
Characteristics of Children and Families Entering Early Intervention

In 1986, 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 (IDEA), as amended in 1997. The ensuing years have seen steady growth in the number of infants and toddlers served under Part C, increasing from an estimated 128,000 in 1988 (U.S. Department of Education, 1990) to almost 200,000 in 1997 (U.S. Department of Education, 1998). 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.

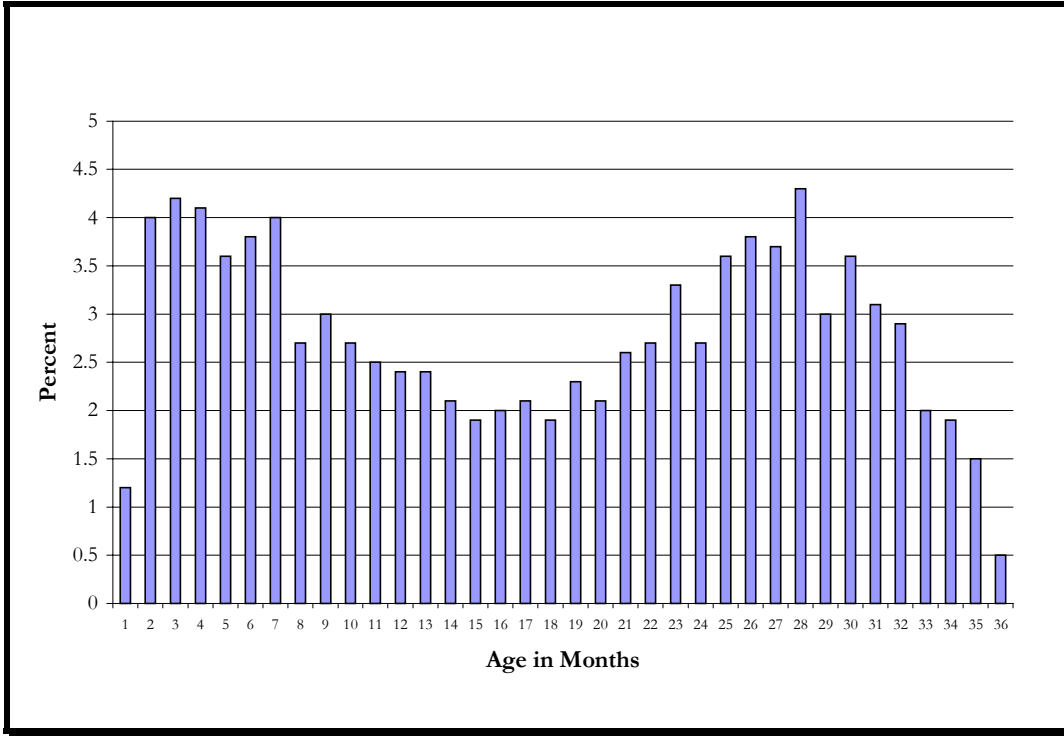
To meet the need for more and better information about Part C and its participants nationally, the Office of Special Education Programs (OSEP) commissioned the National Early Intervention Longitudinal Study (NEILS). NEILS began in 1996 with a design phase; data collection began the following year. NEILS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

The following pages present preliminary descriptive information from NEILS about the children and families entering early intervention services. These data address the reasons for which they are receiving early intervention services, the ages at which children are entering early intervention, and some demographic characteristics of this population. The data presented here are based on a one-page form that early intervention program staff completed on all children and families who entered early intervention for the first time during the study recruitment period ($n=5,668$). Additional information about the study methodology is available in Hebbeler, Wagner, and Spiker (2000).

Age at Entry and Reasons for Receipt of Early Intervention

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 is to identify and serve children with developmental problems in programs as early as possible. The average age at which

Figure IV-1
Age at Time of Individualized Family Service Plan (IFSP)



Source: National Early Intervention Longitudinal Study.

children were referred for early intervention was 15.5 months (S.E.=.66¹). Average age at the completion of the individualized family service plan (IFSP) was 17.1 months (S.E. =.72).

Average age tells only part of the story. Children entered early intervention at every month between birth and 36 months, but there are particular months at which children were more likely to enter. Figure IV-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 children under 36 months who were a given age at entry. As the graph illustrates, more children entered early intervention in the first and third year of life than in the second. More than 38 percent of children entering early intervention for the first time did so between birth and 12 months; in fact, more than one in five entered early intervention in their first 6 months. Another 28 percent entered in their

¹ The S.E. or standard error indicates the precision of the estimate. 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.

second year, and more than one-third of children entered early intervention after their second birthdays.²

IDEA stipulates the parameters for who is to receive 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).

Early intervention program staff were asked to describe the nature of the disability, delay, or risk condition for which the child was eligible for early intervention. Staff provided descriptors such as “motor delay” or “intraventricular hemorrhage.” This information was provided for 93 percent of the children. A total of 305 different terms were provided. 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. These descriptors were then coded as a developmental delay, an established condition, or a risk condition using a classification scheme developed by the research team.

As shown in table IV-1, the most frequently reported reason for receipt of early intervention was a speech/communication impairment or delay. Providers indicated that 41 percent 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 choose 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 are probably more accurately thought of as minimums. The finding is that *at least* 41 percent of the children entering early intervention had speech or communication problems.

² Figure IV-1 shows a noticeable dip around the age of 15 months because children tend to be identified for early intervention services at two key points: at birth, when some congenital disabilities are immediately apparent and, in the second year, when children fail to meet some crucial developmental milestone.

Table IV-1
Frequency of Reasons for Receipt of Early Intervention and Age at IFSP
(n=5,293)

| | Reason for EI | | Age at IFSP | | |
|--|---------------|----------------|----------------------|----------------|-------|
| | Percentage | Standard Error | Average Age (Months) | Standard Error | N |
| Delayed development (global) | 12.24 | 1.15 | 17.64 | .97 | 701 |
| Physical growth abnormality ^{a/} | 1.58 | .36 | 15.34 | 1.91 | 87 |
| Sensory systems impairment | 3.27 | .39 | 15.73 | .89 | 167 |
| Vision impairment ^{a/} | 1.07 | .13 | 11.92 | 1.18 | 61 |
| Hearing impairment ^{a/} | 1.92 | .41 | 15.89 | .48 | 91 |
| Motor impairment or delay | 17.49 | 1.81 | 15.16 | .33 | 934 |
| Physiological or neurological system impairment | 2.22 | .45 | 10.84 | .94 | 123 |
| Intellectual/cognitive impairment or delay | 7.18 | 1.36 | 22.72 | 1.00 | 380 |
| Social/behavioral impairment or delay | 3.74 | .64 | 22.15 | .70 | 209 |
| Speech/communication impairment or delay | 41.07 | 3.9 | 24.87 | .29 | 2,153 |
| Delay in self-help skills | 2.55 | .74 | 20.19 | .99 | 151 |
| Congenital disorders | 8.90 | .94 | 7.86 | .69 | 502 |
| Down syndrome ^{a/} | 4.31 | .48 | 5.80 | .80 | 252 |
| Prenatal/perinatal abnormalities | 18.92 | 2.62 | 8.21 | .59 | 1,020 |
| Low birth weight ^{a/} | 10.99 | 1.64 | 7.17 | .79 | 588 |
| Prenatal exposure to drugs/alcohol ^{a/} | 2.08 | .60 | 11.46 | .82 | 97 |
| Illness or chronic disease | 1.85 | .31 | 13.56 | 1.59 | 91 |
| Musculoskeletal disorders | 1.96 | .23 | 8.9 | .96 | 98 |
| Central nervous system disorders | 6.53 | .56 | 12.2 | .51 | 339 |
| Cerebral palsy ^{a/} | 2.19 | .28 | 17.03 | 1.19 | 118 |
| Receiving medical treatment, disorder not identified | 1.39 | .35 | 9.13 | 1.5 | 73 |
| Social environment risk factors | 3.90 | 1.11 | 15.20 | 1.4 | 172 |

Note: Children could have more than one reason for the receipt of early intervention.

^{a/} Indented categories are also included in the superordinate category above them.

Source: National Early Intervention Longitudinal Study.

Other frequently reported reasons for the receipt of early intervention included prenatal/perinatal problems (19 percent), with the most frequent of these being low birth weight (11 percent of children in early intervention), motor delays (17 percent), and an overall delay in development (12 percent).

Children entering early intervention for different reasons entered at different ages. Table IV-1 also presents the average age at IFSP for different types of disability, delay, or risk conditions. There are highly significant but not surprising differences in the ages at which children with different conditions are entering early intervention. 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 very young. Children with prenatal and perinatal abnormalities also entered early intervention young relative to other conditions, with 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 motor, intellectual, social or speech/communication delays or impairments began early intervention around age 2.

Another way to examine the relationship between age at entry and disability is to look at the percentage of children who enter in the first, second, or third year of life with particular conditions. For children who began early intervention at less than 12 months of age, the most frequent reason for receiving services was perinatal/prenatal abnormalities (at least 40 percent of those who entered at less than 12 months), with low birth weight being the largest type of perinatal/prenatal abnormality (28 percent of children younger than 12 months). The second most common reason for receipt of services for this age group was for motor delays or impairments (20 percent).

The pattern is quite different for older infants. For 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 percent), followed by motor delay (22 percent) and global developmental delay (15 percent). For the oldest children entering early intervention, those over 24 months, three-fourths (75 percent) of the children entered early intervention with speech/communication delays. The next most frequent conditions were intellectual/cognitive delays (12 percent), global developmental delay (12 percent), and motor delays (11 percent).

Reasons for eligibility for early intervention can also be examined with regard to the three eligibility categories in IDEA. Grouping the various disability descriptors into

Table IV-2
Frequency and Average Age at IFSP for Developmental Delay, Diagnosed Condition, and At Risk (n = 5,293)

| | Frequency | | Age at IFSP | | |
|--------------------------------------|------------|----------------|----------------------|----------------|-------|
| | Percentage | Standard Error | Average Age (Months) | Standard Error | N |
| A developmental delay | 64.10 | 4.62 | 21.25 | .43 | 3,425 |
| A diagnosed condition | 20.37 | 2.15 | 10.71 | .44 | 1,078 |
| Being at risk of developmental delay | 15.53 | 2.72 | 8.45 | .73 | 790 |

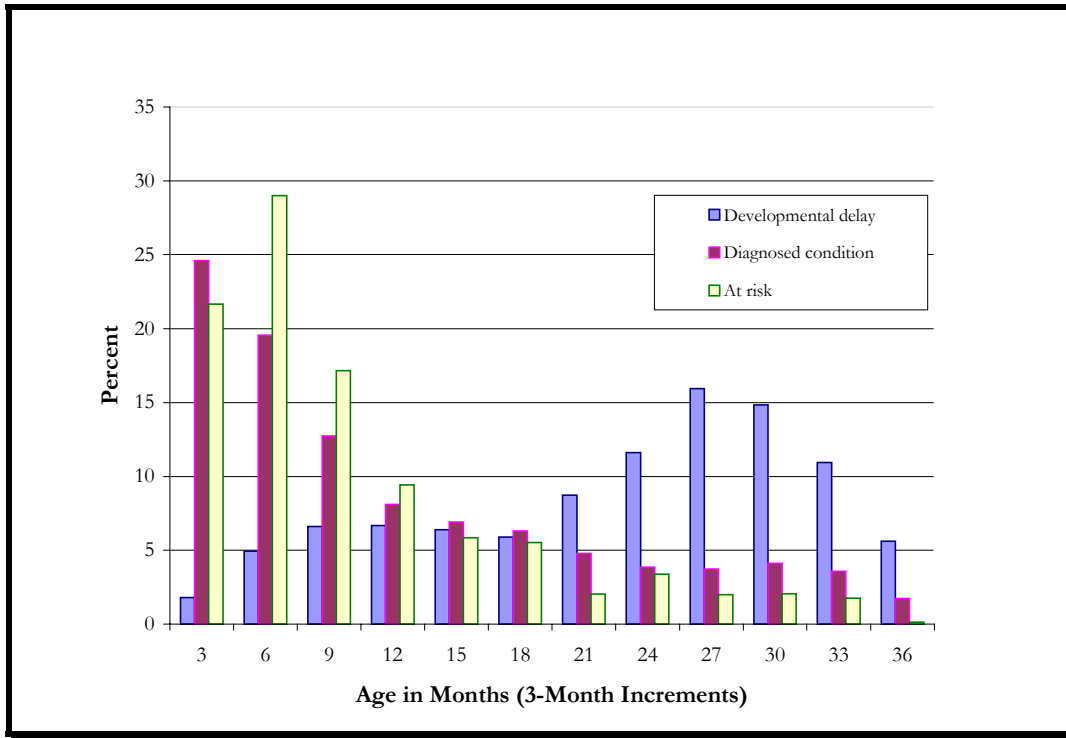
Source: National Early Intervention Longitudinal Study.

the three eligibility classifications in the law shows that most children were eligible for early intervention because of a developmental delay (64 percent), a lesser proportion had a diagnosed condition (20 percent), and far fewer were being served because they were at risk (16 percent)³ (see table IV-2). Children with more than one of these were coded into one category, giving priority to the order in which the terms were just listed (e.g., developmental delay co-occurring with a diagnosed condition was coded as developmental delay for the 4 percent of children with both.)

The average age of children at IFSP differed markedly across the three reasons (see table IV-2). Children who were eligible for early intervention primarily because of a developmental delay were significantly older on average at entry (21.3 months) than children entering because of a diagnosed condition (10.7 months) or being at risk of delay (8.5 months) (for all comparisons, $p < .05$). This is not surprising because developmental delays can only be diagnosed 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).

³ Seven of the 20 States in the study sample were serving at-risk children under Part C at the time these data were collected. Not all of the children classified by the NEILS' categorization scheme as having risk conditions were residents of States that served at-risk children. This apparent anomaly occurs because the dividing line between established conditions and risk conditions is not well defined in practice, with the same conditions being seen by some States as established conditions and other States as risk conditions. Low birth weight is one example of such a condition.

Figure IV-2
Age at IFSP by Reasons for Eligibility



Source: National Early Intervention Longitudinal Study.

Figure IV-2 illustrates the different patterns of age at IFSP for the three 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). Children with diagnosed conditions or risk conditions entered in greater numbers in the first year of life, while children with developmental delays were more likely to be identified in the later part of the first 3 years of life. Of children who were eligible for early intervention primarily because of a diagnosed condition, 44 percent entered early intervention in their first 6 months of life, as did 51 percent of those who were eligible primarily because they were at risk of delay. By contrast, only 7 percent of those who were eligible for early intervention because of developmental delay were younger than 6 months old at entry. Forty-seven percent of children with developmental delays entered early intervention between 24 and 31 months of age, compared to 17 percent of children with diagnosed conditions and 10 percent of children who were at risk.

Table IV-3
Demographic Characteristics of Children Entering Early Intervention

| | Percentage | Standard Error | N |
|----------------------------------|------------|----------------|-------|
| Gender | | | 5,663 |
| Male | 60.91 | 1.09 | |
| Race/ethnicity | | | 5,376 |
| African American | 21.49 | 1.23 | |
| American Indian or Alaska Native | .48 | .20 | |
| Asian or Pacific Islander | 4.84 | 1.86 | |
| Caucasian | 55.60 | 1.98 | |
| Hispanic | 15.19 | 2.30 | |
| Mixed race or "other" | 2.41 | .47 | |
| Socioeconomic status | | | |
| Received public assistance | 42.20 | 1.76 | 5,180 |
| No working telephone at home | 5.48 | .52 | 5,631 |
| In foster care | 7.03 | .58 | 5,636 |

Source: National Early Intervention Longitudinal Study.

Demographic Information

As part of sample recruitment for NEILS, minimal demographic information was collected on all children and families who enrolled in early intervention during the timeframe. Much more demographic information will be available on the children and families who enrolled in the study, but even these minimal data provide interesting information about who is receiving early intervention services.

Gender

Six of 10 children entering early intervention were boys (see table IV-3), a higher rate than their prevalence in the general population of children less than 3 years old (51 percent, U.S. Bureau of the Census, 1998). The disproportion of boys was strongest among those with developmental delays; 65 percent (S.E.=1.79) of these children were male compared to 52 percent (S.E.=1.95) for children with diagnosed conditions and 54 percent (S.E.=3.51) for those at risk of delay ($p<.001$). The overrepresentation of boys in special needs populations has been noted among older children as well (U.S. Department of Education, 1998). Among those with

developmental delays, males were older on average than females at entry to early intervention (22.1 months, S.E.= .38 vs. 19.6 months, S.E.=.51, $p<.001$).

Race and Ethnicity

Children of color were represented in the early intervention population more heavily than in the general population. Whereas 37 percent of the general population of children ages birth to 3 in 1997 were minority, 44 percent (S.E.=1.98) of children entering early intervention during the study period were minority. Most of the disproportion of children of color results from a higher percentage of African American children (21 percent, S.E.=1.23) entering early intervention relative to their numbers in the general population of young children (14 percent). The percentage of children of Hispanic⁴ origin entering early intervention approximated the percentage in the current population: 15 percent (S.E.=2.30) of those entering early intervention were Hispanic, compared with 18 percent in the general population. Asian/Pacific Islander children were 4.8 percent (S.E.=1.86) of those entering early intervention, compared with 4.3 percent of the general population of children birth to age 3. American Indian/Alaska Native children made up less than 1 percent of both the population of children in early intervention and the general population (.5 percent vs. .9 percent, S.E.= .2).

Receipt of Public Assistance

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 & 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 & Broadhurst, 1996).

Although the enrollment information does 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 (TANF), food stamps). A large proportion of children entering early intervention were in families who received some kind of public

⁴ 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 are classified by the racial category.

assistance (42 percent, S.E.=1.76).⁵ This is significantly higher than the rates at which children in the general population received Aid to Families with Dependent Children (AFDC) or general assistance (13.4 percent in 1995; U.S. Department of Health and Human Services, 1999) or food stamps (20.3 percent in 1995; U.S. Department of Health and Human Services, 1999). Children from families in early intervention receiving public assistance were more likely to be minority than children in families not receiving public assistance; 62 percent (S.E.=4.54) of the families receiving public assistance were minority families compared to 30 percent (S.E.=2.3) of those not receiving public assistance.

Children from families receiving public assistance and not receiving public assistance differed in their reasons for eligibility for early intervention. Fewer children in families receiving public assistance were eligible for early intervention because of a developmental delay (61 percent, S.E.=4.73) compared to 67 percent (S.E.=4.48) of families not receiving public assistance ($p<.001$). More children in families receiving public assistance were eligible because of a risk condition (19 percent compared to 12 percent for children in families not receiving public assistance, S.E.s=3.66 and 1.84, respectively).

Children with developmental delays in families receiving public assistance were younger, average age of 19.3 months (S.E.=.58), at entry to early intervention than children with developmental delays in other families, who averaged 22.6 months (S.E.=.37, $p<.05$). This could be because their delays were more serious, because they may be seen by pediatricians and other service providers more often or who were more attuned to possible delays, or a combination of these.

Almost 6 percent (S.E.=.52) of families had no working telephone at home. The lack of a telephone probably means these families have 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.

Foster Care

The frequency of foster care placements for children in this country has increased in recent years, from approximately 262,000 children in 1982 to 483,000 in 1995 (U.S.

⁵ 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.” The kind of public assistance received was not recorded. Additional information about the type of assistance received by families in early intervention will be forthcoming from other NEILS data.

Department of Health and Human Services, 1999). 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, a rate about 10 times the rate at which children in the general population are in foster care (7.3 children per thousand, U.S. Department of Health and Human Services, 1999).⁶ Although the magnitude of this finding is somewhat surprising, its occurrence is not. The same unfortunate life circumstances that have resulted in children being in foster care (e.g., maternal drug abuse, poverty, neglect) may also have significantly impaired their development and certainly place children at risk for developmental problems. Foster care children entering early intervention present a particularly urgent demand for coordinated services across multiple systems, often including child welfare, public health, mental health, and early intervention.

Children in foster care were less likely to receive services for a diagnosed condition (13 percent, S.E.=2.12, compared to 21 percent, S.E.=2.23) than children not in foster care ($p<.001$) and more likely to receive services for a risk condition than children not in foster care (22 percent vs. 15 percent, S.E.s=6.55 and 2.47). Early intervention recipients in foster care were overwhelmingly African American (60 percent, S.E.=4.9). By contrast only 20 percent (S.E.=2.96) of children in early intervention and foster care were Caucasian. With 45 percent of the children under 18 in foster care being African American, there are also a disproportionate number of African American children in foster care in the general population (U.S. Department of Health and Human Services, 1999).

Children in foster care also were significantly more likely to be living with families receiving public assistance. Three-fourths (74 percent, S.E.=5.29) of families with foster children were receiving public assistance compared to 40 percent (S.E.=1.92) of families of children not in foster care ($p<.001$). It is not clear, however, if this means 75 percent of the families with foster care children were low-income families. Service providers might have indicated the family was receiving public assistance because they were receiving public funds for the foster child. Additional information on this point will be available through the family interviews.

⁶ 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. 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.

Summary

Who are the children and families entering early intervention? Preliminary data from NEILS indicate that most children are eligible for early intervention because of a developmental delay, and these children are likely to enter early intervention later than children with a diagnosed condition or a risk condition.

Children enter early intervention at every point throughout the first 3 years of life, but there are time points at which 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.

These initial findings on the demographic characteristics of children in early intervention have shown that they are not a representative cross-section of the birth to 3 population. There are more males in early intervention. Families in early intervention are more likely to be receiving some form of public assistance.

The findings reported here are based on the first data from NEILS, and considerably more information will be available in the future. Analyses of data from the family interviews will provide more data on the characteristics of children and families receiving early intervention, such as information about the children's functioning and their families' initial experiences with early intervention. Detailed information about the nature, amount, and location of services will be forthcoming from data collected from service providers. Program directors and program providers were also surveyed, and those surveys will provide profiles of the types of programs serving young children and their families as well as information about who is providing those services. Finally, NEILS will also collect data on the costs of early intervention services and will relate those costs to the benefits achieved.

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