
Characteristics of Children and Families Entering Early Intervention

In 1999-2000, 205,769 children and their families in the United States received early intervention services under Part C of the Individuals with Disabilities Education Act (IDEA). This figure represents 1.8 percent of the nation's infants and toddlers, according to July 2000 population estimates from the U.S. Census Bureau. What do we know about these children and their families?

To answer this question, the Office of Special Education Programs (OSEP) commissioned the National Early Intervention Longitudinal Study (NEILS). NEILS is following a nationally representative sample of 3,338 infants and toddlers who received early intervention services for the first time between September 1997 and November 1998. Information is being collected repeatedly on these children and their families throughout the early intervention years and then again when the children enter kindergarten. Data from NEILS will play a key role in efforts to improve early intervention services and results for infants and toddlers with disabilities.

Some descriptive information about the characteristics of children and families receiving early intervention was presented in the 22nd *Annual Report to Congress*. Briefly, these initial findings indicated that the average age of the child at the time of the first individualized family service plan (IFSP) was 17.1 months.¹ Most children (64 percent) were eligible for early intervention because of a developmental delay, and these children were most likely to begin early intervention after 21 months of age.

One of the primary reasons for eligibility for service among the youngest children were reasons related to their birth histories. Around 40 percent of the children who began early intervention at 12 months of age or less needed services for reasons related to prenatal/perinatal abnormalities. Among older children, a speech or communication problem was the most frequent reason for receipt of early intervention services.

NEILS data indicate that boys made up 61 percent of the early intervention population and 65 percent of those with developmental delays. The largest racial/ethnic group in the early intervention population was white (56 percent),

¹ All data presented here are weighted to represent the national population of infants and toddlers entering early intervention.

followed by black (21 percent), Hispanic (15 percent), and Asian/Pacific Islander (5 percent). These figures differ somewhat from the State-reported data for 1999-2000, which are reported in table AH7. States reported that 60.7 percent of the Part C population was white, 18.0 percent was black, 16.5 percent was Hispanic, 3.6 percent was Asian/Pacific Islander, and 1.2 percent was American Indian/Alaska Native.² NEILS data also suggest that children in foster care were substantially overrepresented among those in early intervention. Seven percent of the children entering early intervention were in foster care, a rate about 10 times greater than that of the general population (U.S. Department of Health and Human Services, 1998).

This module provides a more detailed description of the children in early intervention based on new data available from NEILS. The module includes data describing the nature of these children's disabilities and their birth histories, health status, and behaviors. The text also includes descriptive demographic data on the children and their families, including family size, structure, and socioeconomic status. The data presented in this report are based on a telephone interview ($N=3,000$) which was conducted with a family member³ within the first few months after the child and family started early intervention services.

Child Characteristics

Child Functioning

To further explore the nature of the abilities and disabilities of children receiving early intervention services, parents were asked a series of questions about various aspects of their child's functioning, including vision, hearing, mobility, and communication. These results are shown in table II-1. Very few parents reported that their child had a lot of trouble seeing or hearing (8 percent and 9 percent, respectively). A hearing aid or other hearing device had been prescribed for 2 percent, and glasses had been prescribed for 2 percent. One-fourth of the children in early intervention were reported as having at least some difficulty with their hands and arms; 7 percent had a lot of trouble or no use of their hands and arms. Similarly, 26 percent of the children in early intervention were reported as having at least some

² For a number of reasons, the State-reported data are expected to differ from the NEILS data. Because collection of race/ethnicity data at the State level has taken place only for the past 2 years and several States have missing data, the race/ethnicity figures must be interpreted with caution. In addition, NEILS is a sample survey, and the sample was not drawn from all 50 States. The States report population data rather than sample data.

³ The adult best able to talk about each child and his/her early intervention experiences was the respondent for the telephone interview; the vast majority were the child's biological, adoptive, or foster mother (90 percent), and respondents are referred to as parents here.

Table II-1
Functional Characteristics of Children Entering Early Intervention
as Reported by Caregivers

	Percent
Diagnosed hearing problem	
Yes	9
No	91
Diagnosed vision problem	
Yes	8
No	92
Use of arms and hands	
Uses both normally	75
Has a little trouble	18
Has a lot of trouble	6
No use of one or both	1
Use of legs and feet	
Uses both normally	73
Has a little trouble	19
Has a lot of trouble	7
No use of one or both	1
How well does child make needs known	
Communicates just as well as other children	30
Has a little trouble communicating	41
Has a lot of trouble communicating	25
Doesn't communicate at all	4
When child talks to people s/he doesn't know, child is*	
Very easy to understand	12
Fairly easy to understand	22
Somewhat hard to understand	38
Very hard to understand	28

Note: Only asked if child used words to communicate.

Source: National Early Intervention Longitudinal Study.

trouble with their legs or feet, while 8 percent had a lot of trouble or no use of one or both legs or feet. Eleven percent of those with a lot of trouble or no use of their legs or feet entered early intervention using some kind of equipment to help them get around.

Substantially greater numbers of infants and toddlers were reported as having trouble communicating. Only 30 percent of the children were seen as communicating their needs as well as other children, and 41 percent were reported to have a little trouble communicating. One-fourth of the children were reported as having a lot of trouble

with communication, and 4 percent did not communicate at all. Parents were also asked about how easy the child is to understand when talking to people he or she doesn't know. Two-thirds of the children were described as somewhat or very hard to understand.

The parent reports were consistent with provider reports on the reasons children were eligible for early intervention. Many different conditions, delays, and disabilities were represented among the population of children entering early intervention, with any one particular difficulty being reported for only a small proportion of the children. The notable exception was difficulty in the area of speech and communication, which characterized a fairly large proportion of those entering early intervention. This was especially true of those over 24 months of age. Children with communication delays might be those who respond well to early intervention and require few or no services in future years. Alternatively, communication delays could be an early marker of other serious developmental problems such as cognitive delays. Additional NEILS data in forthcoming years will provide information on the results these children experience.

Birth History

Because low birth weight⁴ is often associated with developmental difficulties, it is not surprising to find that a substantial portion of children in early intervention were not of normal birth weight. Nearly one-third of the children in early intervention (32 percent) were low birth weight (see table II-2), compared with 7.5 percent of the general population. One in six children (17 percent) receiving early intervention were very low birth weight, compared with 1 percent of the general population (Ventura, Martin, Curtin, & Matthews, 1999).

Very low birth weight places an infant at even greater risk of serious medical and developmental problems (Botting, Powls, Cooke, & Marlow, 1998). Among the children receiving early intervention there was a high incidence of children of very low birth weight in all racial/ethnic groups, but the proportions differed by race/ethnicity. Black infants were most likely to be of very low birth weight; 31 percent of black babies in early intervention were very low birth weight.

Black babies are also more likely to be low birth weight in the general population. The ratio of black to white infants of low birth weight is similar for both the general and early intervention populations; slightly more than 2.5 times as many black babies

⁴ Children who are born weighing less than 2,500 grams are termed "low birth weight," and those weighing less than 1,500 grams are referred to as "very low birth weight."

Table II-2
Birth Histories of Children Entering Early Intervention

	Percent
Birth weight	
Less than 1000 grams	10
1000 to 1499 grams	7
1500 to 2499 grams	15
2500 grams or more	68
Percentage of babies from each ethnic group under 1500 grams	
White	12
Black	31
Hispanic	16
Asian/Pacific Islander	13
Mixed or Other	18
Stayed in neonatal intensive care unit after birth	
Yes	37
No	59
Don't know	4
Stayed in hospital after birth because of medical problems	
No	55
1 to 4 days	6
5 to 14 days	12
15 to 30 days	7
31 or more	19

Source: National Early Intervention Longitudinal Study.

as white babies were born of low birth weight in both groups (2.6 for those in early intervention vs. 2.8 for the general population). Hispanic babies in early intervention were 1.3 times more likely than white infants to be very low birth weight, comparable to the ratio of 1.1 in the general population.

Another important indicator of birth problems and possible later difficulties is whether the child was hospitalized in the neonatal intensive care unit after birth. A sizable proportion of the early intervention population—37 percent—was in neonatal intensive care (see table II-2). Consistent with the findings for low birth weight, race/ethnicity was related to use of neonatal intensive care. Black infants were in intensive care most frequently relative to other groups; nearly half of the black children in early intervention had been in intensive care after they were born.

One last indicator of difficulties at birth is whether the baby stayed at the hospital after birth for a medical reason. Forty-four percent of the children entering early intervention were required to stay in the hospital after birth. Eighteen percent stayed

2 weeks or less. At the other extreme, 19 percent stayed in the hospital for more than a month. Parent-reported data on these children's birth histories indicate that a relatively high percentage of children in early intervention had difficulties at birth, especially prematurity and low birth weight. This finding is consistent with provider information about the relatively high proportions of children who entered early intervention in the first year of life because of prenatal and perinatal abnormalities.

General Health and Health Care

Parents were asked several questions regarding their child's current health, health care, and health insurance status. Although some children receive early intervention for disabling conditions related to their health, many children are eligible for services because of developmental problems rather than health per se. Most parents (84 percent) reported their children's health to be good, very good, or excellent (see table II-3). This is a lower figure, however, than reported for the general population. Figure II-1 shows the distribution of responses on health status for both the early intervention and general population. Nearly all parents in the general population (98 percent) report their children to be in good, very good, or excellent health.⁵

Consistent with the ratings of overall health, 26 percent of the children in early intervention were reported to be taking prescription medication for a chronic condition. Sixteen percent were reported to be using a medical device of some sort, with the most common medical devices being respirators, breathing monitors, and nebulizers. Over a third (34 percent) had been hospitalized at least 1 night since coming home from the hospital, with 7 percent hospitalized for 15 or more days.

With regard to health care, families of nearly all children in early intervention (97 percent) reported that their children had a place to go for regular medical care. Similarly, nearly all children (95 percent) were covered by health insurance. Health insurance can be a powerful determinant of whether children have access to routine health care and even to treatment in the event of illness. Slightly less than half (44 percent) of children were insured through a government insurance program. Last, about one in five families (19 percent) reported that their insurance company had refused to pay for something they tried to get for their child.

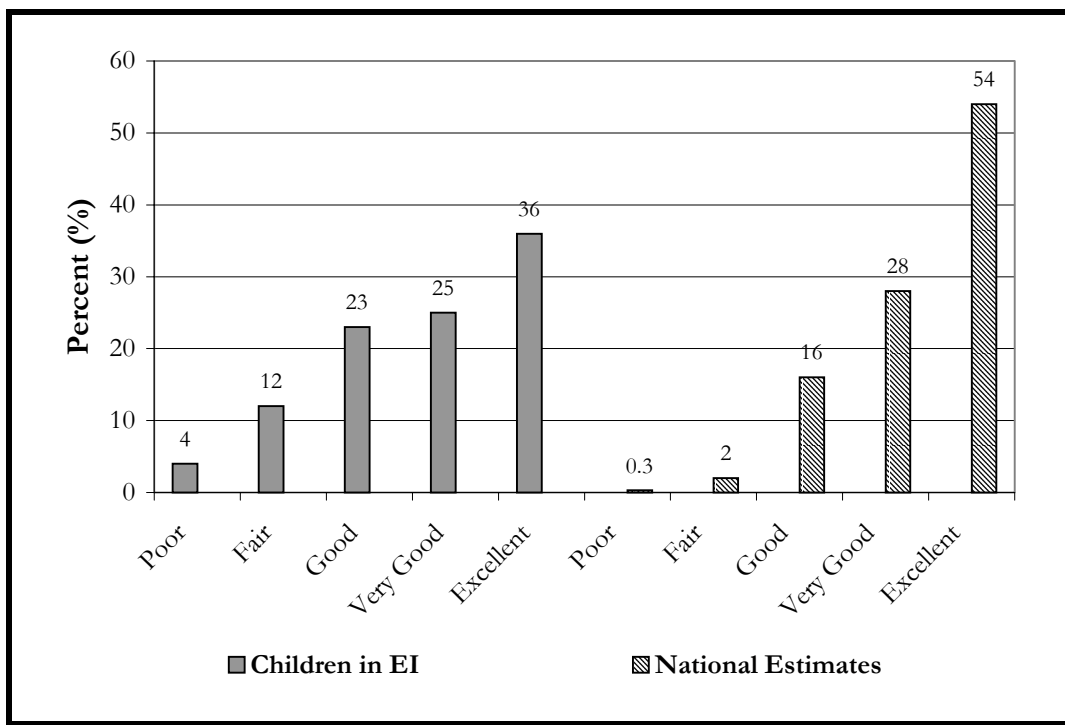
⁵ The national data are for children under age 5. For this reason, some of the differences between the national data and the early intervention data could be due to the older children included in the national data.

Table II-3
Health Status of Children Entering Early Intervention

	Percent
Health Status	
Excellent	36
Very good	25
Good	23
Fair	12
Poor	4
Regularly taking any prescription medication for a specific condition or problem	
Yes	26
No	74
Uses any kind of medical device like an oxygen tank, catheter, or a breathing monitor	
Yes	16
No	84
Hospitalized since coming home from hospital after birth	
No	66
1 to 4 days	16
5 to 14 days	11
15 or more	7
Has a place to go for regular medical care	
Yes	97
No	3
Covered by any health insurance	
Yes	95
No	5
Covered by government-assisted health insurance	
Yes	44
No	56
Ever tried to get insurance to pay for something for child that it wouldn't pay for	
Yes	19
No	81

Source: National Early Intervention Longitudinal Study.

Figure II-1
Distribution of General Health Status Rating of Children in Early Intervention Versus Children Under 5 General Population



Source: Adams, P.F. et al., 1996; National Early Intervention Longitudinal Study.

Behavior

Children vary in temperament and personality style from a very early age. The importance of some of these differences is not readily apparent. Does a 2-year-old who pays attention for a long period of time become the child who stays focused in first grade? Does the aggressive toddler become the 5-year-old with behavior problems? Part of the significance of the NEILS behavioral data rests in their stability or the extent to which early behavior serves as a predictor of later behavior. Across many different behavior items, the same pattern emerged (see table II-4). Some children, usually about half, were reported by their caregiver to have no trouble with a given behavior. Another third of the children were reported as having some difficulty, and 10 to 40 percent of the early intervention children are described as having behavioral challenges. For example, 19 percent of parents reported that it was not like their child to pay attention and stay focused; 25 percent reported that their child was easily startled; 39 percent reported their child was very active and excitable; 11 percent reported their child was often aggressive with other children;

Table II-4
Behaviors of Children Entering Early Intervention as Reported
by Their Caregivers

	Percent
Does things on own even if hard	
Very much like this child	53
A little like this child	32
Not like this child	14
Pays attention and stays focused	
Very much like this child	43
A little like this child	38
Not like this child	19
Jumpy and easily startled	
Very much like this child	25
A little like this child	30
Not like this child	45
Very active and excitable	
Very much like this child	39
A little like this child	31
Not like this child	29
Trouble playing with other children	
No trouble	56
Some trouble	32
A lot of trouble	10
Not around other children	2
Aggressive with other children	
Not at all	39
Sometimes	50
Often	11
Child has sleep trouble	
Rarely or never	53
Sometimes	28
Often	19
How easy is it to take child to the store or an appointment	
Easier than other children his/her age	23
Just as easy	45
A little harder	21
Much harder	11

Source: National Early Intervention Longitudinal Study.

and 19 percent reported that their child has sleep problems. About 1 in 10 parents (11 percent) reported that their child was much harder to take to the store or to an appointment than other children the same age. This could be because of the child's behavior or because the child has medical or other problems which might require special care. These are not all the same children having difficulties in different behavioral areas; rather the findings suggest that there are numerous ways for young children to present challenges within their families, and a minority of early intervention children present each of these challenges. Longitudinal data will reveal whether these challenges persist over time and thus their importance for future growth and development.

Family Characteristics

The family characteristics of young children are extremely powerful predictors of how these children will develop (National Research Council/Institute of Medicine, 2000). In addition to issues related to birth history, health, and health care, there are other factors that constitute risks or facilitators to development. One of the most powerful factors is poverty. The impacts of poverty begin prenatally and accumulate throughout childhood. The following sections present information on family structure and family socioeconomic characteristics. Both of these relate to the issue of resources, human and fiscal, that are available to the child. A well-educated mother of moderate to high income has many resources available to assist with child-rearing, while a poor, uneducated, single mother continually faces new challenges around the type of environment she is able to provide for her children. These differences might be especially significant for a young child with a delay or disability who might need more caregiving than a typically developing infant.

Family Structure

The number of adults in the child's household reveals an interesting picture (see table II-5). Two-thirds of the children entering early intervention were living with two adults in the household. Fifteen percent were living with only one adult, and 18 percent lived in households with three or more adults. The other adult(s) in the household was not necessarily the child's other parent. Recent population data indicate that 23 percent of the birth to 4 population live with a single parent, and 74 percent live with two parents (Federal Interagency Forum on Child and Family Statistics, 2001). Whereas most children entering early intervention (91 percent) were living with their biological or adoptive mother, only 66 percent were in households with their biological or adoptive father. Given that these are children under the age of 3, the percentage of them living with their biological fathers will almost certainly decrease over time.

Table II-5
Family Structure of Children Entering Early Intervention

	Percent
Number of adults in household	
One	15
Two	67
Three	11
Four or More	7
Number of children in household	
One	30
Two	36
Three	19
Four or More	15
Other children in household with special needs	
None	80
One	16
Two	3
Three or More	1
Living with biological or adoptive parent	
Mother	91
Father	66
Age of biological mother at birth of child	
13 to 18	4
18 to 22	16
22 to 30	37
30 to 35	25
35 to 40	14
40 and above	4

Source: National Early Intervention Longitudinal Study.

The data on other children in the household show that 30 percent of those in early intervention had no siblings or other children in their households, and 36 percent were living with only one other child. One-third of the children in early intervention were from households with three or more children. In 20 percent of the households, there was another child with special needs and sometimes more than one. The biological mothers of the children in early intervention were a wide range of ages at the time the child was born. Four percent were born to teenage mothers and another 4 percent were born to mothers over 40, with all of the age groups in between well-represented.

Socioeconomic Characteristics

The level of education of the primary caregiver is also a powerful predictor of a child's development. Many studies have shown a marked difference between children of less-well-educated and educated mothers (Furstenberg, Brooks-Gunn, & Morgan, 1987; Sameroff, Seifer, Barocas, Zax, & Greenspan, 1987; Werner & Smith, 1992). Primary caregivers of the children, most of whom were the child's biological mother, in early intervention came from a variety of education levels. About half had a high school diploma or less; 16 percent had not finished high school. One-fourth of the caregivers had finished college. Hispanic and black children receiving early intervention services were more likely than children from other racial/ethnic groups to have caregivers with less than a high school education, 29 and 25 percent respectively. Fathers were slightly better educated than mothers, with 32 percent of the fathers having graduated from college.

A little more than one-half the mothers were not working, and only 22 percent were working full time. Nearly all the fathers (90 percent) were employed, and most of them were working full time. The data on household income show that more families in the Part C early intervention program tend to be low income than in the general population. Forty-one percent of the families of children in the early intervention system reported family incomes of less than \$25,000 a year. Another 29 percent had incomes between \$25,000 and \$50,000. Although data on families of children ages birth to 3 are not available for the general population, data on families with children 18 and under highlight the extent of poverty among the population served by the Part C program. Only 20 percent of families with children 18 and under in the general population report household incomes of less than \$25,000. Some of the difference in income could be due to the presumably greater work experience of the parents in households with 18-year-old children versus those with infants and toddlers. The differences are so large, however, that age of parent or work force history is not likely to explain the entire difference in income. Another indicator of the relative poverty of families of children in early intervention was the high proportion of families, one in three, who had received welfare or food stamps some time during the past year. A small proportion of families had received Supplemental Security Income (SSI) payments for their child. Despite the relatively low income levels of families in early intervention, slightly more than half reported that they own their home.

Conclusion

The data on the characteristics of children and families receiving early intervention through the Part C program are diverse but do include a few trends. Children are

Table II-6
Socioeconomic Characteristics of Families of Children Entering
Early Intervention

	Percent
Education level of mother/female caregiver	
Less than high school	16
High school diploma/GED	32
Some college	28
BA, BS or higher	24
Education level of father/male caregiver	
Less than high school	11
High school diploma/GED	34
Some college	23
BA, BS or higher	32
Employment status of mother/female caregiver	
Not employed	56
Part time	21
Full time	22
Employment status of father/male caregiver	
Not employed	10
Part time	6
Full time	84
Family Income	
Less than \$25,000	41
\$25 – 50,000	29
\$50 – 75,000	17
Over \$75,000	13
Received welfare or food stamps in the past year	
Yes	32
No	68
Ever received SSI payments for the child	
Yes	15
No	85
Type of Housing	
Own	54
Rent	36
Public housing	8
Other	2

Source: National Early Intervention Longitudinal Study.

eligible for early intervention for a large number of different conditions. When viewed from the perspective of children's functional skills, the data show a small proportion of children who have significant difficulties with hearing, vision, use of arms and hands, or use of legs and feet. A much larger proportion have difficulty communicating. A substantial portion of children in early intervention have poor birth histories, especially black children. Some children in early intervention are in good health, but compared to the general population, higher percentages of early intervention children are reported to be in poor or fair health. Some children in early intervention also present challenging behaviors, while others do not.

The families of children in early intervention are equally diverse. Relatively high proportions of them are low income, even though almost all of their fathers and nearly half of their mothers were employed. Nearly one in three early intervention families had received welfare or food stamps in the past year. However, some families of children in early intervention reported moderate to high education and income levels. In sum, both the children and families in early intervention represent a wide cross-section of all characteristics examined. These child and family characteristics will be examined in future NEILS analyses to see how they relate to outcomes in early intervention and kindergarten.

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