born to Washington Mothers December 1992 to December 1994				% FPL Among Ch Reported to Have (NHIS 1991-1993	
	All Washington Enrolled Births Washington Births			All Children Under Three	Children under Three with Limitations
	(N = 161,657)	(N = 2,883)			
Medicaid Eligible	45%	70%	At or below 200% FPL	46%	61%
Not Medicaid Eligible	55%	30%	Above 200% FPL	54%	39%

Enrollment and Family Income Distribution

- Among all children born in Washington under the age of three, 45% were Medicaid eligible, while 70% of children enrolled in early intervention programs were Medicaid eligible.
- Similarly, in the national sample 46% of all children under the age of three had family incomes at or below 200% FPL, while 61% of children with reported limitations had family incomes at or below 200% FPL.

Distribution of Enrolled Children by Risk Factors

Infant characteristics at birth and maternal prenatal characteristics can influence an infant's risk of encountering an adverse outcome later in life. This report examines the relationship of risk factors to the enrollment of children under the age of three with disabilities and special health care needs in public early intervention programs. The First Steps Database was used for the analysis of twelve risk factors including infant's birthweight, gestational age, Apgar score, gender, timing and adequacy of prenatal care, smoking status, maternal diagnosed substance abuse, maternal age, marital status, maternal Medicaid eligibility, number of prior births and maternal race/ethnicity.

Infant Characteristics At Birth

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

	Enrolled Children		All Washing	Enrollment	
Risk Factor	(N = 2,883)	(100.0 %)	(N = 161,657)	(100.0 %)	Rate (1.8%)
Birthweight					
Very Low (< 3.3 lbs)	190	6.6%	1,023	0.6%	18.6%
Medium Low (3.3 - 5.5 lbs)	355	12.3%	5,692	3.5%	6.2%
Normal (> 5.5 lbs)	2,104	73.0%	151,090	93.5%	1.4%
Mult. Gestation (Twins, etc.)	219	7.6%	3,638	2.3%	6.0%
Unknown Birthweight	15	0.5%	214	0.1%	7.0%
Gestational Age at Birth					
Extremely Preterm (< 28 wks)	122	4.2%	673	0.4%	18.1%
Moderately Preterm (28 - 36 wks)	774	26.8%	18,703	11.6%	4.1%
Full Term (37+ wks)	1,987	68.9%	142,281	88.0%	1.4%
Apgar Score					
less than 8	419	14.5%	4,993	3.1%	8.4%
8	454	15.7%	14,311	8.9%	3.2%
9	1,817	63.0%	128,877	79.7%	1.4%
10	159	5.5%	12,829	7.9%	1.2%
Unknown	34	1.2%	647	0.4%	5.3%
Gender					
Female	1,212	42.0%	78,943	48.8%	1.5%
Male	1,671	58.0%	82,713	51.2%	2.0%

Infant Characteristics at Birth and Early Intervention Enrollment

Low Birthweight

Birthweight is a primary indicator of the health of the newborn infant. Low birthweight is associated with increased risk of death and a wide range of disorders, including neurodevelopmental conditions, learning disorders, behavior problems, and lower respiratory tract infections (*Healthy People 2000*, 1991).

- The enrollment rate for very low birthweight infants (18.6%) was over thirteen times higher than that for normal birthweight infants (1.4%).
- The enrollment rates for medium low birthweight infants (6.2%) and infants from multiple gestations (6.0%) were over four times higher than the enrollment rate for normal birthweight children (1.4%).
- Low birthweight infants (very low and medium low birthweight) had an enrollment rate (8.1%) over six times higher than that for full term infants (1.4%).

Gestational Age

The gestational age of a newborn infant is a measure of the maturity of the newborn at delivery. Infants with a gestational age of 37 weeks or greater are considered full-term. Infants with a gestational age of less than 37 weeks are considered preterm. Preterm delivery is one of the two main causes of low birthweight.

- Preterm infants had an enrollment rate (4.6%) three times that for full term infants (1.4%).
- The enrollment rate for extremely preterm infants (18.1%) was over twelve times higher than that for full term infants (1.4%)

Apgar Score

The Apgar score rates the overall health of an infant. The Apgar score is given on a scale of 1 to 10, with 10 indicating optimum health status.

• The enrollment rate for children with an Apgar score of less than 8 (8.4%) was over seven times higher than that for children with an Apgar score of 10 (1.2%).

Gender

Previous studies have shown that males are more likely to be placed in special education programs than females (Andrews et al., 1995).

• Males had a higher enrollment rate (2.0%) than females (1.5%).

Prenatal Care and Maternal Behaviors

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

	Enrolle	d Children	All Washington Births		Enrollment Rate	
Risk Factor	(N = 2,883)	(100.0 %)	(N = 161,657)	(100.0 %)	(1.8%)	
Trimester Prenatal Care B	egan					
No Prenatal Care	55	1.9%	1,019	0.6%	5.4%	
1st Trimester	2,033	70.5%	125,538	77.7%	1.6%	
2nd Trimester	518	18.0%	22,779	14.1%	2.3%	
3rd Trimester	98	3.4%	4,277	2.6%	2.3%	
Unknown	179	6.2%	8,044	5.0%	2.2%	
Adequacy of Prenatal Care	e					
Adequate Plus	918	31.8%	35,804	22.1%	2.6%	
Adequate	1,029	35.7%	77,601	48.0%	1.3%	
Intermediate	466	16.2%	28,956	17.9%	1.6%	
Inadequate	107	3.7%	4,421	2.7%	2.4%	
Unknown	363	12.6%	14,875	9.2%	2.4%	
Mother Smoked During Pr	egnancy					
Yes	781	27.1%	27,679	17.1%	2.8%	
No	2,030	70.4%	130,653	80.8%	1.6%	
Unknown	72	2.5%	3,325	2.1%	2.2%	

Prenatal Care, Smoking Status and Early Intervention Enrollment

Prenatal Care

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

- The enrollment rate for children of mothers who did not receive prenatal care (5.4%) was over three times higher than that for children of mothers who received prenatal care in the first trimester (1.6%). Children of mothers who began receiving prenatal care in the second or third trimester also had a higher enrollment rate (2.3%).
- The enrollment rate for children of mothers with inadequate prenatal care (2.4%) was nearly twice that for children of mothers who received adequate prenatal care (1.3%). (Note: adequate plus prenatal care had a high enrollment rate (2.6%), as relatively high risk pregnancies (e.g., multiple gestation, premature birth) tend to receive a greater amount of care.)

Smoking Status

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

• The enrollment rate for children born to women who smoked during pregnancy (2.8%) was nearly twice that for children born to nonsmoking women (1.6%).

Diagnosed Maternal Substance Abuse among Medicaid Served Women and Early Intervention Enrollment

	Enrolled	Enrolled Children		All Medicaid Births		
Risk Factor	(N = 1,786)	(100.0%)	(N = 66,070)	(100.0 %)	Rate (2.7%)	
Diagnosed Substance Abuse						
Alcohol Only	56	3.1%	1,228	1.9%	4.6%	
Drugs Only	131	7.3%	1,828	2.8%	7.2%	
Both Alcohol and Drugs	120	6.7%	1,092	1.7%	11.0%	
Any Substance Abuse	307	17.2%	4,148	6.3%	7.4%	
No Substance Abuse	1,479	82.8%	61,922	93.7%	2.4%	

Substance Abuse

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

The First Steps Database uses diagnoses on Medicaid claims to identify maternal substance abuse. As a result, analysis of maternal substance abuse in this report is limited to children whose mothers received Medicaid paid prenatal care and/or delivery services. This is a unique group within the context of the report because these children are equal to or less than 185% FPL, which is a subgroup of the children equal to or less than 200% FPL.

- For all Medicaid served mothers, the enrollment rate for children born to women with any diagnosed substance abuse (7.4%) was over three times higher than that for children born to women without diagnosed substance abuse (2.4%).
- For all Medicaid served mothers, the enrollment rate for children born to women diagnosed as both drug and alcohol abusers (11.0%) was over four times higher than that for children born to women not diagnosed as substance abusers (2.4%).

Maternal Demographic Characteristics

Examination of maternal demographic characteristics including age, marital status, Medicaid eligibility, number of prior births and race/ethnicity found the following:

	Enrolled	Children	All Washing	ton Births	Enrollment Rate
Risk Factor	(N = 2,883)	(100.0%)	(N = 161,657)	(100.0%)	(1.8%)
Age					
< 15 Years Old	14	0.5%	321	0.2%	4.4%
15 - 19 Years Old	170	5.9%	17,447	10.8%	1.0%
20 - 29 Years Old	1,540	53.4%	86,465	53.5%	1.8%
30 - 39 Years Old	847	29.4%	54,166	33.5%	1.6%
40 + Years Old	73	2.5%	3,142	1.9%	2.3%
Unknown	2	0.1%	116	0.1%	1.7%
Marital Status					
Married	1,741	60.4%	119,669	74.0%	1.5%
Single	1,134	39.3%	41,718	25.8%	2.7%
Unknown	8	0.3%	270	0.2%	3.0%
Medicaid Eligibility *					
Grant Recipient	923	32.0%	27,758	17.2%	3.3%
Pre-FS Medicaid Only	474	16.4%	16,874	10.4%	2.8%
FS Expansion	375	13.0%	21,123	13.1%	1.8%
Served, No Elig. Record	15	0.5%	327	0.2%	4.6%
Non-Medicaid	1,096	38.0%	95,575	59.1%	1.1%
Number of Prior Births					
None	1,014	35.2%	66,174	40.9%	1.5%
1 Child	865	30.0%	50,810	31.4%	1.7%
2 Children	499	17.3%	24,282	15.0%	2.1%
3 - 5 Children	398	13.8%	14,980	9.3%	2.7%
6 + Children	43	1.5%	1,540	1.0%	2.8%
Unknown	64	2.2%	3,871	2.4%	1.7%
Race / Ethnicity					
White (Non-Hispanic)	2,133	74.0%	122,816	76.0%	1.7%
Hispanic	308	10.7%	15,043	9.3%	2.0%
Asian/Pacific Islander	100	3.5%	9,624	6.0%	1.0%
African American	144	5.0%	6,275	3.9%	2.3%
Native American	121	4.2%	3,389	2.1%	3.6%
Other/Unknown	77	2.7%	4,510	2.8%	1.7%

Maternal Demographic Characteristics and Early Intervention Enrollment

* The mother's Medicaid eligibility at the time of delivery is used as a measure of income. In general, women eligible for grants have a family income at or below 65% of FPL. Pre-First Steps (FS) Medicaid only women had incomes at or below 90% of FPL. FS Expansion women had incomes between 100% and 185% of FPL. Some women received Medicaid paid prenatal care or delivery services but did not have a Medicaid eligibility record.

Maternal Age

• Children of women who were younger than 15 years old at the time of delivery had an enrollment rate (4.4%) more than twice that of all children born in Washington (1.8%). Children of women 40 and older (2.3%) also had a higher enrollment rate.

Marital Status

• The enrollment rate for children of unmarried mothers (2.7%) was nearly twice the rate for children of married mothers (1.5%).

Maternal Medicaid Eligibility

• The enrollment rate for children of women who were not receiving Medicaid at the time of delivery (1.1%) was substantially lower than that for all children born in Washington (1.8%). Children of women in the lowest income eligibility groups, grant recipients (3.3%) and pre-FS Medicaid only (2.8%), had a higher enrollment rate than all Washington children.

Number of Prior Births

• The enrollment rate for children of mothers with three or more prior births (2.7%) was higher than that for children of mothers with no prior births (1.5%).

Race/Ethnicity

- The enrollment rate for White children (1.7%) was slightly lower than that for all Washington children (1.8%).
- African American (2.3%), Hispanic (2.0%) and Native American (3.6%) children were enrolled in early intervention programs at higher rates than all children born in Washington (1.8%). The enrollment rate for Asian/Pacific Islander children (1.0%) was substantially lower than that for all Washington children.

Enrollment Rates by County Groupings

The question of whether Washington counties differ in the degree to which they enroll children under three in public early intervention programs was examined by this report. Relying on the First Steps Database the ITEIP study was able to distribute all children who received Medicaid services and all children born in Washington from December 1992 to December 1994 to the identified county of residence for their mother at the time of the child's birth. The following table shows the degree to which counties and groupings of counties have enrolled more or fewer children in the total population and, in particular, among Medicaid served families. That is, are families who receive Medicaid services enrolled at different rates by county?

This is an important question as apparent differences in overall enrollment rates by county may be due to different proportions of low income families by county and to the tendency for more rural areas to have higher percentages of Medicaid eligible families.

For this analysis Washington counties were grouped by population density, resulting in three groups: metropolitan, small urban and rural. Counties classified as metropolitan had the largest and most concentrated populations. Small urban counties had smaller, although still concentrated, populations. Rural counties had the smallest populations and no large population centers.

Numbers of children enrolled in early intervention services are shown by county and county group in column a, for Medicaid served children, and column e, for all children. Total births by county and county group are shown in column b, for Medicaid eligible children, and column f, for all children. Early intervention enrollment rates by county and county group are shown in column c, for Medicaid served children, and column g, for all children. Indices were calculated comparing each county's and county group's enrollment rate to Washington State's enrollment rate. An index of less than 1.00 means that an enrollment rate was less than the rate for the state of Washington. County and county group indices are shown in column d, for Medicaid served children, and column h, for all children.

The table on the following page shows enrollment rates by county grouped by population density:

- Enrollment rates by county are highly variable, but rural counties as a group have a slightly higher enrollment rate (2.5%) than small urban counties (2.3%) and a substantially higher enrollment rate than metropolitan counties (1.6%).
- Among children who received Medicaid paid services, the enrollment rate for children in rural or small urban counties (3.2%) was higher than that for children in metropolitan (2.7%) counties.

Some of the variability among rural counties may be attributed to very small numbers, which produce unreliable rates. The variability among more metropolitan and urban counties may reflect different organization of services as well as varying degrees of rurality in parts of these counties.

Enrollment Rates by County and County Grouping for Medicaid Eligible Children and All Washington Children Born to Washington Mothers December 1992 to December 1994

		Medi	icaid			All Bi	irths	
	BT3	All	Percent		BT3	All	Percent	
County	Enrolled	Births	Enrolled	Index	Enrolled	Births	Enrolled	Index
	а	b	c=a∕b	d	е	f	g=e/f	h
Clark	78	3,526	2.2%	0.80	123	8,824	1.4%	0.78
King	438	16,471	2.7%	0.97	653	46,008	1.4%	0.80
Pierce	235	8,759	2.7%	0.97	344	20,694	1.7%	0.93
Snohomish	163	5,715	2.9%	1.04	299	16,377	1.8%	1.02
Spokane	182	5,603	3.2%	1.18	249	11,469	2.2%	1.22
Metro Total	1,096	40,074	2.7%	0.99	1,668	103,372	1.6%	0.90
Benton	63	1,873	3.4%	1.22	94	4,056	2.3%	1.30
Cowlitz	59	1,420	4.2%	1.51	74	2,484	3.0%	1.67
Franklin	51	1,524	3.3%	1.21	62	2,060	3.0%	1.69
Kitsap *	33	2,252	1.5%	0.53	71	6,672	1.1%	0.60
Lewis	56	1,106	5.1%	1.84	64	1,756	3.6%	2.04
Skagit	34	1,404	2.4%	0.88	55	2,659	2.1%	1.16
Thurston	50	2,146	2.3%	0.85	82	5,062	1.6%	0.91
Walla Walla	26	912	2.9%	1.03	35	1,430	2.4%	1.37
Whatcom	52	1,780	2.9%	1.06	81	4,013	2.0%	1.13
Yakima *	114	6,914	1.6%	0.60	128	9,001	1.4%	0.80
S.U. Total *	391	12,165	3.2%	1.17	547	23,520	2.3%	1.30
Adams	9	514	1.8%	0.64	10	655	1.5%	0.86
Asotin	15	329	4.6%	1.65	17	516	3.3%	1.85
Chelan	40	1,404	2.8%	1.03	43	2,005	2.1%	1.20
Clallam	34	782	4.3%	1.58	43	1,331	3.2%	1.81
Columbia	2	60	3.3%	1.21	2	97	2.1%	1.16
Douglas	15	612	2.5%	0.89	16	929	1.7%	0.97
Ferry	0	126	0.0%	0.00	1	169	0.6%	0.33
Garfield	0	25	0.0%	0.00	0	36	0.0%	0.00
Grant	40	1,685	2.4%	0.86	52	2,419	2.1%	1.21
Grays Harbor	69	1,231	5.6%	2.03	79	1,784	4.4%	2.48
Island	18	586	3.1%	1.11	36	2,132	1.7%	0.95
Jefferson	21	308	6.8%	2.47	25	473	5.3%	2.96
Kittitas	4	333	1.2%	0.44	4	613	0.7%	0.37
Klickitat	5	342	1.5%	0.53	9	481	1.9%	1.05
Lincoln	3	102	2.9%	1.07	3	234	1.3%	0.72
Mason	25	623	4.0%	1.46	32	1,068	3.0%	1.68
Okanogan	36	944	3.8%	1.38	38	1,182	3.2%	1.80
Pacific	11	324	3.4%	1.23	11	474	2.3%	1.30
Pend Oreille	8	199	4.0%	1.46	9	280	3.2%	1.80
San Juan	2	109	1.8%	0.67	5	218	2.3%	1.29
Skamania	3	105	2.9%	1.04	4	181	2.2%	1.24
Stevens	14	577	2.4%	0.88	17	867	2.0%	1.10
Wahkiakum	0	41	0.0%	0.00	2	72	2.8%	1.56
Whitman	6	369	1.6%	0.59	10	863	1.2%	0.65
Rural Total	380	11,730	3.2%	1.18	468	19,079	2.5%	1.38
State Total **	2,015	73,141	2.8%	1.00	2,883	161,657	1.8%	1.00

* Enrollment counts in Kitsap and Yakima counties are incomplete. Yakima and Kitsap counties are not included in the calculation of the small urban total.

** Some children could not be assigned a county of residence. Actual column totals may, therefore, differ slightly from the totals shown.

Enrollment Rate by Condition and Average First Year Medicaid Expenditures for Medicaid Served Children

Of further interest, particularly to medical providers, is the relationship between specific medical conditions and enrollment in early intervention programs. Information available through the First Steps Database makes it possible to study early intervention enrollment rates for various congenital and acquired conditions diagnosed in the first two years of life.

The First Steps Database includes medical records, which contain diagnostic information in the form of ICD-9 codes, for children born in Washington with Medicaid paid services. Medical diagnoses were reviewed and categorized by methods described in detail elsewhere (Cawthon et al., 1995).

Children may be receiving early intervention services for developmental delays which may or may not be related to their medical diagnoses. Or their developmental delays may be associated with treatments for their medical conditions (such as prolonged hospitalization). The medical diagnoses do not necessarily provide the basis for eligibility for birth-to-three services and only serve to describe the range of conditions affecting these children.

Matching Medicaid records with early intervention enrollment information yielded the following findings:

- The highest early intervention enrollment rates were reported for the following conditions: cerebral palsy (85.5%), Down's syndrome (82.7%), and cleft lip/palate (51.4%).
- Other conditions associated with high levels of early intervention enrollment include: developmental language and speech disorders (31.6%); other developmental disorders or delays (36.5%); congenital and chromosomal anomalies other than Down's syndrome and cleft lip/palate (16.9%); and hearing loss and congenital anomalies of the ear, face, and neck (15.9%).
- The average first year Medicaid expenditure for children enrolled in early intervention programs was \$19,286.
- Among children enrolled in early intervention programs, those diagnosed with cerebral palsy had the highest average first year Medicaid expenditures (\$57,094). Cerebral palsy is often associated with complications of prematurity and occurs more frequently among low birthweight infants who may experience costly hospitalizations.
- The lowest average first year Medicaid expenditure was reported for children diagnosed with developmental speech and language disorder (\$1,582). This condition often occurs in otherwise healthy children and may not be diagnosed and treated until after the first year of life.
- The average first year Medicaid expenditure for all other Medicaid children, not enrolled and with no diagnosis of congenital or acquired medical conditions, was \$1,532.

Parents and providers suggest that the high average first year Medicaid costs for developmentally disabled children reflect only a portion of these children's medical costs. They indicate that the true costs incurred in caring for these children are many times what is paid by Medicaid. Medicaid generally reimburses at approximately 60% of billed medical costs. The balance of medical costs may be met through private pay, private insurance, alternative payers (e.g.; military, Indian Health Service, Tribal Health Service), charitable grants, as well as hospital and physician deferral, forgiveness or non-recoverable write-offs.

CONCLUSIONS

The analyses and results presented here provide baseline data for planning and discussion in decision making and priority setting at the state and local levels for Washington's early intervention programs for infants and toddlers. Many questions remain to be explored in future studies. The relationship between the enrolled population compared to the population that has received services has not been addressed here. As well, the comprehensiveness or appropriateness of the services received compared to the individual child's needs is another issue for further study. Tracking outcomes for enrolled children at older ages could address many concerns about the long term effectiveness of these programs.

This study, an extension of the Birth to Three Study, is sponsored by the State Interagency Coordinating Council (SICC) and funded by DSHS Infant Toddler Early Intervention Program (ITEIP). This is the third of four reports which provide snapshot views of Washington State children less than three years old who receive public services as a result of experiencing developmentally delaying or disabling conditions. The final report, available September 1996, will consist of a comprehensive presentation of results and discussion of enrollment counts, rates and patterns for four data collection points: May 1, 1993, May 1, 1995, December 1, 1995, and May 1, 1996.

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DICTIONARY OF SELECTED ABBREVIATIONS AND ACRONYMS

CDC	Centers for Disease Control and Prevention
CSHCN	Children with Special Health Care Needs (DOH)
DDD	Division of Developmental Disabilities
DOH	Washington State Department of Health
DSHS	Washington State Department of Social and Health Services
FPL	Federal Poverty Level
FRC	Family Resources Coordinator
FSDB	First Steps Database
ICD-9	International Classification of Diseases, 9th Revision
ITEIP	Infant Toddler Early Intervention Program
NHIS	National Health Interview Survey
ORDA	Office of Research and Data Analysis
OSPI	Office of the Superintendent of Public Instruction
SICC	State Interagency Coordinating Council