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ABSTRACT

The National Early Intervention Longitudinal Study (NEILS) is being conducted to address important questions related to the implementation and outcomes of Part C of the Individuals with Disabilities Education Act (IDEA). NEILS is following a nationally representative sample of children from birth to 3 years old and their families through and after their early intervention experiences. This report presents the first information on children and families available from NEILS, information reported by early intervention professionals about children and families who were enrolling in early intervention for the first time. The report provides data on the gender, race/ethnicity, age at entry and reasons for eligibility of the children. It also presents information about families receiving public assistance and children in foster care who are receiving early intervention. The final section of the report summarizes what has been learned, discusses the significance of the findings, and highlights next steps in the NEILS analysis agenda. Appendix A presents detailed information about the study's methodology. Appendix B contains information on the various disabilities of children found eligible to receive early intervention services. Appendix C contains additional data tables related to the analyses presented in the report. (Contains 18 references.) (Author/SG)

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National Early Intervention Longitudinal Study

A FIRST LOOK AT THE CHARACTERISTICS OF CHILDREN AND FAMILIES ENTERING EARLY INTERVENTION SERVICES

NEILS Data Report 1

SRI Project 7879

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collaborative effort of SRI International, the Frank Porter Graham Center for Child Development at the University of North Carolina Chapel Hill, Research Triangle Institute, and American Institutes for Research.

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Acknowledgments

A study as large as NEILS is the work of many people in addition to the authors whose names appear on the cover. We gratefully acknowledge the many dedicated project staff of the collaborating institutions who made this report possible. In particular, we would like to recognize the contributions of Kathy Valdes of SRI who constructed the database that has tracked the recruitment of families and receipt of all data forms; Patti McKenna, formerly of SRI, who assisted in recruiting the sites which participated in the study; and Annikka Anderberg, formerly of SRI, who worked so diligently with the early intervention staff at the sites during the recruitment of the study families.

We would also like to acknowledge and thank the families of children with special needs who have so graciously agreed to be part of this study and have given their time to be interviewed by us. In addition, we would like to thank the service providers and directors of early intervention programs around the country who recruited the families for the study and have found time in their busy schedules to complete NEILS data forms. The study families and the service providers who work with them are the backbone of NEILS. This study would not be possible without their cooperation and support. We thank them on behalf of the next generation of infants and toddlers with special needs who will benefit from their contributions.

1 INTRODUCTION

In 1986, federal legislation (P.L. 99-457) created the Early Intervention Program for Infants and Toddlers with Disabilities, now contained in Part C of the Individuals with Disabilities Education Act, as amended in 1997 (IDEA '97). Through this legislation, states have received funds to build coordinated, interagency systems of early intervention services. The ensuing years have seen steady growth in the number of infants and toddlers (birth to age 3) served through Part C, increasing from an estimated 128,000 in 1988 (U.S. Department of Education, 1990) to 189,000 in 1998, the most recent year for which data are available (U.S. Department of Education, 1999). Yet, very little is known about the characteristics of these children or their families, about the services they receive, or about the outcomes they achieve.

To meet the need for more and better information about Part C and its participants nationally, the Office of Special Education Programs (OSEP) of the U.S. Department of Education commissioned SRI International to conduct the National Early Intervention Longitudinal Study (NEILS). NEILS began in 1996 with a design phase; data collection began the following year. NEILS findings are based on a nationally representative sample of children and families who were recruited into the study from September 1997 through November 1998 as they entered early intervention. Information will be collected repeatedly about participating children and families through their early school years.

Here, we report the first information on children and families available from NEILS—information reported by early intervention professionals about children and families who were enrolling in early intervention for the first time. This report provides a partial answer to the question who are the children and families receiving early intervention services. This report presents data on the gender, race/ethnicity, age at entry and reasons for eligibility of children receiving early intervention. It also presents information about families receiving public assistance and children in foster care who are receiving early intervention This is only the first look at these issues; we will learn much more about the children and families as additional data become available over the course of the study. The remainder of this section briefly summarizes the methodology of the study. Findings are presented in Section 2. The final section summarizes what has been learned, discusses the significance of the findings, and highlights next steps in the NEILS analysis agenda. Appendix A presents detailed information about the study's methodology. Appendix B contains information on the various disabilities of children found eligible to receive early intervention services. Appendix C contains additional data tables related to the analyses presented in the report.

Data Collection and Analysis

The data presented in this report are based on a nationally representative sample of families who entered early intervention for the first time between September 1997 and November 1998. These data were collected from early intervention programs in 93 counties in 20 states. The 20 states are diverse with regard to population, region of the country, lead agency, whether they serve at-risk children under Part C of IDEA, and the percentage of the birth-to-3 population served through Part C. Three to seven counties within each of the 20 states recruited families for the study. Each county was assigned a target number of children and families to recruit.

As part of the recruitment process, program staff completed a one-page form on every family for whom an Individualized Family Service Plan (IFSP) was written during the recruitment period. (This form is included as Exhibit A-1 in Appendix A.) The form was completed and mailed to SRI for 5,668 families. The form contained basic descriptive data such as the child's date of birth, gender, date of the IFSP, and reason for early intervention eligibility. This form contained no personally identifiable information. (A subset of this sample was recruited for participation in the longitudinal study, as will be described in subsequent NEILS reports.)

Early intervention program staff also were asked to write in the nature of the disability, delay, or risk condition that made the child eligible for early intervention. These descriptors were coded with a classification scheme created by the research team, as described in Appendix B.

All data presented in this report are weighted—that is, numerical weights have been applied to the raw data. The procedures for calculating the weights are described in detail in Appendix A. Because of the nature of the sample selection procedures employed and the weights applied to the data, the percentages and means presented in this report represent national estimates. For example, the reader should view the percentage of boys in early intervention presented in the next section as the best available estimate of the percentage of boys in early intervention in the nation. It should not be read as the percentage of boys in the sample.

The percentages and means presented are only estimates of the actual percentages and means that would have been obtained if all children entering early intervention in the country had been included in the study. The estimates vary in how closely they approximate the true measures. To examine the precision of an estimate, researchers use a statistic called "standard error." To aid the reader in determining the precision of the estimates, the tables present the standard error for each percentage and mean and the unweighted number of cases on which the statistic is based.

To determine the precision of a particular percentage or mean, the reader can construct a confidence interval for the estimate by multiplying the standard error by 1.96. The result is the range around the estimate within which the true measure would be found 95 out of 100 times. For example, NEILS estimates that 60.9% of children receiving early intervention are male. The standard error of that estimate, 1.1, is multiplied by 1.96, letting us assume with 95% confidence that the true percentage of males falls within a range of ±2.1 percentage points of 60.9 or 58.7% to 63.1%.

Limitations

The most notable limitation on the data reported here involves the potential for bias resulting from incomplete data. SRI made every effort to obtain enrollment information for every family that lived in the sample counties and enrolled in early intervention for the first time during the study recruitment period. However, there were several reasons that we did not receive information for all such families.

Three counties that were sampled for the study refused to participate. In such cases, a county in the same state that was closest in population to the selected county was chosen as a replacement. Although we believe that the families enrolled in the replacement counties were generally comparable to those in the original counties, there may be some differences between them that we cannot quantify.

Also, some early intervention programs in the sampled counties refused to participate in the study. Although this occurred very infrequently, it is possible that the families who would have been enrolled by the refusing programs were different from those enrolled by the participating programs in the county.

An additional reason that information was not collected on all enrolling families was uneven adherence to study recruitment procedures by some enrolling programs. Despite the importance placed on completing the data form for all families, we have reason to believe that not all early intervention personnel completed forms for all families. Some staff misunderstood the directions, and others reported excessive workloads; as a result, they completed forms for some families but not all. We have no reason to believe that families for whom we do not have data differ in any systematic way from families for whom we do have data. To the extent this belief is true, there should be no bias introduced by the incompleteness of information.

Finally, as explained in Appendix A, there is the potential for bias resulting from the weighting approach that was used to represent the portion of the served population in unsampled states in the Eastern and Southern regions of the country. However, given the budgetary limitations on the number of states that could be sampled, we believe that our weighting approach resulted in decreased variability in the sample at the risk of a small potential bias.

2 FINDINGS

Overview

The gender differences seen in older populations of children with special needs also exist among the youngest children. Six of 10 children entering early intervention were boys (See Table 1), a higher rate than their prevalence in the general population of children less than 3 years old (51%; U.S. Census, 1990). The overrepresentation of boys in special needs populations has been noted among school-age children, as well (U.S. Department of Education, 1999).

Children of color were represented more heavily in the early intervention population than in the general population. Whereas 37% of the general population of children ages birth to 3 in 1997 were minority, 44% of children entering early intervention during the study period were minority. The disproportion of children of color results from a higher percentage of African-American children (21%) relative to their numbers in the general population of young children (14%). The percentage of children of Hispanic[1] origin entering early intervention approximated the percentage in the general population: 15% of those entering early intervention were Hispanic, compared with 18% in the general population. Asian/Pacific Islander children were 4.8% of those entering early intervention, compared with 4.3% of the general population of children birth to age 3. American Indian/Alaska Native children made up less than 1 % of both the population of children in early intervention and the general population (.5% vs. .9%).

Table 1
GENDER AND RACE/ETHNICITY OF CHILDREN ENTERING EARLY INTERVENTION

	N	Percentage	Standard Error
Gender	5,663		
Male		60.9	1.1
Race/ethnicity	5,376		
African-American		21.5	1.2
American Indian or Alaska Native		.5	.2
Asian or Pacific Islander		4.8	1.9
Caucasian		55.6	2.0
Hispanic		15.2	2.3
Mixed race or “other”		2.4	.5

The philosophical and empirical basis for early intervention is that providing appropriate services early is of potentially greater impact than beginning services later. Accordingly, an important policy goal

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[1] Children were classified as Hispanic apart from the racial classification. In reducing these two variables to a single variable, Hispanic children were classified as Hispanic regardless of race, whereas other children were classified by the racial category.

is to identify and get children with developmental problems into programs as early as possible. At what age do children receive early intervention? The average age of the children when the referral to early intervention was made was 15.5 months (SE=.7, n=5,346). Their average age at the completion of the Individualized Family Service Plan (IFSP) was 17.1 months (SE=.7). The average age at entry does not adequately describe the study findings with regard to age, however. Figure 1 shows the distribution of the ages in months of children at the time of the IFSP. Each bar shows the percentage of all entering who were a given age in months at entry. The figure clearly shows that children enter early intervention with different frequencies at different ages. More than 38% of children entering early intervention for the first time did so between birth and 12 months of age; in fact, more than one in five entered early intervention in their first 6 months. Another 28% entered in their second year, and more than one-third of children entered early intervention after their second birthdays. Additional data on age at entry is presented in Appendix C, Table C-1.

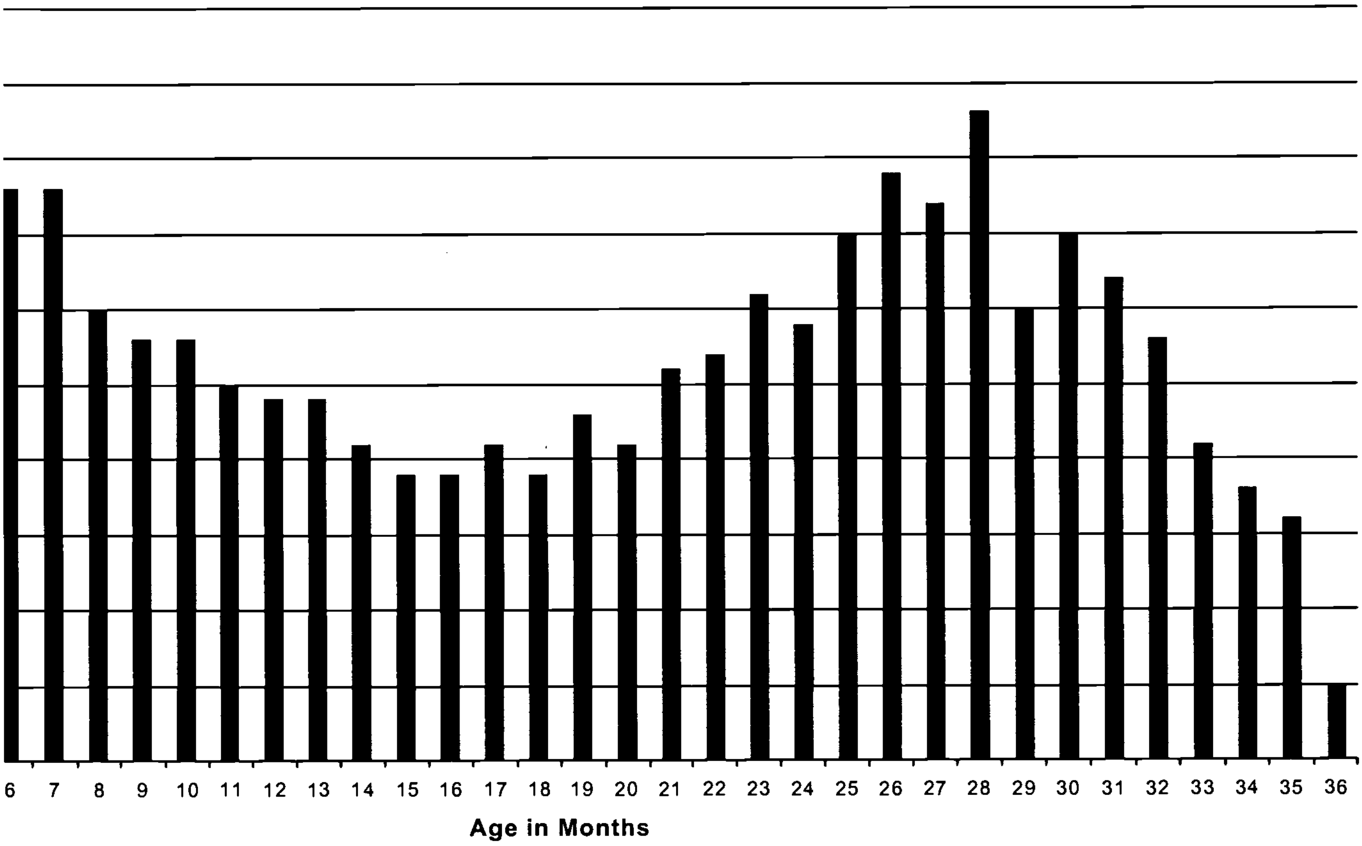
One way to describe children entering early intervention is with regard to the reason for receipt of services. Federal law stipulates the categories of eligibility for receipt of early intervention services. A child is to be provided early intervention services because s/he "(i) is experiencing developmental delays in one or more of the areas of cognitive development, physical development, communication development, social or emotional development, and adaptive development; or (ii) has a diagnosed physical or mental condition which has a high probability of resulting in developmental delay." The federal law also allows states to serve children considered to be "at risk of experiencing a substantial developmental delay if early intervention services were not provided to the individual" (20 U.S.C. §1432, as amended by the Individuals with Disabilities Education Act of 1997).

Local early intervention staff were asked to indicate which eligibility category (diagnosed condition, developmental delay, at risk) was the basis for the child's eligibility for early intervention. More than half of children (58%) were reported to be eligible for early intervention because of a developmental delay, 28% of children had a diagnosed condition that qualified them for early intervention, and 13% were reported to have entered early intervention primarily because they were at risk of developmental delay (see Table 2).

Table 2
REASONS FOR RECEIPT OF EARLY INTERVENTION

	N	Percentage	Standard Error
Providers' selection of reason for receipt of early intervention	5,500		
A developmental delay		58.4	4.7
A diagnosed condition		28.3	2.6
Being at-risk for developmental delay		13.3	3.1
Inferred reasons for receiving early intervention	5,293		
A developmental delay		64.1	4.6
A diagnosed condition		20.4	2.2
Being at risk of developmental delay		15.5	2.7

Figure 1
AGE AT IFSP



We do not know the extent to which the three categories of eligibility in the federal law are used consistently by local service providers. Other study data suggests some inconsistencies in the application of these terms. In addition to checking an eligibility category, local staff were to specify the nature of the diagnosed condition, delay, or risk condition. Staff provided descriptors such as "motor delay" or "intraventricular hemorrhage." A comparison of the descriptors that were written with the category that was checked alerted the research team to some possible variation in use of the terms *diagnosed condition*, *developmental delay*, and *at risk*. For example, a child who was indicated as being at risk was described as being at risk because of a "visual impairment." Another was described as being at risk because of "cerebral palsy." Both of these would be more appropriately classified as diagnosed conditions. Another indicator of inconsistencies in how service providers were using the three terms was that in states that did not serve at-risk children, 10% of the children were identified as being eligible for early intervention because of a risk condition.

To provide a second look at whether children were receiving early intervention because of a diagnosed condition, a developmental delay, or a risk condition, the research team coded each of the descriptors as one of these three categories (see Appendix B for details and the conditions included in each category).

The findings when diagnosed condition, delay, or a risk condition was inferred by the researchers on the basis of the descriptors provided about the reason for early intervention present a similar overall picture to the previous analysis, although the percentages change (Also in Table 2). Most children were eligible for early intervention because of a delay (64%), fewer had a diagnosed condition (20%), or were being served because they were at risk (16%). Additional information about why children are receiving early intervention will be provided by the telephone interviews being conducted with families as part of the study.

Differences by Eligibility Category

Do children who were receiving early intervention because of a diagnosed condition, a developmental delay, or a risk condition differ in other significant ways in addition to their reason for eligibility? For the remainder of the report, we use the reason for eligibility that was inferred by the research team rather than the reason checked by the provider in analyses that include reason for receipt of early intervention.

Gender and Race/Ethnicity. Gender and reason for eligibility were related. The majority of children in each of the three eligibility groups were male, although the disproportion of males was greatest among children with developmental delays (see Table 3). Nearly two-thirds (65%) of these children were male, compared with 52% of children with diagnosed conditions and 54% of those with risk conditions ($p < .001$).

Caucasian children constituted the majority within each of the three eligibility groups, although they made up a higher percentage of children with diagnosed conditions (59%) than of those with developmental delays (57%) and risk conditions (52%). African-American children, on the other hand, were 26% of those with risk conditions but only 21% of those with developmental delays and 19% of those with diagnosed conditions ($p < .001$).

Table 3
DEMOGRAPHIC CHARACTERISTICS OF CHILDREN ENTERING EARLY INTERVENTION, BY REASON FOR ELIGIBILITY

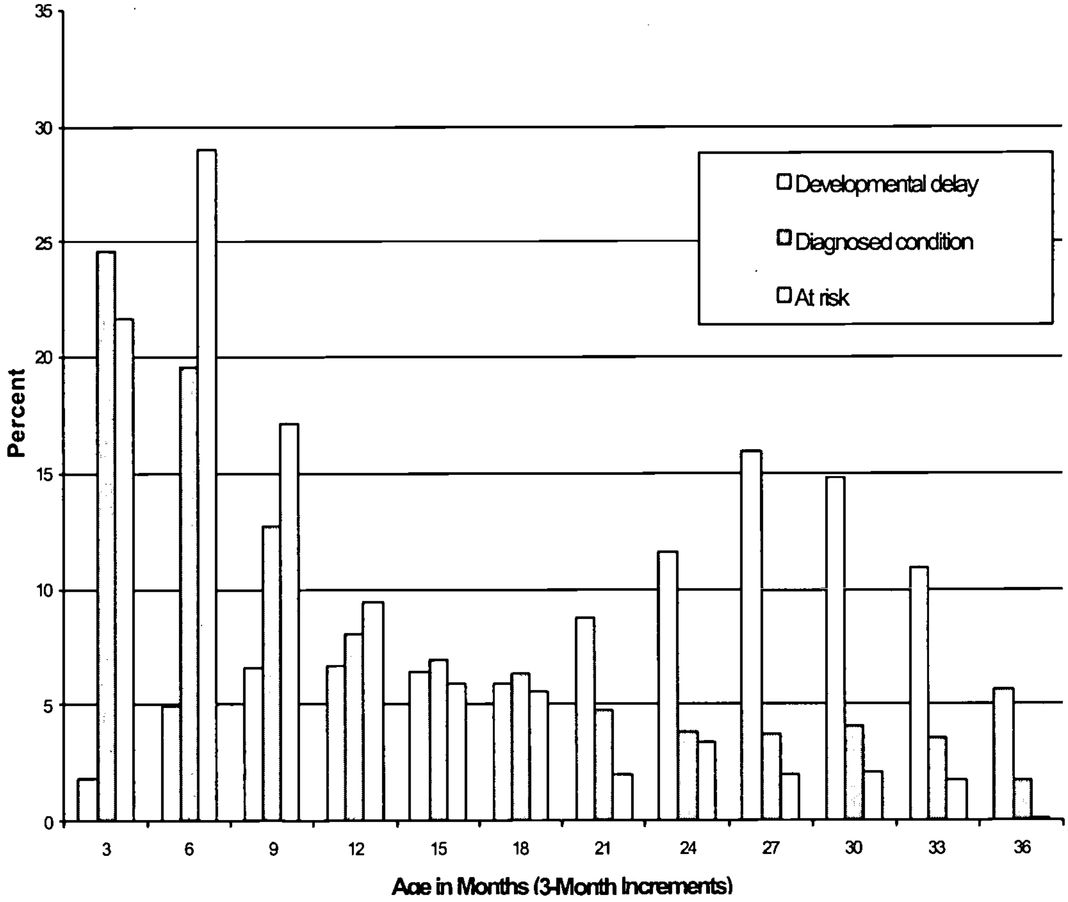
	Inferred Reason for Eligibility[a]		
	Developmental Delay	Diagnosed Condition	At Risk of Delay
Gender—Percentage male	65.0	52.4	54.3
Race/ethnicity (percentage)			
African-American	20.9	19.1	25.8
American Indian or Alaska Native	.6	.2	.2
Asian or Pacific Islander	4.6	4.9	5.6
Caucasian	56.5	58.6	51.7
Hispanic	15.1	15.1	13.1
Mixed race or "other"	2.3	2.2	3.6
Standard Errors			
Gender—Percentage male	1.8	2.0	3.5
Race/ethnicity (percentage)			
African-American	1.4	1.8	3.4
American Indian or Alaska Native	.2	.2	.2
Asian or Pacific Islander	1.6	2.3	2.9
Caucasian	2.2	2.9	3.0
Hispanic	2.2	2.5	4.0
Mixed race or "other"	.4	.6	1.2
N=	3,196 to 3,423	968 to 1,076	706 to 790

[a] Coding of reason for eligibility was based on provider's description of child's disability or risk condition.

Age at IFSP. As noted earlier, early intervention has had a long-standing goal of getting children into services at the earliest possible ages. To begin to understand why some children enter earlier or later, it is important to understand who is entering early intervention at different ages. The average age of children at IFSP differed markedly across the three eligibility categories. Children who were eligible for early intervention primarily because of a developmental delay were significantly older, on average, at entry (21.3 months, SE=.4, n=3,425) than children entering because of a diagnosed condition (10.7 months, SE=.4, n=1,078) or being at risk of delay (8.5 months, SE=.7, n= 790) ($p < .05$ for all comparisons). This finding is not surprising because developmental delays can be diagnosed only when children are old enough to be expected to have developed particular skills and have not yet done so. Some common diagnosed conditions, in contrast, are evident at birth (e.g., Down syndrome, spina bifida), as are some factors that put children at risk for delay (e.g., drug or alcohol exposure, low birth weight).

Previously, we reported that overall more children entered early intervention in the first and third year of life than in the second. Figure 2 illustrates the different patterns of age at IFSP for the three eligibility groups. Each bar shows the percentage of children eligible for that reason who entered early intervention in the 3-month age grouping (e.g., birth to 3 months). The differences in reasons for eligibility explain the age clustering described earlier. Children with diagnosed conditions or risk conditions entered in greater numbers in the first year of life, whereas children with developmental delays were more likely to be identified in the later part of the first three years of life. Of children who were eligible for early intervention primarily because of a diagnosed condition, 44% entered early intervention in their first 6 months of life, as did 51% of those who were eligible primarily because they were at risk of delay. Only 7% of those who were eligible for early intervention because of developmental delay were less than 6 months old at entry. By contrast, 47% of children with developmental delays entered early intervention between 24 and 36 months of age compared with 13% of children with diagnosed conditions and 6% of children who were at risk. The percentage distribution for age at IFSP for the three eligibility groups is included in Appendix C, Table C-2.

Figure 2
AGE AT IFSP BY REASONS FOR ELIGIBILITY



Within each of the three eligibility categories, there were differences in age at entry by gender and race/ethnicity for children with developmental delays but not for those with diagnosed conditions or risk conditions. Males with developmental delays entered services at later ages than developmentally delayed females. Males with developmental delays were 22.1 months old, on average, at the IFSP date, compared with females, who were an average age of 19.6 months (see Table 4, $p < .001$). Within each of the three eligibility groups, children from different racial or ethnic backgrounds entered services at roughly the same ages. A few exceptions occurred among those with developmental delays. Caucasian children were older at IFSP than African-American children ($p < .05$), American Indians ($p < .05$), and "other" or mixed-race children ($p < .001$). Also, Hispanic children were older than African-American children ($p < .01$) and children of "other" or mixed race ($p < .001$).

Table 4
AVERAGE AGE IN MONTHS AT IFSP, BY REASON FOR ELIGIBILITY AND DEMOGRAPHIC CHARACTERISTICS

	Inferred Reason for Eligibility		
	Developmental Delay	Diagnosed Condition	At Risk of Delay
Gender			
Male	22.1	10.9	8.6
Female	19.6	10.6	8.3
Race/ethnicity			
African-American	20.0	10.6	8.0
American Indian or Alaska Native	17.4	--	--
Asian or Pacific Islander	20.7	12.2	9.4
Caucasian	21.7	10.9	8.6
Hispanic	21.6	9.4	7.1
Mixed race or "other"	19.2	10.3	9.2
Standard Errors			
Gender			
Male	.4	.7	.9
Female	.5	.5	.7
Race/ethnicity			
African-American	.7	1.7	.6
American Indian or Alaska Native	2.0	--	--
Asian or Pacific Islander	1.8	1.6	.9
Caucasian	.4	.6	1.2
Hispanic	.5	1.4	1.2
Mixed race or "other"	.6	4.4	3.2
N =	21 to 3,227	24 to 1,030	23 to 756

Note: Average age not reported for sample sizes less than 5.

Disability Descriptors

Earlier in the report, we noted that local staff were asked to provide additional information about the nature of the reason for eligibility for early intervention services. In addition to indicating that the child had a developmental delay, the child's provider also described the nature of the delay, for example, "speech and motor." This additional information was provided for 93% of the children. A total of 305 different terms were used to describe the reasons the children were receiving early intervention. The average number of different descriptors for children with at least one descriptor (n=5,293) was 1.5; the range was 1 to 11.

Each term was coded by using a multilevel, multidimensional classification scheme developed by the research team, as explained in Appendix B. The levels of the coding scheme and the frequencies for each level also are shown in Appendix B. Based on a review of these frequencies, a summary set of frequencies was developed that collapsed some of the less frequent categories at the highest level of the coding scheme and retained some of the more frequent conditions at the lower levels. These findings are shown in Table 5.

Table 5
DESCRIPTIONS OF REASONS FOR RECEIPT OF EARLY INTERVENTION

	Percentage	Standard Error
Delayed development (global)	12.2	1.2
Physical growth abnormality [a]	1.6	.4
Sensory systems impairment	3.3	.4
Vision impairment [a]	1.1	.1
Hearing impairment [a]	1.9	.4
Motor impairment or delay	17.5	1.8
Physiological or neurological system impairment	2.2	.4
Intellectual/cognitive impairment or delay	7.2	1.4
Social/behavioral impairment or delay	3.7	.6
Speech/communication impairment or delay	41.1	3.8
Delay in self-help skills	2.6	.7
Congenital disorders	8.9	.9
Down syndrome [a]	4.3	.5
Prenatal/perinatal abnormalities	18.9	2.6
Low birth weight [a]	11.0	1.6
Prenatal exposures [a]	2.1	.6
Illness or chronic disease	1.8	.3
Musculoskeletal disorders	2.0	.2
Central nervous system disorders	6.5	.6
Cerebral palsy [a]	2.2	.3
Receiving medical treatment	1.4	.4
Social environment risk factors	3.9	1.1

Note: N=5,293

[a] Indented categories also are included in the superordinate category above them.

The most frequently reported reason for receipt of early intervention was a speech/communication impairment or delay. Providers indicated that 41% of the children were eligible for early intervention for problems related to speech or communication. The reader is advised that these data are limited by what providers chose to write down about a child. For children with multiple delays or impairments, some providers probably opted to write down the one or two primary reasons for receipt of services. The percentages are thus conservative estimates of presenting problems and probably are more accurately thought of as minimums. The finding is thus that *at least* 41% of the children entering early intervention had speech or communication problems. Other frequently reported reasons for the receipt of early intervention included prenatal/perinatal problems (19%), motor delays (17%), and an overall delay in development (12%).

As noted above, children began early intervention at different ages, depending on the nature of the reason for their eligibility. Table 6 presents the average age at IFSP for children with each of the disability descriptors. The differences in the average ages at which children with different conditions were entering early intervention were large and highly significant but not surprising. These differences verify that children are entering the early intervention system at ages that are reasonable, given the particular nature of their disability or delay. Children with congenital disorders were the youngest group at entry to early intervention, with an average age at IFSP of 7.9 months. Many of these conditions are identifiable at birth, and these children, therefore, should be entering early intervention when very young. Children with prenatal and perinatal abnormalities also entered early intervention young relative to those with other conditions, the average age at IFSP being 8.2 months. Children with physical growth abnormalities, sensory impairments, or motor delays entered at around 15 months, on average. Children with intellectual, social, or speech/communication delays or impairments began early intervention around age 2.

Table 6
AGE IN MONTHS AT IFSP FOR CHILDREN WITH DIFFERENT DISABILITY DESCRIPTORS

	Mean	Standard Error	N
Delayed development (global)	17.6	1.0	701
Physical growth abnormality	15.3	1.9	87
Sensory systems impairment	15.7	.9	167
Vision impairment	11.9	1.2	61
Hearing impairment	15.9	.5	91
Motor delays	15.2	.3	934
Physiological or neurological system impairment	10.8	.9	123
Intellectual/cognitive impairment or delay	22.7	1.0	380
Social/behavioral impairment or delay	22.2	.7	209
Speech/communication impairment or delay	24.9	.3	2,153
Delay in self-help skills	20.2	1.0	151
Congenital disorders	7.9	.7	502
Down syndrome	5.8	.8	252
Prenatal/perinatal abnormalities	8.2	.6	1,020
Low birth weight	7.2	.8	588
Prenatal exposures	11.5	.8	97
Illness or chronic disease	13.6	1.6	91
Musculoskeletal disorders	8.9	1.0	98

Central nervous system disorders	12.2	.5	339
Cerebral palsy	17.0	1.2	118
Receiving medical treatment	9.1	1.5	73
Social environment risk factors	15.2	1.4	172

Another way to examine the relationship between age at entry and disability is to look at the percentage of children with particular conditions who entered early intervention in the first, second, or third year of life. These data are presented in Figures 3a, 3b, and 3c.

Among children who began early intervention at less than 12 months of age, the most frequent reason for receiving services was prenatal/perinatal abnormalities (at least 40% of those who entered at less than 12 months), with low birth weight being the largest type of prenatal/perinatal abnormality (25% of children less than 12 months old). The second most common reason for receipt of services for this age group was for motor delays or impairments (20%).

The pattern is quite different for older children. Among children who began services between the ages of 12 and 24 months, the most frequent reason for receipt of early intervention was a speech/communication delay or impairment (49%), followed by motor delays (22%) and global developmental delay (15%). Among the oldest children entering early intervention, those 24 months or older, three-fourths (75%) entered early intervention with speech/communication delays. The next most frequent conditions were intellectual/cognitive delays (12%), global developmental delay (12%), and motor delays (11%).

Poverty: Public Assistance and Having a Telephone

Childhood poverty is associated with a variety of detrimental effects on children's development, including physical health, cognitive ability, school achievement, emotional and behavioral outcomes, and later teenage out-of-wedlock childbearing. Poverty that occurs earlier in children's lives and extends over more years has been found to have particularly negative effects (Brooks-Gunn and Duncan, 1997). Poverty occurring in families with young children also can place considerable stress on the families raising them; in fact, poverty has been the one factor most consistently related to child abuse and neglect (Sedlak and Broadhurst, 1996).

Although the enrollment information did not contain a direct measure of poverty, early intervention professionals did report whether the families whose children were entering early intervention received any kind of public assistance (e.g., Temporary Assistance to Needy Families, food stamps)[2]. They also reported on whether or not the family had a working phone in the home.

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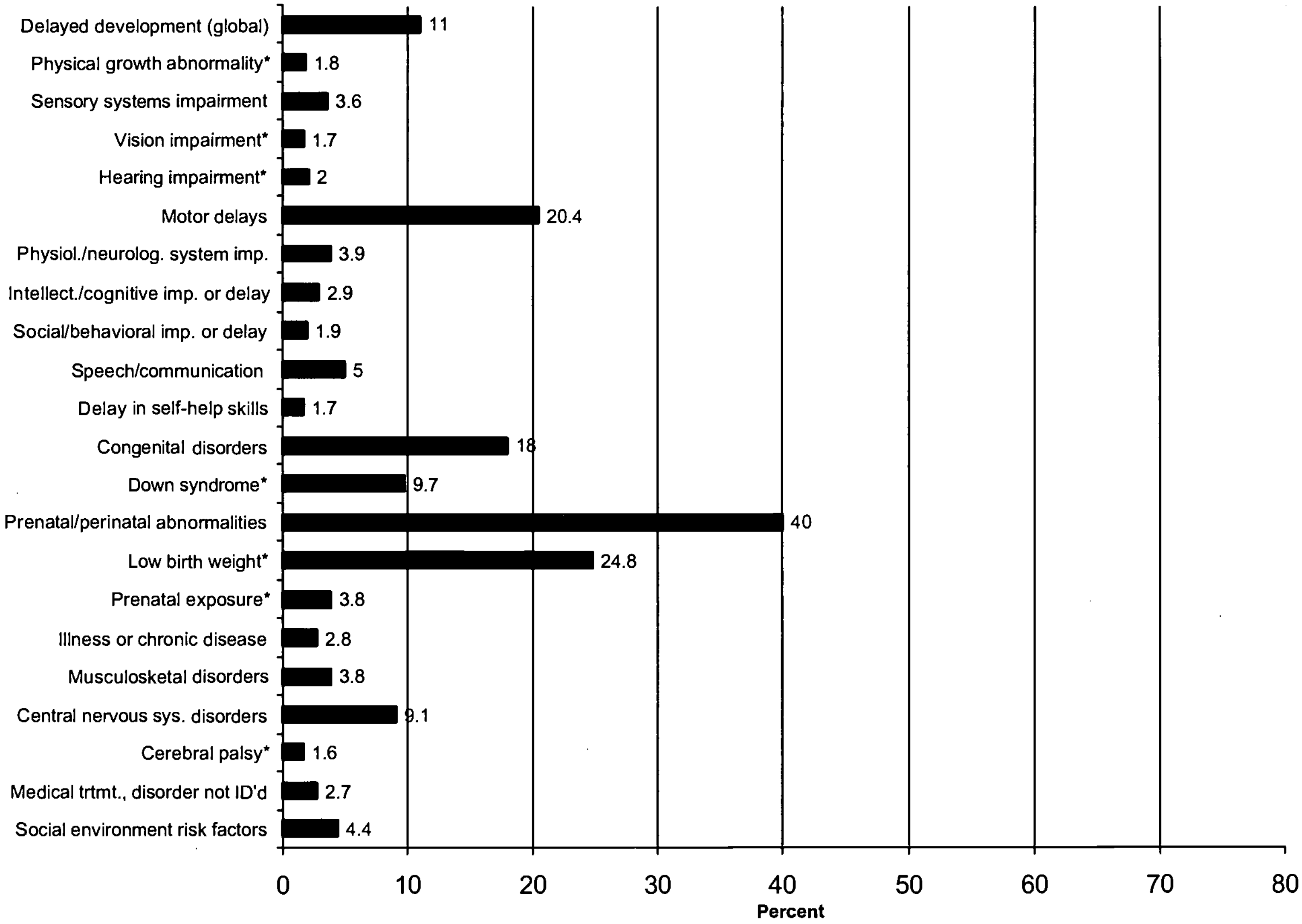
[2] Early intervention professionals were asked to indicate whether anyone in the household "received any kind of public assistance. Public assistance can include food stamps, public housing, welfare benefits (AFDC, TANF), etc." (NEILS, 1997). The kind of public assistance received was not recorded. Additional information about the type of assistance received by families in early intervention will be forth coming in other NEILS data.

Figure 3a
DISABILITY DESCRIPTORS FOR ELIGIBILITY, BY AGE GROUP

Children less than 12 months



Note: Children could have more than one condition. Percentages for all categories are percentages of all children in the age group. Categories with * are subcategories of the major category above them in the list.

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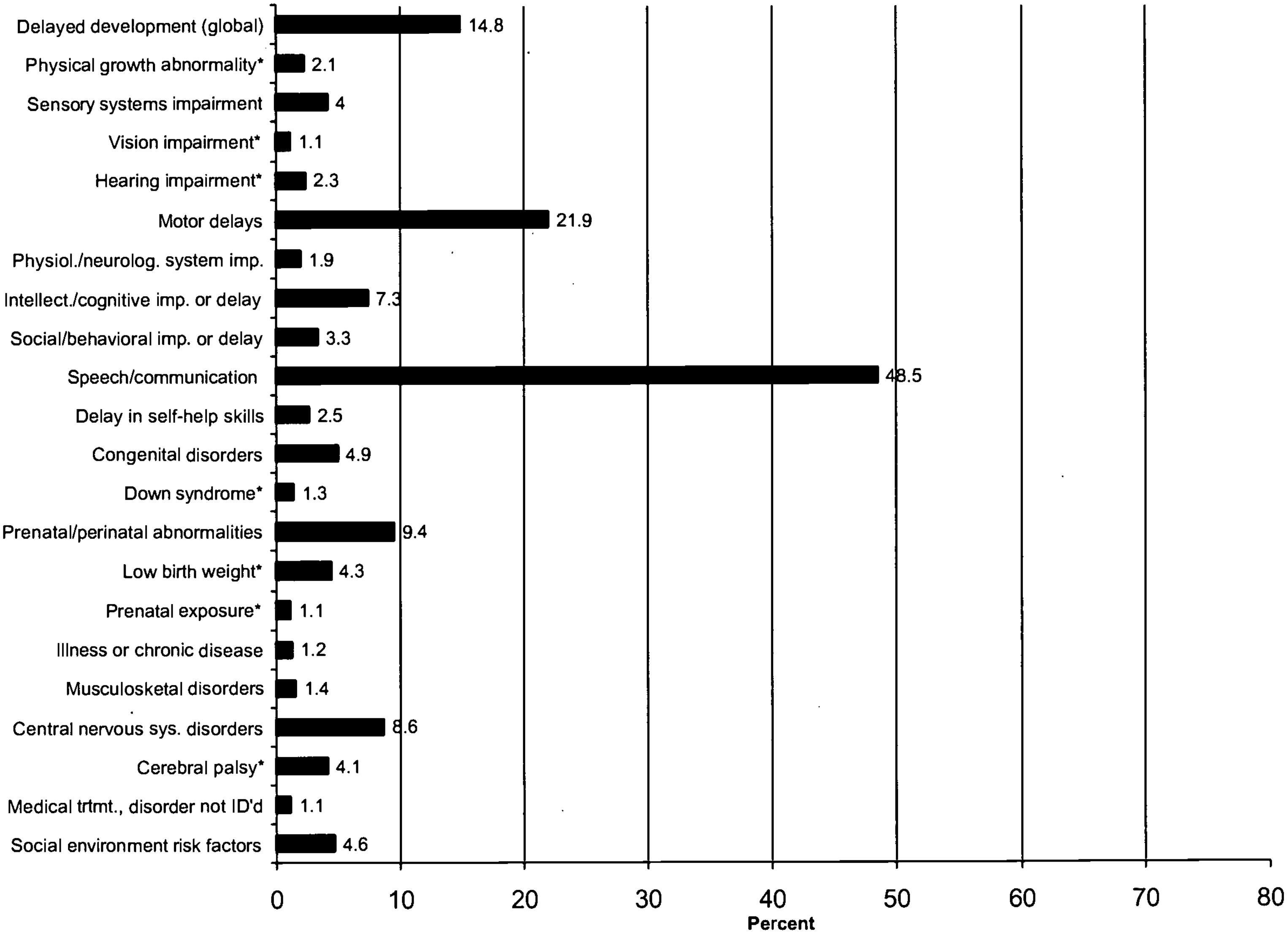
Figure 3b
DISABILITY DESCRIPTORS FOR ELIGIBILITY, BY AGE GROUP

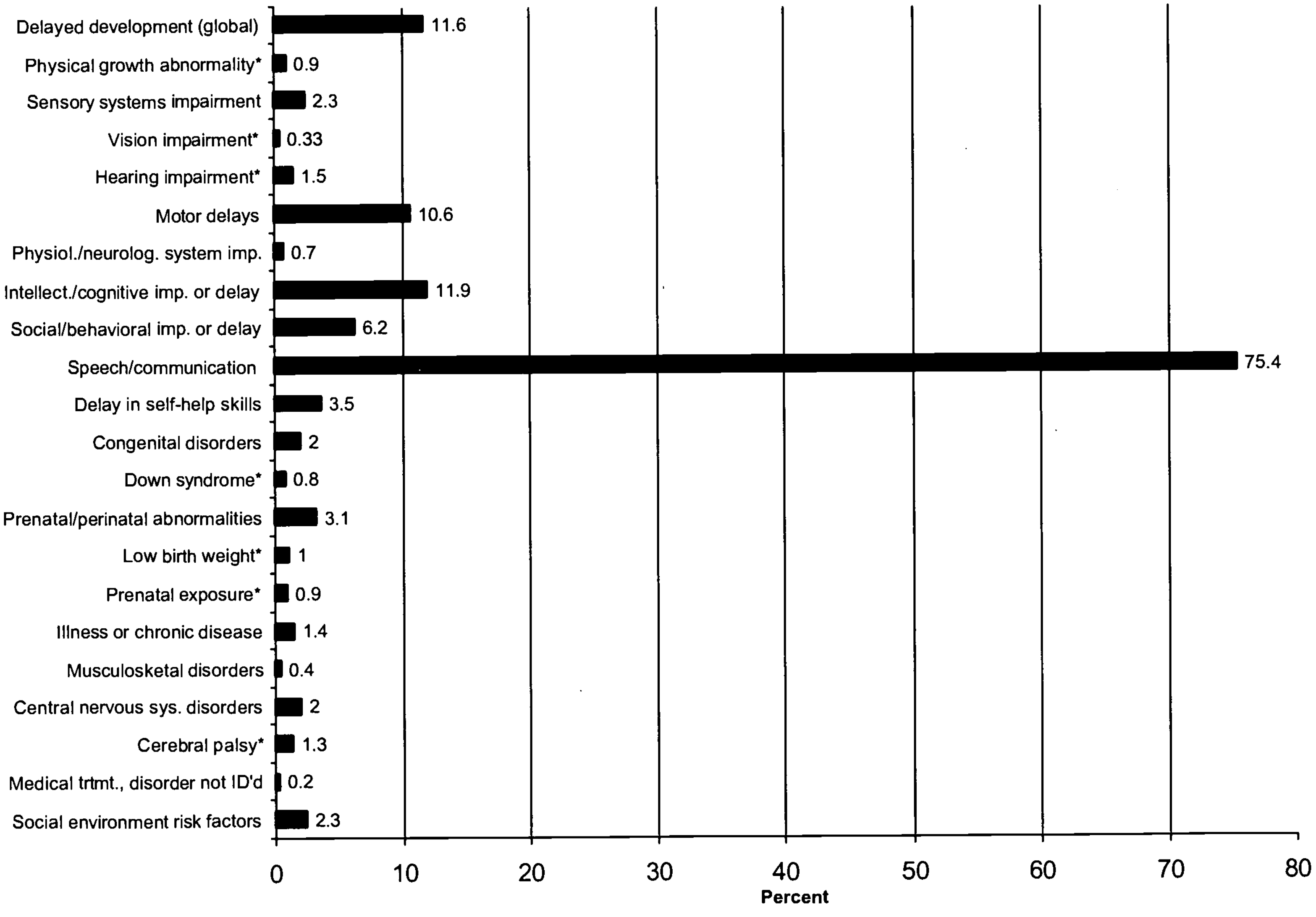
Children 12 months to less than 24 months old



Note: Children could have more than one condition. Percentages for all categories are percentages of all children in the age group. Categories with * are subcategories of the major category above them in the list.

Figure 3c
DISABILITY DESCRIPTORS FOR ELIGIBILITY, BY AGE GROUP

Children 24 months to less than 36 months old



Note: Children could have more than one condition. Percentages for all categories are percentages of all children in the age group. Categories with * are subcategories of the major category above them in the list.

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A large proportion of children entering early intervention were in families who received some kind of public assistance (42%). This is significantly higher than the rates at which families in the general population received AFDC or general assistance (13% in 1995; HHS, 1999) or food stamps (20% in 1995; HHS, 1999). About 5% of families had no working telephone at home. The lack of a telephone probably means that these families had a more difficult time communicating with early intervention professionals about their child and their services, which could translate into less service (e.g., missed home visits) or less effective service for these families.

Infants and toddlers from families receiving public assistance were significantly younger at IFSP than children from families not receiving public assistance (see Table 7; 15.6 months vs. 18.4 months, $p < .001$). Receipt of public assistance also was related to reason for eligibility, with children in families receiving public assistance being less likely to have a developmental delay (61% vs. 67%) and more likely to have a risk condition (19% vs. 12%, $p < .001$). This pattern is consistent with the age differences; children with risk conditions were identified earlier than children with developmental delays.

Children with developmental delays in families receiving public assistance entered services earlier than children in families who were not receiving public assistance (19.3 vs. 22.6 months, $p < .001$). Children with diagnosed conditions from families receiving public assistance were also younger at entry to services (10.0 months vs. 11.3 months, $p < .05$). The reverse pattern occurred for children at risk. Children from families who received public assistance and received early intervention for risk conditions were older than at-risk children in other families (9 months vs. 7.4 months, $p < .05$). There were no differences in age at IFSP within the three categories for families with and without a working phone.

As shown in Table 7, children from families receiving public assistance were less likely to be male (59% vs. 63%, $p < .01$). The racial/ethnic distribution of families in early intervention receiving public assistance differed from that of families who were not receiving public assistance ($p < .001$). Higher percentages of African-Americans were found among families in early intervention receiving public assistance than among those who were not (34% vs. 11%). The pattern was similar for Hispanic families (20% vs. 12%) and reversed for Caucasian families (38% vs. 70%). These differences reflect the racial and ethnic differences in the country as a whole. In 1998, 21% of Caucasian families had an average annual income of less than $25,000, compared with 43% and 41% of African-American and Hispanic families, respectively (U.S. Census Bureau, 1998).

The percentage of children in households with no working telephone was significantly higher among those receiving public assistance, which is not surprising. One in 10 families receiving public assistance had no working phone at home, compared with only 2% of the families in early intervention who were not receiving public assistance ($p < .001$).

Table 7
AGE AT REFERRAL, AGE AT IFSP AND DEMOGRAPHIC CHARACTERISTICS BY RECEIPT OF PUBLIC ASSISTANCE

	Receive Public Assistance	
	Yes	No
Average age in months at referral	13.9	16.7
Average age in months at IFSP	15.6	18.4
Inferred eligibility (percentage)		
Eligible for early intervention primarily because of:		
A developmental delay	61.5	67.2
A diagnosed condition	19.6	20.4
Being at-risk of developmental delay	18.9	12.4
Gender		
Percentage male	58.7	62.5
Race/ethnicity (percentage)		
African-American	34.3	10.9
American Indian or Alaska Native	.8	--
Asian or Pacific Islander	4.0	5.4
Caucasian	37.8	69.9
Hispanic	19.8	11.6
Mixed race or "other"	3.3	1.9
<u>Standard Errors</u>		
Average age in months at referral	.6	.8
Average age in months at IFSP	.6	.8
Eligible for early intervention primarily because of:		
A developmental delay	4.7	4.5
A diagnosed condition	1.5	2.9
Being at-risk of developmental delay	3.7	1.8
Gender		
Percentage male	1.4	1.1
Race/ethnicity (percentage)		
African-American	2.8	1.4
American Indian or Alaska Native	.5	--
Asian or Pacific Islander	2.5	1.5
Caucasian	4.5	2.3
Hispanic	4.2	1.6
Mixed race or "other"	.6	.5
N =	2,027 to 2,162	2,858 to 3,018

Foster Care

The number of children in foster care in this country has increased in recent years, from approximately 262,000 children at the end of 1982 to 483,000 in 1995 (HHS, 1998). More than half of children in foster care are placed there to protect them from adults in their own homes (Tatara, 1990).

Seven percent of children entering early intervention were in foster care at the time, about 10 times the rate at which children in the general population are in foster care (7.3 children per thousand; HHS, 1998).[3] Although the magnitude of this finding is somewhat surprising, its occurrence is not. The same unfortunate life circumstances that have resulted in the child's being in foster care (e.g., maternal drug abuse, neglect) also may have significantly impaired the child's development, and they certainly place the child at risk for developmental problems. Children in foster care entering early intervention present a particularly urgent demand for services coordinated across multiple systems, often including child welfare, public health, mental health, and early intervention (Spiker and Silver, 1999).

Table 8 describes the characteristics of foster care children entering early intervention, compared with children entering early intervention who were not in foster care. Children in foster care were younger at referral than other children, on average. Their average age was 13.2 months, compared with 15.6 months for children who were not in foster care ($p < .001$).

Foster care placement and reason for eligibility were related for children entering early intervention. Children in foster care were less likely to be eligible because of a diagnosed condition than children who were not in foster care (13% versus 21%, $p < .001$) and more likely to be receiving early intervention based on a risk condition (22% vs. 15%). Similarly, the percentage of children in foster care was significantly lower among children with diagnosed conditions (4.4%) than among children with developmental delays (7.0%) or children at risk (9.6%) ($p < .01$). Children in foster care with developmental delays entered early intervention at younger ages than children with delays who were not in foster care (17.8 vs 21.5 months, $p < .001$). There were no differences between those in and not in foster care for children with diagnosed conditions or risk conditions with regard to age at IFSP.

There were no gender differences between children in foster care and other children entering early intervention. Differences in race/ethnicity were startling, however. Although African-Americans were only 14% of children birth to age 3 in this country (U.S. Census, 1990) and 21% of children entering early intervention, 60% of children in foster care entering early intervention were African-American. In contrast, only 20% of those in foster care entering early intervention were Caucasian, whereas 58% of those not in foster care were Caucasian ($p < .001$). With 45% of the children under age 18 in foster

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[3] Early intervention professionals who enrolled children were asked to report "if the child is cared for by someone in a foster care arrangement (e.g., placed with a family by a social services agency), whether or not the child has a legal foster parent" (NEILS, 1997). The difference between the foster care placement rate of children entering early intervention and that for the general population may be affected to an unknown degree by the difference in age between the two groups. The early intervention population is children younger than 3, whereas the figure for the general population includes all children younger than 18.

care being African-American, there is also a disproportionate number of African-American children in foster care in the general population (DHHS, 1999).

Children in foster care also were significantly more likely to be living with families receiving public assistance. Three-fourths (74%) of families with foster children were receiving public assistance, compared with 40% of families with children not in foster care ($p < .001$). It is not clear, however, whether this means that 74% of the families with foster care children were low-income families. Service providers might have indicated the family was receiving public assistance because the family was receiving public funds for the child in foster care. Additional information on this point will become available through the interviews with families.

Table 8
AGE AT REFFERAL AND AT IFSP, AND DEMOGRAPHIC CHARACTERISTICS BY FOSTER CARE STATUS

	Child in Foster Care	
	Yes	No
Average age in months at referral	13.2	15.6
Average age in months at IFSP	15.0	17.3
Eligibility (percentage)		
Eligible for early intervention primarily because of:		
A developmental delay	65.3	64.1
A diagnosed condition	13.0	20.9
Being at risk of developmental delay	21.6	15.0
Gender		
Percentage male	59.5	61.0
Race/ethnicity (percentage)		
African-American	60.2	18.7
American Indian or Alaska Native	--	.5
Asian or Pacific Islander	--	4.9
Caucasian	19.9	58.3
Hispanic	12.0	15.3
Mixed race or "other"	--	2.3
Socioeconomic status (percentage)		
Received public assistance	74.3	39.8
No working telephone at home	--	5.6
Standard Errors		
Average age in months at referral	1.0	.6
Average age in months at IFSP	1.1	.7
Eligibility (percentage)		
Eligible for early intervention primarily because of:		
A developmental delay	7.8	4.4
A diagnosed condition	2.1	2.2
Being at risk of developmental delay	6.6	2.5
Gender		
Percentage male	3.0	1.2
Race/ethnicity (percentage)		
African-American	4.9	1.2
American Indian or Alaska Native	--	.2
Asian or Pacific Islander	--	1.8
Caucasian	3.0	2.2
Hispanic	3.7	2.3
Mixed race or "other"	--	.4
Socioeconomic status (percentage)		
Received public assistance	5.3	1.9
No working telephone at home	--	.5
N =	370 to 426	4,791 to 5,206

3 CONCLUSIONS AND IMPLICATIONS

Who are the children and families entering early intervention? The children are more likely to be male than female, especially if they are receiving services because of a developmental delay. There are more minority children, specifically African-American, among those receiving early intervention than in the general population. Looking at why children are eligible for early intervention, we see that the majority are eligible for services because of a developmental delay. Children enter early intervention at every point throughout the first 3 years of life, but children are more likely to enter in the first year and third year of life. Children with diagnosed conditions and risk conditions constitute the majority of children entering before the first birthday. Children with developmental delays are the majority of those entering after their second birthday. The primary reasons for eligibility for those who begin services as infants are prenatal or perinatal abnormalities, followed by motor delays or impairments. Older children are most likely to be eligible because of a speech/communication impairment or delay. Motor delays continue to be identified through toddlerhood. We have also learned that many families receiving early intervention are receiving some form of public assistance. Children in foster care are substantially overrepresented among children in early intervention.

One of the basic principles of early intervention is that "earlier is better." A sizable body of research substantiating the importance of early development has led policy-makers and program developers to support programs for young children, such as early intervention, and to seek to get children into programs at younger and younger ages. For program administrators and policy-makers, this raises the critical question of whether early intervention is getting children and families into programs at the youngest possible ages. This is not an easy question to answer because, as we have found, children between birth and age 3 experience a tremendous variety of disabilities, limitations, and delays. Many of these conditions currently cannot be identified in early infancy. Considerably more information will be available on this question as more NEILS data become available, but the findings reported here do suggest some possible insights and raise additional questions.

If all children are entering services at the earliest possible ages, then the variation seen in age at entry should be systematic and explainable. For instance, children with conditions related to their birth history or with conditions identifiable at birth should be entering early intervention far earlier than children with developmental delays, which, in fact, we have found to be the case.

When we look within the three eligibility categories to see whether other factors are associated with age at entry, we find that there is little variation for children with diagnosed conditions and risk factors, but that the age of entry for children with developmental delay is associated with several other variables. Of the three eligibility categories, developmental delay is the most subjective, as evidenced by the wide variation in the criteria states have developed for determining developmental delay (Shackelford, 1998). Considerably less consensus exists among professionals as to what constitutes developmental delay than what constitutes a physically based impairment or condition. Furthermore, diagnosing developmental delay requires someone to have sufficient knowledge of development in general and the specific child's development in particular to note a discrepancy and act on it. Minor delays in motor skills or communication can easily go undetected until they become significant delays.

Among children with developmental delays:

- Girls enter early intervention younger than boys (19.6 vs. 22.1 months).
- African-American children enter younger than Caucasian and Hispanic children (20.0, 21.7, and 21.6 months, respectively).
- Children in families receiving public assistance enter earlier (19.3 vs. 22.6 months).
- Children in foster care enter earlier (17.8 vs. 21.5 months).

There are several possible explanations for this variation among children with developmental delays. One explanation is that the children are different. The children being identified earlier may be more seriously delayed, so they would be identified at younger ages. The direction of difference for the latter three findings above is consistent with this explanation, in that African-American children (who typically are poorer than Caucasian children), low-income children, and foster care children are at greater risk and thus could develop more significant delays.

An alternative but not competing explanation for the variation in age at entering services among children with developmental delays is that the service system is seeing or treating different children differently. Girls may be entering services early because parents and primary referral sources may be more alarmed by slower development in girls. People may expect boys to develop, especially talk, later than girls, so they are more likely to wait and see whether the boys catch up. Similarly, primary referral services may be more sensitive to slower development in poor children or foster care children because they are expecting it and therefore watching these children's development more carefully. Also, children in very poor families and in foster care might be better connected to medical care and other primary referral sources likely to detect a possible delay because they have publicly funded health care and use other forms of public assistance. Very young children in families who do not use public services may have less contact with a professional who would notice a delay.

In sum, these data cannot answer the question of whether children are entering early intervention at the earliest possible ages. The data do suggest that children with diagnosed and risk conditions enter at far younger ages than children with developmental delays. This pattern is reasonable, but we don't know whether children within all three groups could be identified and begin services earlier. Within the category of developmental delay, age at entry to services is related to several different factors, raising the possibility that a need exists to further examine and possibly improve the identification process for children with delays.

The apparent predominance in early intervention of children from families receiving public assistance is another important finding from this first NEILS data set. On the basis of the enrollment data alone, it appears that the population of families in early intervention is disproportionately poor. This could be seen as both a negative and a positive finding. It is not surprising that the occurrence of disability and delay in infancy would be related to poverty, since poverty is associated with so many other factors that can impair development (e.g., lack of prenatal care, prematurity, low birth weight, poor nutrition, substance abuse). What is especially troubling for the developmental prospects for these infants and toddlers is that the negative correlates of poverty often continue to hinder development throughout early and middle childhood. The positive aspect of a high proportion of low-income families in early intervention is that these families and children are receiving services that have the potential to positively alter the course of the children's development. Available research suggests that developmental problems would occur more frequently among children from low-income families, so it would be somewhat surprising if they were not overrepresented among those receiving services. On the other hand, there is no benchmark as to what the "true" proportion of low-income families should be. The possibility still remains that poor children with disabilities are not receiving early intervention to the extent they should be.

Children with delays, disabilities, and risk conditions who are also in foster care are beginning life with the odds stacked heavily against them. They have the possible disadvantages of similar children in low-income families plus the added environmental risk of changing caregivers one or more times in early childhood. The outcomes experienced by this group of children will be especially important to watch over the course of the longitudinal study.

In conclusion, this examination of some of the demographic characteristics of children in early intervention has shown that they are not a cross-section of the birth-to-3 population. There are proportionately more males in early intervention than in the general population. Families in early intervention are more likely to be receiving some form of public assistance. Young children in early intervention are far more likely than children in the general population to be in foster care. When we look at the reasons for which children are receiving early intervention, we see that most children are eligible because of a developmental delay and that these children are likely to enter early intervention later than children with a diagnosed condition or a risk condition. We also see that although there are patterns of entry, children enter early intervention at every month within the birth-to-3 age span and that they are receiving early intervention for many different conditions.

Additional information from the National Early Intervention Longitudinal Study will be summarized in a series of reports over the next several years. The next reports will focus on data from the interviews conducted with families shortly after they entered early intervention services. These reports will look in more depth at the characteristics of children and families in early intervention and at their initial experiences with the early intervention system. Additional reports will address the services received and the characteristics of the providers and their programs.

APPENDIX A

METHODS

In this section, we describe the sampling procedures for selecting the NEILS states, counties, and families; the weighting procedures that enable us to generalize from the sample to children and families who enroll in Part C early intervention programs nationally; the source of the enrollment data reported; data analysis procedures; and limitations of the data.

Sampling Procedures

State Sample

A sample of 20 states was selected for the study. The nine states serving the largest number of children in early intervention were selected for the sample with certainty: California, Florida, Illinois, Massachusetts, New York, North Carolina, Ohio, Pennsylvania, and Texas. At the time of the state sample selection, these nine states served about 60% of all Part C children in the country. To select the remaining states, the country was divided into three regions, and states were selected from each region. The additional 11 states are: Arkansas, Colorado, Hawaii, Idaho, Kansas, Maryland, Michigan, Minnesota, New Mexico, South Carolina, and South Dakota. The 20 NEILS states are diverse with regard to population, region of the country, lead agency, whether they serve at-risk children, and the percentage of the birth-to-3 population served in Part C.

County Sample

The concept of "community" within the context of Part C is difficult to describe because of the within-state variation in how early intervention is implemented. Although all states are divided into local jurisdictions for the provision of services, the nature and size of these jurisdictions vary from state to state and within states. For the NEILS sample, counties were selected as the local sampling unit because they exist in all states, their boundaries are clear and do not overlap, and many public service-providing agencies are organized by counties.

Three to seven counties per state were selected to recruit families for the study, for a total of 93 counties across the 20 states. Counties were selected randomly, with the probability of selection being proportional to the size of the birth-to-3 population in the county, with the additional criterion that there be at least 10 children projected to be served annually under Part C in a county. This latter provision was necessary to assure a level of efficiency and cost-effectiveness in sample recruitment.

Originally 83 counties were selected for the study. Three counties declined to participate, and were replaced with comparable, preselected counties in their states. At least one early intervention program in each of these 83 counties agreed to participate in the study. Several months before the end of the enrollment period (described below), it became clear that the desired number of children would not be recruited in these counties. At this point, 10 counties were added to the sample, following the same sampling procedures, for a total of 93 counties. Additional information about the sampling procedures is presented in Hebbeler and Wagner (1998).

Child Sample

Each county was assigned a number of children and families to recruit for the study. The number was based on the number of children served in early intervention in the state and on the county's population.

Two samples have been recruited as part of NEILS. The first sample, referred to as the enrollment sample, is the sample on which all of the analyses in this report are based. It includes all children who lived in the sample counties[4] and were being enrolled in Part C early intervention for the first time[5] during their county's recruitment period.[6] This sample includes 5,668 children.

A second sample, which is a subset of the first, will be used in the majority of NEILS analyses; it is referred to as the study sample. These are children who met criteria for study participation and for whom an adult provided written consent for the child's and family's participation in the study. Eligibility for the study participant sample required that the child and family meet the criteria for the first sample, as well as:

- Being less than 31 months of age at the time the IFSP was signed.
- Having an English- or Spanish-speaking adult in the household who could answer questions about the child and family.
- Being the only child in the family recruited for the study (siblings and other children of multiple birth sets were excluded).

No analyses in this report are based on the study sample.

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[4] Children who were enrolled during the recruitment period but who had already been in Part C early intervention previously were excluded from the enrollment data collection. However, children were not excluded if they were enrolled for the first time but were part of a family that had received early intervention previously for a different child. Multiple children in a family were included in the enrollment sample, although not in the study sample, as long as all children were being enrolled for the first time during the recruitment period.

[5] Recruitment periods were assigned to each county by NEILS staff. The length of the period for each recruiting program was calculated by dividing the number of families needed for the study sample by an estimate of the total number of families who entered early intervention at the recruiting program in a year. This proportion was then multiplied by 12 months to determine the number of months the program was estimated to need to enroll the target number of study families. For example, if 50 families were needed for the study sample and the recruiting program reported recruiting 300 families in a year, the recruitment period would be 2 months (i.e., 50/300 x 12). The enrollment period was extended for programs whose enrollment rate was slower than expected, which would have resulted in a recruitment shortfall without an extension to the recruitment period. Despite extensions of the recruitment period for some counties, not all reached their recruitment targets by November 30, 1998, the end of the study recruitment period.

[6] December 1 is the date on which the state child count is taken for federal reporting purposes.

Data Source

The data reported here were provided by early intervention personnel in sample counties who enrolled families into early intervention. They were asked to complete a *NEILS Family Information Form A* (Exhibit A-1) for all children who met the criteria for the enrollment sample during their county's study recruitment period. Local personnel were asked to complete an enrollment form within 30 days of the signing of each family's IFSP. Completed forms were mailed to SRI, where they were reviewed for completeness and processed for computer analysis. There was no personally identifying information on these forms. An additional form was completed for children who met the criteria for the study sample and whose parents agreed to participate in NEILS.

Sample Weighting Procedures

Three weights were calculated for each child enrolled in early intervention in sampled counties during the enrollment period for whom enrollment data were provided:

- Weight 1 (denoted W1) was the value necessary to project the enrollees in each sampled county to the total number of early intervention enrollees in that county during an entire year.
- Weight 2 (denoted W2) was the value necessary to project the total number of enrollees during a year in the sampled counties to the total number of enrollees in the state on December 1, 1997.[6]
- Weight 3 (denoted W3) was the value necessary to project the total number of enrollees on December 1, 1997, in the sampled states to the number of early intervention enrollees on that date in the region containing those states.

The final weight for each sample enrollee was the product of the three weights (that is, W1 x W2 x W3). The procedure for determining each weight is described below.

Weighting to County Totals

The first step in weighting the sample enrollees was to weight the enrollees in each sampled county to the total number of early intervention enrollees in that county during a 1-year interval. For example, if there were 20 sample enrollees in a county and we had estimated that during a year the county would enroll 200 early intervention participants, then the first weight (W1) for each sample enrollee in the county would be 10. The challenge in performing this calculation was that the yearly number of early intervention enrollees in a county was not known and needed to be estimated.

Two estimates of the number of early intervention enrollees in the sampled counties were available. The first estimate was derived via the following two-step process:

Exhibit A-1

NEILS Family Information Form—Form A

Complete for EVERY family who reside in this county and who have completed their first IFSP.

1. Child's date of birth *(MM/DD/YY)* ______________
2. Child's gender *(Circle one number)* **1**----Female **2**----Male
3. Is child of Hispanic origin? *(Circle one number)* **1**----Yes **2**----No **3**----Don't know
4. Child's race *(Circle one number):*
    - **1**----White **2**----Black or African American **3**----American Indian or Alaskan Native
    - **4**----Asian or Pacific Islander **5**----Other ____________________________ **6**----Don't know
5. Is child in foster care? *(Circle one number)* **1**----Yes **2**----No
6. Does family have a working phone at home? *(Circle one number)* **1**----Yes **2**----No
7. Does family receive any kind of public assistance? *(Circle one number)* **1**----Yes **2**----No
8. Reasons for child's eligibility for early intervention services *(Circle one number)*
    - **1**----Diagnosed condition--Please specify: ______________________________
    - **2**----Developmental delay--Please describe: ______________________________
    - **3**----At risk--Please describe: ______________________________
9. Date of referral for early intervention services *(MM/DD/YY)* ______________________
10. Date IFSP signed/completed *(MM/DD/YY)* ______________________

NEILS INVITATION CRITERIA

1. Was the child younger than 31 months old on the date the IFSP was signed? *(Circle one number)*
    1----Yes **2**----No
2. Is there an English- or Spanish-speaking adult in the household to respond to a phone interview? (Circle one number)
    1----Yes **2**----No
3. ONLY ONE CHILD PER FAMILY IS ELIGIBLE FOR NEILS. Is this **the only child** from this family starting early intervention **OR** if there are multiple children from the same family in early intervention, is this the **one child** eligible for NEILS (per instructions on pages 5-6 of the NEILS Enrollment Procedures Manual)?
    1----Yes **2**----No

☐ If **YES** to **ALL** of the criteria above, invite the family to participate in NEILS.
Go to the NEILS Enrollment Form–Part B.

☐ If **NO** to **ANY** of the criteria above, the family is not eligible for NEILS.

STOP HERE. Return forms to the NEILS Enrollment Coordinator for your site for mailing to SRI.

Questions? Call the NEILS Hotline toll free: 1-800-682-9319

- The number of early intervention enrollees in the state on December 1, 1997, was divided by 3.0 to account for the fact that the participants on this date were enrolled over the preceding 3-year period and we needed a yearly enrollment value.
- The resulting number of early intervention enrollees in the state was allocated to the counties on the basis of U.S. Census Bureau information concerning the number of residents in the county.

This estimate was relatively easy to calculate but had the following limitations:

- The number of early intervention participants on December 1, 1997, underestimates the total number of enrollees over a 3-year period, because some enrollees in the 3 prior years would have left the program before this date.
- The estimation procedure does not adjust for county wealth. Research suggests that poorer counties may have proportionally more early intervention enrollees.

The second estimate of the number of early intervention enrollees over a 1-year period was derived from the IFSP dates of the early intervention enrollees during the study enrollment period. That is, we calculated the number of enrollees per day during the enrollment period and multiplied that value by the number of days per year. This estimate had the following limitations:

- The IFSP dates were not always within the period of time spanned by the study. Dates before the start of the study enrollment period were not counted in the enrollment estimation process.
- Some counties appeared to start the enrollment process, record the IFSP dates of one or two early intervention participants, then stop enrollment for an extended period of time. Presumably, these were counties with a "false start." We used an outlier estimation procedure to identify these false starts and did not count the outliers in the enrollment estimation process.
- Some counties appeared to start the enrollment process, eventually stopped enrolling, and then many days later enrolled one or two more children. Presumably, these were counties that stopped enrolling thinking that they had reached their study enrollment target, realized that they were still marginally short of the target, and then enrolled the last few children that were needed. We used an outlier estimation procedure to identify these "restarts" and did not count the outliers in the enrollment estimation process.
- Some counties enrolled only a portion of their early intervention participants. Typically, this occurred when there were multiple sites or persons involved in enrollment and only a portion of those sites or persons participated in the study.

Our final estimate of the number of yearly early intervention enrollees in each county was the maximum of the first and second estimates, subject to the limitation that the number estimated could not exceed three times the first estimate (derived from the county population projection procedure).

One variation on this procedure involved substitute counties. Three counties that were selected for the sample were unwilling or unable to participate, and others that participated were not able to fulfill their quotas. In this situation, we selected one or more substitute counties for each selected county. Substitute counties typically were those with the closest number of children in the birth-to-3 age range and, therefore, with almost equal probabilities of county selection. If the originally selected county did not participate, enrollees from the substitute counties were weighted as if the substitute county had been selected from the start. If the originally selected county was able to provide some enrollees, the additional enrollees from the substitute counties were weighted as if they had been enrolled in the originally selected county. However, in the latter case, they were not counted when determining the number of enrollees in a year from the originally selected county.

Weighting to State Totals

The estimated numbers of enrollees in sampled counties over a 1-year period were weighted to state totals of the number of early intervention participants on December 1, 1997, via a four-step process:

- The inverse of the probability of county selection was calculated for each selected county, denoted as Y. For example, if the probability of selecting a particular county was 20%, then the inverse would be Y = 5. (Counties were originally selected from a state with probabilities that were proportional to the population-based estimate of the number of early intervention enrollees. Consequently, large counties tended to have larger probabilities of selection and smaller Y values, and vice-versa for small counties. However, counties with fewer than 10 estimated early intervention enrollees were not candidates for selection for budgetary reasons.)
- The quantity W1 x Y was calculated for each sample enrollee and summed over all enrollees in the state, denoted as Z. This is an estimate of the number of early intervention enrollees per year in the entire state.
- Let Q denote the total number of early intervention participants in the state on December 1, 1997. The quantity (Q/Z) was calculated. This is a ratio of the estimated number of early intervention participants in the state on December 1, 1997, to the estimated number of yearly enrollees in the state.
- The second weight was calculated as W2 = (Q/ Z) x Y. This weight projects the number of yearly enrollees in the sampled counties during an entire year to the number of early intervention participants on December 1, 1997.

Weighting to Regional Totals

The numbers of early intervention enrollees on December 1, 1997, in the sampled states were weighted to the numbers of early intervention enrollees on December 1, 1997, in the regions containing those states. For example, the Southern region contained 10 states, of which 6 were sampled. The total early intervention enrollment on December 1, 1997, in those 10 states was 52,895, and the total early intervention enrollment in the sampled states on that date was 36,283. The third weight for all enrollees in the sampled Southern states was calculated as W3 = 52,895 / 36,283 = 1.458. The other regions were the East, the West excluding California, and California. In the East, there were a total of 7 sampled states out of 20 states, accounting for 73,617 early intervention families out of 98,629 in the region. In the West excluding California, there were a total of 6 sampled states out of 17 states, accounting for 10,890 early intervention families out of 24,000.

In calculating W3, we did not adjust for the relative probabilities of state selection. States with the largest early intervention enrollments in a region were selected with certainty; a few others in each region were selected with probability proportional to early intervention enrollments. Use of traditional weighting formulas would have resulted in the states selected with certainty having W3 = 1.0 and states selected with less than certainty having larger weights. (For example, in the Southern region, the three states selected with less than certainty would have had weights averaging about 3.0.) Allowing the few states not selected with certainty to represent the remaining nonselected states would result in substantial variance in our estimates. We felt that the set of all selected states was as similar to the nonselected states as was the set of states that were not selected with certainty; we were willing to trade off the possibility of some small bias for the resulting reduction in sample estimate variance.

Data Analysis Procedures

All data were analyzed by using SUDAAN (Shaah, Barnwell, and Bieler, 1997). Standard errors in SUDAAN were estimated by the method of pseudo-replication. Twenty replicate samples were generated. Each sample consisted of half of the states, except that all samples included California (which was its own region). Each replicate contained half of the counties in California. Replicates were balanced in the sense that all states and California counties appeared in exactly half of the replicates. Separate weights were calculated for each replicate with the same procedure as was used for the full sample.

The data tables included in this report present data for the full sample of infants and toddlers with disabilities and for important subgroups (e.g., children who were eligible for early intervention for different reasons). Most of the variables presented in the tables are reported as weighted percentages of the children in the full sample or in the subgroups. In some cases, rather than percentages, the figures refer to means, such as the mean age at which children entered early intervention. Percentages and means are weighted to represent the national population of children entering early intervention. However, the percentages and means are only estimates of the actual percentages and means that would be obtained if all children entering early intervention were included in the study. These estimates vary in how closely they approximate the true measures that would be derived from a study of all children entering early intervention. To aid the reader in determining the precision of the estimates, for each percentage and mean the tables present the approximate standard error and the unweighted number of cases on which the statistic is based.

To determine the precision of a particular percentage of mean, the reader can construct a confidence interval for the estimate by multiplying the standard error by 1.96. The result is the range around the estimate within which the true measure would be found 95 out of 100 times. For example, NEILS estimates that 60.91% of the children entering early intervention are male. The standard error of that estimate, 1.09, is multiplied by 1.96, letting us assume with 95% confidence that the true percentage of males falls within a range of ± 2.14 percentage points of 60.91%, or between 58.77% and 63.05%.

Readers also may want to compare percentages or means for different subgroups to determine, for example, whether the difference in the average age at enrollment into early intervention between children who are eligible because of a developmental delay and those who are eligible because of a diagnosed condition is statistically significant. To calculate whether the difference between two values is statistically significant with 95% confidence (denoted as $p < .05$), the squared difference between the two values of interest is divided by the sum of the two squared standard errors. If the result is larger than 3.84, the difference is statistically significant. Presented as a formula, a difference between two values is statistically significant at the .05 level if:

$$\frac{(V_1-V_2)^2}{SE_1^2 + SE_2^2} > 1.96^2$$

where V_1 and SE_1 are the first value and its standard error and V_2 and SE_2 are the second value and its standard error.

In comparisons between two or more groups, the level of significance of the differences between the groups is indicated in the text.

Data Limitations

As explained in the introduction to the report, the most notable limitation on the data reported here involves the potential for bias resulting from incomplete data. SRI made every effort to obtain enrollment information for every family that lived in the sample counties and enrolled in early intervention for the first time during the study recruitment period. However, there were several reasons that we did not receive information for all such families.

Three counties that were sampled for the study refused to participate. In such cases, a county in the same state that was closest in population to the selected county was chosen as a replacement. Although we believe that the families enrolled in the replacement counties were generally comparable to those in the original counties, there may be some differences between them that we cannot quantify.

Also, some early intervention programs in the sampled counties refused to participate in the study. This occurred very infrequently. The first reason involved the refusal to participate in the study on the part of some early intervention programs in a few counties. In this case, the target number of families needed for recruitment into the study were allocated to the remaining programs in the county. However, it is possible that the families who would have been enrolled by the refusing program were different from those enrolled by the participating programs in the county. This could occur, for example, if the refusing program served a geographic area in the county with a population that differed markedly from that of the geographic area served by the other programs (e.g., a center city vs. a suburban area) or if the refusing program enrolled children with a specific kind of disability and those children generally were not enrolled by the participating programs. If refusing programs did enroll a different clientele than participating programs, bias would be introduced into the enrolled sample. However, it is impossible to know the extent to which bias has been introduced into the study or the kind or amount of bias that may have resulted from the refusal of some programs to participate in the study.

An additional reason that information was not collected on all enrolling families was uneven adherence to study recruitment procedures in some enrolling programs. Local enrollment personnel were told that "It is critical that we get the information on the *NEILS Family Information Form A* for all families who complete their initial IFSP during your county's enrollment period. This information will allow us to describe the population of children and families entering early intervention for the first time and to determine the extent to which families who choose to participate differ from those who choose not to participate in NEILS" (NEILS, 1997). No family identification information was included on Form A, to remove any disincentive to completing the form that might have resulted from concerns about anonymity.

Despite the importance placed on completing Form A for all enrolling families, we have reason to believe that not all early intervention personnel completed forms for all families. Sometimes this resulted from a misunderstanding of enrollment procedures that was corrected by SRI site liaisons when it was discovered. In other sites, program staff reported that excessive workloads led them to complete forms during some time periods only for families who also agreed to participate in the study. When this circumstance was discovered by SRI, we were sometimes able to have sites complete enrollment information for the missed families retroactively, using data available in their program files. We were not successful in recovering data in all cases, however.

We have no particular reason to believe that families for whom we do not have data differ in any systematic way from families for whom we do have data, so there is no known bias introduced by this incompleteness of information.

Appendix B

CODING OF DISABILITY TERMS

Coding System

The NEILS research team developed a system to code the terms supplied by early intervention providers to describe the reason why the child was eligible for early intervention. The coding system is based on the premise that infants or toddlers who are eligible for early intervention services manifest delays in basic domains of development, have the presence of a condition that serves as a proxy for developmental delay, or are subject to environmental factors that are highly associated with developmental delay. The basic domains of development where delay is manifested are associated with limitations of body or organ functions (e.g., sensory, motor, mental) or manifested as limitations in the performance of skills and activities (e.g., learning, communication, self-help, social interaction).

Assignment to the developmental delay category assumes that some form of measurement has been made that meets the criteria established for developmental delay in that state (Shackelford, 1998). Eligibility criteria for intervention in most states are based on documentation of one or more of three forms of evidence: (a) impairments of function and/or limitations in performance of activities, as measured by deviation units or percentage deficit; (b) specific medically diagnosed conditions known to be associated with developmental delay; or (c) the presence of biological or environmental factors that place children at risk for developmental delay.

Coding the reasons for eligibility for Part C services was based on the premise that the eligibility terms supplied by providers could be associated with at least one of these three forms of evidence. A preliminary review of a sample of 225 terms from Form A revealed 130 distinct codable terms, but no single available coding system was sufficient to code a majority of the terms. Of the classification systems reviewed, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH, WHO, 1980; ICIDH-2, WHO, 1997) captured the majority of terms related to impairments of function and/or limitations in performance of activities, which are most closely related to the various developmental delay criteria. The International Classification of Diseases, 9th Revision (ICD-9, 1999) permitted coding of medically diagnosed conditions and biological risk conditions, such as prematurity. Environmental risk factors were coded by using V codes, as summarized in *The Classification of Child and Adolescent Mental Diagnoses in Primary Care (DSM-PC)* (Wolraich, Felice, & Drotar, 1996) and detailed in the ICD-9.

Coding Process

A decision tree was developed for use in reviewing and coding (see Table B-1) the reasons provided for documenting a particular child's eligibility. The coder used the decision tree to assign appropriate codes from the selected classification systems. The use of the decision tree was accompanied by summary charts for the ICIDH (WHO, 1980, 1997) for specific impairments and activity limitations, the ICD-9 for medically diagnosed conditions, and the DSM-IV PC (Wolraich, Felice, & Drotar, 1996) and ICD-9 (1999) V codes for environmental risk characteristics. To code the reason for a given child's eligibility, the term(s) written by the early intervention provider were reviewed sequentially for applicability to questions A through D of the decision tree. If the answer to the first question was affirmative, the term was coded using the item and subitem that was applicable, using either the alphabetized or numbered summary chart of specific codes. If the answer was negative, the coder proceeded to the next question to examine applicability. Using this approach through question D allowed assignment of all reasons to applicable codes.

A research assistant who was familiar with eligibility terms and the various coding systems reviewed all the terms provided by providers for each participating child. Codes were entered directly into a database that was used to create the file for data analysis. Approximately 7,000 terms were coded. These codes were used to electronically generate a systematized code list based on the question hierarchy (Table B-1). An independent coder checked a random sample consisting of about half the terms, using the generated code list and the ICD-9. Computer programming was used to check codes for consistency, providing a near perfect level of accuracy. Questionable terms were reviewed by three members of the research team to determine codability. The resulting frequencies for the most detailed level of the coding system are shown in Table B-2.

Recoding of Developmental Delay, Diagnosed Condition, and At Risk

The research team developed a second system to classify the resulting codes into the categories of developmental delay, diagnosed condition, or risk conditions. Although the providers had indicated the child as being eligible on the basis of one of these criteria, the inconsistency with which these three categories were applied led the researchers to question the validity of the data. To maintain consistent usage, the research team reclassified each child into one of the three eligibility categories on the basis of derived codes.

The complete list of terms was circulated among four members of the research team, and each independently indicated which of the three eligibility conditions applied to each term. Any terms on which the team did not agree were then discussed until a consensus was reached as to how they should be classified. The classification applied to each term is shown in the last column of Table B-2. These classifications are the basis for the findings related to "inferred eligibility" described in the report. For children with descriptors classified as more than one of the three eligibility conditions, hierarchical assignment to an eligibility condition followed the order: children with developmental delay and either or both of the other two eligibility conditions were classified as developmental delay; children with a diagnosed condition and a risk condition were classified as having a diagnosed condition.

Table B-1
QUESTION HIERARCHY FOR CODING REASONS FOR RECEIPT OF EARLY INTERVENTION

A. Does the reason documenting eligibility describe a significant variation in development, form, or function of physical, sensory, motor, physiological, neurological, or psychological systems? A significant variation includes delay, loss, restriction, impairment, and deficiency of development of function.

No [Go to question B.]

Yes

↓

CATEGORY I

- A: Development
  - Development – Mental
  - Development – Physical
- B: Somatic systems
- C: Sensory Systems
  - Sensory Systems: Vision
  - Sensory Systems: Hearing
- D: Motor Systems
  - Motor Systems: Gross
  - Motor Systems: Fine
  - Motor Systems: Oral
  - Motor Systems: Apraxia
- E: Physiological Systems
  - Physiology: Cardiovascular
  - Physiology: Respiratory
  - Physiology: Digestive
  - Physiology: Endocrine/metabolic
  - Physiology: Urological
  - Physiology: Lymphatic/hematol/immunologic
- F: Neurological
- G: Psychological
  - Psychological: Intellect/cognitive
  - Psychological: Affective
  - Psychological: Language

B. Does the reason documenting eligibility describe a limitation or delay in the performance of one or more activities of daily life?

No [Go to question C.]

Yes

↓

CATEGORY II

- I: Learning
- J: Transferring Body
- K: Moving Around
- L: Communication
- M: Self-Help
  - Self-Help: Daily living
  - Self-Help: Toileting
  - Self-Help: Feeding skills
  - Self-Help: Instrumental activities: Daily living
- N: Social Interaction
- O: Behavior
  - Behavior
  - Behavior: With objects
  - Behavior: With people
- P: Other Specified

C. Does the reason for documenting eligibility describe specific health conditions, syndromes, or diagnoses associated with delayed or atypical growth or development?

No [Go to question D.]

Yes

↓

CATEGORY III

- Q: Congenital Disorders
  - Congenital: Chromosomal/gene
  - Congenital: Other anomaly
- R: Prenatal/Perinatal Factors
- S: Infections
- T: Other Illness/Injury
- U: Chronic Diseases/Neoplasms
- V: Musculoskeletal Disorders
- W: Central Nervous System Disorders
- X: Other Specified

D. Does the reason for documenting eligibility describe environmental factors (i.e., lack of, atypical, restricted, etc.) highly associated with risk for delayed or atypical development?

No

Yes

↓

CATEGORY IV

- Y: Physical Environment
  - Physical Environment
  - Physical Environment: Product/objects/materials
  - Physical Environment: Immediate environment
- Z: Social Environment
  - Social Environment
  - Social Environment: Family/caregivers
- AA: Cultural Environment
- BB: Communal Infrastructure/Environment
  - Communal Environment: Education
  - Communal Environment: Social services
  - Communal Environment: Health services
- CC: Other Specified
- DD: Unspecified

Table B-2
WEIGHTED PERCENTAGES FOR DISABILITY DESCRIPTORS AND CORRESPONDING INFERRED ELIGIBILITY CODES (N = 5,293)

Variable	Percent	Standard Error	Inferred Eligibility Code[a]
Grp_A: Development	12.241	1.151	
ALG A: Development	10.839	1.301	
315.5: Mixed development disorder	0.706	0.344	2
315.9: Developmental disorder, NOS	9.576	0.746	2
319: Disorder of infancy, NOS	0.565	0.623	2
V79.3: Developmental handicaps	0.007	0.007	2
ALG Aa: Development: Physical	1.582	0.359	
Aa: Development: Physical	0.813	0.294	2
783.4: Lack of expected physical growth	0.768	0.117	2
Grp_C: Sensory Systems	3.273	0.388	
ALG C: Sensory Systems	0.480	0.146	
C: Sensory Systems	0.480	0.146	1
ALG Ca: Sensory Systems: Vision	1.071	0.133	
365.9: Glaucoma	0.008	0.009	1
368: Vision impaired, blind	0.967	0.121	1
377: Optic nerve atrophy	0.028	0.057	1
379.2: Disorder of the vitreous body	0.015	0.017	1
379.5: Nystagmus, oculomotor apraxia	0.053	0.041	1
ALG Cb: Sensory Systems: Hearing	1.922	0.409	
389.9: Hearing loss, deaf	1.922	0.409	1
Grp_D: Motor Systems	17.489	1.806	
ALG Da: Motor Systems: Gross	14.532	1.147	
315.4: Gross motor delay, coordination	14.519	1.149	2
781.2: Abnormality of gait	0.012	0.013	2
ALG Db: Motor Systems: Fine	5.309	1.077	
a306: Fine motor	5.309	1.077	2
ALG Dc: Motor Systems: Oral	0.230	0.061	
Dc: Motor Systems: Oral	0.230	0.061	2
ALG Dd: Motor Systems: Apraxia	0.093	0.036	
784.69: Symbolic dysfunction, apraxia	0.093	0.036	2
Grp_E: Physiological Systems	1.835	0.379	
ALG Ea: Physiology: Cardiovascular	0.540	0.101	
416: Pulmonary hypertension	0.011	0.013	3
424.1: Aortic stenosis	0.008	0.009	3
425.1: Idiopath hyperton subaort stenos	0.011	0.013	3
427.89: Bradycardia, tachycardia	0.126	0.039	3
428: Congestive heart failure	0.015	0.015	3
453.8: Thrombosis, leg	0.031	0.037	3
785.2: Heart murmur	0.048	0.022	3
s401: Cardiac problems	0.289	0.076	3
ALG Eb: Physiology: Respiratory	0.251	0.113	
478.3: Vocal cord paralysis	0.051	0.031	3
478.74: Glottic stenosis	0.024	0.030	3

493.9: Asthma	0.136	0.087	1
493: Reactive airway disease/disorder	0.050	0.030	1
ALG Ec: Physiology: Digestive	0.271	0.070	
530.1: Esophagitis	0.011	0.013	3
530.81: Gastroesophageal reflux, GERD	0.049	0.027	3
557: Necrotizing enterocolitis, NEC	0.070	0.034	3
579.3: Short bowel, short gut syndrome	0.081	0.036	3
787.2: Dysphagia	0.050	0.030	3
789.1: Enlarged liver	0.009	0.011	3
ALG Ed: Physiology: Endocrine/metabolic	0.440	0.126	
251.2: Hypoglycemia	0.010	0.009	3
253: Soto's syndrome	0.011	0.011	1
253.2: Panhypopituitarism	0.010	0.013	1
259.4: Dwarfism, short skeletal structure	0.094	0.056	3
263: Malnutrition	0.037	0.024	3
268: Rickets	0.018	0.015	1
270.1: PKU	0.011	0.013	1
270.2: Albinism, ocular albinism	0.135	0.050	1
270.3: Maple syrup urine disease	0.015	0.015	1
271: Glycogen storage disease	0.015	0.017	1
272: Lipid metabolism disorders	0.038	0.032	1
272.7: Niemann-Pick/Wolman/Mucolipidosis	0.025	0.023	1
276: Hypernatremia	0.009	0.011	1
277.4: Hyperbilerubinia	0.031	0.037	1
ALG Ee: Physiology: Urological	0.020	0.029	
593.7: Urethral reflux	0.020	0.029	3
ALG Ef: Physiology: Lymphatic/hematol/immun	0.371	0.172	
Ef: Physiology: Lymphatic/hematol/immun	0.068	0.074	1
243: Hypothyroidism (congenital)	0.115	0.072	1
279.11: DiGeorge syndrome	0.031	0.020	1
282.4: Thalessemia, beta sickle	0.022	0.019	1
282.6: Sickle cell anemia	0.091	0.044	1
286: Hemophilia	0.010	0.013	1
287.5: Thrombocytopenia	0.034	0.075	1
Grp_F: Neurological	0.396	0.174	
ALG F: Neurological	0.396	0.174	
F: Neurological	0.271	0.146	3
307.4: Sleep disturbance	0.033	0.020	3
359.9: Mitochondrial myopathy	0.093	0.080	1
Grp_G: Psychological	41.555	4.460	
ALG Ga: Psychological: Intellect/cognitive	7.409	1.375	
299.8: PDD, pervasive development disord	0.546	0.173	1
299: Autism, Asperger's syndrome	0.535	0.160	1
314: Attention deficit	0.089	0.059	2
314.01: ADHD	0.107	0.046	2
314.1: Development delay w/hyperkinesis	0.008	0.009	2
314.9: Hyperactivity, hyperkinesis	0.076	0.050	2
a101: Learning	0.053	0.063	2
i00400: Cognitive, cognition	6.111	1.327	2
ALG Gb: Psychological: Affective	0.067	0.036	

312.1: Tantrums	0.028	0.026	3
312.3: Impulse control	0.010	0.010	3
313:Reactive Attachment Disorder	0.030	0.029	2
ALG Gc: Psychological: Language	37.803	3.911	
315.3: Developmental speech/language	26.713	4.638	2
315.31: Expressive language delay	9.372	2.150	2
315.32: Receptive language delay	1.463	0.341	2
315.39: Articulation, phonological disorder	0.741	0.226	2
Grp_L: Communication	3.396	0.504	
ALG L: Communication	3.396	0.504	
a201: Communication delays, disorders	3.396	0.504	2
Grp_M: Self-Help	2.554	0.736	
ALG M: Self-Help	2.187	0.779	
a500: Adaptive self-help skills	2.187	0.779	2
ALG Ma: Self-Help: Daily living	0.421	0.121	
a50310: Toileting	0.038	0.039	2
a505: Feeding skills	0.393	0.112	2
Grp_N: Social Interaction	2.965	0.633	
ALG N: Social Interaction	2.965	0.633	
a700: Social skills, psycho-social	2.965	0.633	2
Grp_O: Behavior	0.750	0.173	
ALG O: Behavior	0.668	0.157	
D19: Behavior concerns	0.668	0.157	2
ALG Oa: Behavior: With objects	0.016	0.017	
Oa: Behavior: With objects	0.016	0.017	2
ALG Ob: Behavior: With people	0.066	0.027	
Ob: Behavior: With people	0.066	0.027	2
Grp_Q: Congenital Disorders	8.904	0.941	
ALG Qa: Congenital: Chromosomal/gene	6.421	0.722	
758: Down Syndrome, Trisomy 21	4.305	0.481	1
758.01: Trisomy 22	0.024	0.025	1
758.1: Trisomy 13	0.036	0.018	1
758.2: Trisomy 18	0.065	0.042	1
758.3: Cri-du-chat syndrome	0.019	0.027	1
758.5: Trisomy 8, trisomy 2	0.097	0.026	1
758.6: Turner Syndrome	0.101	0.062	1
758.7: Klinefelter's syndrome	0.010	0.009	1
758.81: XXX, XXXXY syndrome	0.079	0.057	1
758.9: Other chromosome/genetic anomaly	0.504	0.134	1
759.3: Situs inversus	0.022	0.019	3
759.5: Tuberous sclerosis	0.076	0.038	1
759.81: Prader Willi syndrome	0.042	0.037	1
759.82: Marfan syndrome	0.007	0.008	1
759.83: Fragile X	0.039	0.023	1
759.89: Other spec congenital syndrome	0.994	0.243	1
ALG Qb: Congenital: Other anomaly	2.578	0.474	
525.8: Cleft alveoli	0.010	0.009	3
743: Anophthalmos	0.018	0.015	1
743.1: Microphthalmos	0.015	0.017	1
743.3: Congenital cataracts	0.045	0.026	1

743.4: Coloboma, anterior eye anomalies	0.036	0.027	3
743.6: Eyelid/orbital/lacrimal anomalies	0.022	0.024	3
743.8: Other specified eye anomalies	0.016	0.017	3
743.9: Optic dysplasia or hypoplasia	0.161	0.055	1
744.2: Other specified anomalies of ear	0.055	0.041	3
745: Aortic septal defect (ASD)	0.057	0.048	3
745.1: Transposition of great arteries	0.018	0.015	3
745.2: Tetralogy of Fallot	0.074	0.058	3
745.4: Ventricular septal defect, VSD	0.109	0.044	3
745.5: Patent foramen ovale, PFO	0.030	0.036	3
745.6: Endocardial cushion defect	0.010	0.013	3
746.01: Cardiopulmonary hypoplasia	0.020	0.029	3
746.02: Pulmonic stenosis	0.040	0.058	3
746.4: Bicuspid aortic arch	0.008	0.009	3
746.7: Hypoplastic left heart syndrome	0.054	0.042	3
746.87: Malposition of heart	0.053	0.033	3
746.89: Other specified heart anomalies	0.010	0.009	3
746.9: Unspecified heart anomaly	0.192	0.069	3
747: Other congen circulatory anomalies	0.124	0.055	3
747.1: Coarctation of aorta	0.019	0.018	3
747.4: Anomalies of great veins	0.016	0.017	3
747.6: Peripheral vascular anomalies	0.010	0.013	3
748: Choana atresia	0.010	0.009	3
748.3: Tracheomalacia, bronchomalacia	0.046	0.030	3
748.5: Pulmonary hypoplasia	0.006	0.006	3
749: Cleft palate	0.795	0.195	1
749.1: Cleft lip	0.344	0.088	1
750.3: Tracheal esophageal fistula (TEF)	0.058	0.023	3
750.6: Congenital hiatus hernia	0.022	0.019	3
751.1: Atresia of small intestine	0.028	0.026	3
751.2: Atresia/stenosis, lg intestn/anus	0.068	0.062	3
751.3: Hirschsprung's disease	0.040	0.028	3
751.4: Anomalies of intestinal fixation	0.038	0.018	3
751.6: Gallbladder/duct/liver anomalies	0.010	0.013	3
752.6: Hypospadias, epispadias	0.031	0.037	3
753: Congenital urinary anomalies	0.029	0.017	3
753.12: Polycystic, multicystic kidney	0.021	0.025	3
753.29: Congenital hydronephrosis	0.006	0.006	3
756.7: Anomalies of abdominal wall	0.050	0.024	3
757.33: Pigmentary anomalies of the skin	0.028	0.026	3
759.6: Sturge-Weber syndrome	0.010	0.009	1
759.9: Congenital anomaly, unspecified	0.344	0.189	1
Grp_R: Prenatal/Perinatal Factors	18.917	2.624	
ALG R: Prenatal/Perinatal Factors	18.917	2.624	
362.21: Retinopathy of prematurity, ROP	0.456	0.181	3
362.81: Retinal hemorrhage	0.010	0.010	3
363.7: Retinal detachment	0.012	0.024	3
430: Hemorrhage, subarachnoid	0.015	0.015	1
431: Hemorrhage, cerebellar	0.025	0.015	1
432.1: Hemorrhage, subdural	0.015	0.015	1

432.9: Hemorrhage, intercranial	0.115	0.081	1
436: Stroke, intercranial infarction	0.229	0.062	1
645: Post term, prolonged pregnancy	0.023	0.025	3
663: Umbilical deficiency	0.012	0.013	3
760: Maternal prenatal hypertension	0.030	0.036	3
760.7: Prenatal substance exposure	1.165	0.276	3
760.71: Fetal alcohol syndrome, FAS	0.564	0.307	1
760.72: Prenatal exposure to narcotics	0.046	0.039	3
760.75: Prenatal cocaine/crack exposure	0.518	0.342	3
760.79: Prenatal exposure, other	0.046	0.050	3
761.5: Multiple pregnancy	0.365	0.111	3
762.5: Compression of umbilical cord	0.015	0.017	3
763.9: Unspec labor/birth complication	0.365	0.116	3
764: Small for gestational age, SGA	0.062	0.037	3
764.9: Fetal growth retardation	0.220	0.083	1
765: Prematurity, low birth weight	10.985	1.640	3
766.1: Large, heavy for dates	0.023	0.025	3
767: Subdural and cerebral hemorrhage	0.034	0.014	1
767.5: Facial nerve injury	0.019	0.017	3
767.6: Brachial plexus injury	0.645	0.139	3
769: Hyaline membrane disorder, RDS	0.621	0.336	3
770.1: Meconium aspiration	0.060	0.042	3
770.7: Bronchopulmonary dysplasia, BPD	0.541	0.268	3
770.8: Other respiratory prob after birth	0.737	0.294	3
771: Rubella, congenital	0.010	0.009	1
771.1: Congenital cytomegalovirus	0.252	0.123	1
771.2: Other congenital infections	0.022	0.019	3
771.8: Other perinatal infection	0.011	0.013	3
772.1: Intraventricular hemorrhage, IVH	0.799	0.321	1
773.1: ABO hemolytic disease	0.016	0.017	3
773.3: Isoimmunization hydrops fetalis	0.016	0.017	3
775.7: Late metabolic acidosis	0.015	0.014	3
778: Fetal hydrops, not isoimmunization	0.010	0.009	3
779: Convulsions in newborn	2.088	0.373	1
779.5: Newborn drug withdrawal syndrome	0.077	0.034	3
779.8: Abnormal muscle tone	2.182	0.243	3
783.3: Feeding/sucking problems	0.345	0.121	3
799: Anoxia, hypoxemia, hypoxia	0.123	0.049	3
Grp_S: Infections	0.593	0.148	
ALG S: Infections	0.593	0.148	
008.61: Rotavirus	0.018	0.015	3
42: AIDS, HIV	0.031	0.026	3
79.6: RSV, respiratory synctial virus	0.023	0.025	3
90.9: Syphilis, congenital	0.038	0.032	3
320.9: Bacterial meningitis	0.024	0.019	3
322.9: Meningitis, CNS infection	0.124	0.066	3
382.9: Otitis media	0.325	0.092	3
446.1: Kawasaki disease	0.020	0.024	3
Grp_T: Other Illness/Injury	0.385	0.232	
ALG T: Other Illness/Injury	0.385	0.232	

T: Other Illness/Injury	0.154	0.187	3
285.9: Anemia	0.014	0.017	3
568: Adhesions (postop, intestinal)	0.015	0.017	3
803: Skull fracture	0.026	0.024	3
835: Hip dislocation	0.076	0.033	3
851: Brain damage, brain injury	0.057	0.021	1
942.5: Deep third degree burn	0.031	0.052	3
949: Burn, unspecified	0.007	0.007	3
995.3: Allergy, unspecified	0.011	0.013	3
Grp_U: Chronic Diseases/Neoplasms	0.870	0.097	
ALG U: Chronic Diseases/Neoplasms	0.870	0.097	
190.5: Retinal blastoma	0.019	0.017	1
191: Malignant neoplasm of the brain	0.062	0.035	1
208.9: Leukemia	0.015	0.015	1
228: Hemangioma	0.058	0.050	1
229.8: Fibery tumor in neck	0.014	0.017	1
237.7: Neurofibramatosis	0.146	0.095	1
250: Diabetes	0.022	0.023	1
277: Cystic fibrosis	0.151	0.058	1
277.5: Hurler's syndrome	0.019	0.021	1
277.9: Metabolic disorder/abnormality	0.126	0.051	1
584.5: Tubular necrosis	0.014	0.017	1
585: End-stage renal disease	0.035	0.035	1
i701: Chronic renal/kidney problems	0.048	0.035	1
s40230: Lung disease	0.142	0.075	1
Grp_V: Musculoskeletal Disorders	1.955	0.225	
ALG V: Musculoskeletal Disorders	1.955	0.225	
550.9: Bilateral inguinal hernia	0.011	0.013	3
709.9: Neurocutaneous melanosis	0.012	0.015	3
728.3: Arthrogryposis	0.041	0.038	3
728.9: No muscle in hands	0.015	0.015	3
754: Musculoskel skull/face deformities	0.054	0.044	1
754.1: Torticollis	0.426	0.105	3
754.2: Scoliosis	0.015	0.017	3
754.44: Bowed legs	0.022	0.023	3
754.5: Varus deformities of feet	0.215	0.092	3
754.6: Valgus deformities of feet	0.018	0.017	3
754.89: Oth spec musculoskel deformities	0.033	0.025	3
755: Other congenital limb anomalies	0.063	0.061	3
755.1: Syndactyly, webbing of digits	0.018	0.015	3
755.21 Absence of forearm, hand	0.084	0.082	3
755.26: Agenesis of radius	0.020	0.024	3
755.3: Reduction deformities of leg	0.010	0.013	3
755.37: Absence of fibula	0.022	0.019	3
755.6: Other anomalies of lower limb	0.114	0.078	3
756: Anomalies of skull and face bones	0.554	0.192	1
756.13 Congenital absence of vertebra	0.012	0.014	3
756.4: Chondrodystrophy	0.065	0.033	3
756.5: Osteodystrophies	0.060	0.034	1
756.6: Anomalies of diaphragm	0.042	0.034	3

756.89: Amyoplasia congenita	0.009	0.011	3
756.9: Oth and unspec musculoskeletal	0.096	0.037	1
Grp_W: Central Nervous System Disorders	6.537	0.560	
ALG W: Central Nervous System Disorders	6.537	0.560	
323.9: Encephalitis	0.063	0.033	1
330: Leukodystrophy, myelination disord	0.043	0.029	1
330.1: Gangliosidosis, Tay-Sach's	0.060	0.035	1
330.8: Leigh's disease, syndrome	0.098	0.068	1
334.3: Cerebellar atoxia, acute	0.018	0.015	1
335.1: Spinal muscular atrophy	0.054	0.045	1
342.9: Hemiparesis, hemiplegia	0.439	0.115	1
343: Spastic, atonic diplegia	0.087	0.051	1
343.2: Spastic quadriplegia	0.041	0.029	1
343.9: Cerebral palsy	1.667	0.244	1
348: Subarachnoid cyst	0.015	0.017	3
348.1: Hypoxic ischemic encephalopathy	0.212	0.051	1
348.3: Encephalopathy	0.224	0.091	1
348.9: PVL, periventricular leukomalacia	0.267	0.117	1
356.1: Charcot-Marie-Tooth syndrome	0.043	0.027	1
356.9: Peripheral neuropathy	0.016	0.017	3
359.1: Muscular dystrophy	0.066	0.049	1
359.2: Myotonic dystrophy	0.034	0.038	1
434.9: Encephalomalacia	0.016	0.018	1
437.2: Hypotonic encephalopathy	0.030	0.036	1
741: Spina bifida with hydrocephalus	0.153	0.041	1
741.9: Spina bifida w/o mention hydrocephalus	0.599	0.071	1
742: Encephalocele	0.035	0.023	1
742.1: Microcephalus	0.616	0.159	1
742.2: Reduction deformities of brain	0.234	0.081	1
742.3: Hydrocephalus	1.188	0.171	1
742.4: Other specified brain anomalies	0.258	0.094	1
742.9: Unspecified brain/CNS anomalies	0.313	0.089	1
Grp_X: Other Specified	0.782	0.258	
ALG Xa: Other: Hospital/medical treatment	0.782	0.258	
Xa: Other: Hospital/medical treatment	0.581	0.225	3
i409: Respiratory problem, ventilation	0.260	0.097	30
Grp_Y: Physical Environment	2.319	0.926	
ALG Y: Physical Environment	1.206	0.695	
Y: Physical Environment	1.206	0.695	3
ALG Ya: Physical Envir: Product/obj/mat'l	0.754	0.236	
V44: Tracheostomy, trachtube placement	0.232	0.108	3
V44.1: Gastrostomy, g-tube	0.221	0.141	3
V44.3: Colostomy	0.055	0.051	3
V44.4: J tube	0.028	0.026	3
V45.2: Hydrocephalus and shunt	0.337	0.143	1
V53.31: Pacemaker	0.007	0.007	3
V58.2: Blood transfusion	0.011	0.013	3
ALG Yb: Physical Envir: Immediate environ	0.387	0.313	
984.9: Lead poisoning	0.071	0.047	3

V15.49: Trauma PTSD	0.016	0.017	3
V60: Homelessness, live in shelter	0.198	0.171	3
V60.1: Inadequate housing	0.080	0.084	3
V60.2: Inadequate food, mat'l resources	0.124	0.130	3
Grp_Z: Social Environment	1.887	0.730	
ALG Z: Social Environment	0.279	0.233	
V62.4: Social risk factors	0.279	0.233	3
ALG Za: Social Environ: Family/caregivers	1.810	0.684	
Za: Social Environ: Family/caregivers	0.374	0.227	3
995.5: Child neglect/abuse, unspecified	0.319	0.191	3
995.52: Child neglect, nutritional	0.018	0.015	3
995.55: Shaken baby syndrome	0.100	0.051	3
V20: Abandoned infant, foundling	0.023	0.025	3
V61.2: Parent/child issues, bonding	0.190	0.183	3
V61.29: Foster care, adopted child	0.387	0.201	3
V61.4: Parent has chronic illness	0.087	0.065	3
V61.8: Parent/sib mental/behav/disability	0.451	0.156	3
V61.9: Substance/drug abuse in the home	0.212	0.182	3
V62.8: Domestic violence	0.016	0.017	3
Grp_BB: Communal Infrastructure/Environment	0.792	0.393	
ALG BBa: Communal Environ: Education	0.664	0.417	
BBa: Communal Environ: Education	0.664	0.417	3
ALG BBb: Communal Environ: Social services	0.107	0.094	
BBb: Communal Environ: Social services	0.107	0.094	3
ALG BBc: Communal Environ: Health services	0.021	0.019	
BBc: Communal Environ: Health services	0.021	0.019	3

[a] This column shows how the reasons for eligibility were classified by the research team: 1= diagnosed condition, 2 = developmental delay, 3 = risk condition.

Appendix C

Table C-1
AGE AT WHICH CHILDREN ENTER EARLY INTERVENTION (N=5,346)

Sample Size	Percentage or Mean
Percentage whose age at referral was:	
Less than 6 months	27.2
6 months up to 12 months	15.1
12 months up to 18 months	12.0
18 months up to 24 months	16.8
24 months up to 30 months	21.2
30 months or older	7.6
Percentage whose age at IFSP was:	
Up to 6 months	20.9
6 months up to 12 months	17.2
12 months up to 18 months	12.3
18 months up to 24 months	15.7
24 months up to 30 months	22.0
30 months or older	12.0

Standard Errors	Standard Error
Percentage whose age at referral was:	
Less than 6 months	3.0
6 months up to 12 months	.7
12 months up to 18 months	.7
18 months up to 24 months	1.3
24 months up to 30 months	1.1
30 months or older	.6
Percentage whose age at IFSP was:	
Up to 6 months	2.7
6 months up to 12 months	1.0
12 months up to 18 months	.6
18 months up to 24 months	1.3
24 months up to 30 months	1.1
30 months or older	1.0

Table C-2
PERCENTAGE DISTRIBUTION FOR AGE AT IFSP, BY REASON FOR ELIGIBILITY FOR EARLY INTERVENTION

	Inferred Reason for Eligibility[a]		
	Developmental Delay	Diagnosed Condition	At Risk of Delay
Sample size	3,425	1,078	790
Percentage whose age was:			
Up to 6 months	6.7	44.2	50.6
6 months up to 12 months	13.3	20.8	26.6
12 months up to 18 months	12.3	13.2	11.4
18 months up to 24 months	20.3	8.6	5.4
24 months up to 30 months	30.8	7.8	4.1
30 months or older	16.6	5.3	1.9
Standard Errors			
Percentage whose age was:			
Up to 6 months	1.4	2.2	5.5
6 months up to 12 months	.8	1.7	2.8
12 months up to 18 months	.7	1.1	2.2
18 months up to 24 months	1.2	1.5	.9
24 months up to 30 months	1.1	.8	1.0
30 months or older	1.0	.6	.9

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[a] Coding of reason for eligibility was based on provider's description of child's disability or risk condition.

Table C-3
PERCENTAGE DISTRIBUTION OF AGE AT REFERRAL AND IFSP, BY RECEIPT OF PUBLIC ASSISTANCE

	Receive Public Assistance	
	Yes	No
Sample Size		
Average age in months at referral	13.9	16.7
Percentage whose age at referral was:		
Up to 6 months	32.3	23.0
6 months up to 12 months	17.6	13.3
12 months up to 18 months	12.2	12.2
18 months up to 24 months	14.8	18.1
24 months up to 30 months	16.7	24.8
30 months or older	6.4	8.5
N =	2,027	2,858
Average age in months at IFSP	15.6	18.4
Percentage whose age at IFSP was:		
Up to 6 months	24.0	18.3
6 months up to 12 months	20.8	14.4
12 months up to 18 months	13.4	11.7
18 months up to 24 months	13.8	16.8
24 months up to 30 months	18.1	25.2
30 months or older	9.8	13.7
N =	2,162	3,018
Standard Errors		
Average age in months at referral	.6	.8
Percentage whose age at referral was:	2.0	4.0
Up to 6 months		
6 months up to 12 months	1.2	.8
12 months up to 18 months	.6	1.0
18 months up to 24 months	1.2	1.7
24 months up to 30 months	.9	1.2
30 months or older	.8	1.1
N =	2,027	2,858
Average age in months at IFSP	.6	.8
Percentage whose age at IFSP was:	2.4	3.1
Up to 6 months		
6 months up to 12 months	1.4	.9
12 months up to 18 months	.8	.9
18 months up to 24 months	1.0	1.8
24 months up to 30 months	1.4	.9
30 months or older	1.0	1.4
N =	2,162	3,018

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NOTICE

Reproduction Basis