



NATIONAL EARLY INTERVENTION LONGITUDINAL STUDY

**Birth History and Health Status of Children
Entering Early Intervention**

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NEELS Data Report 5

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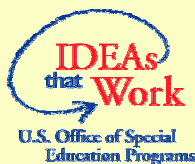
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NEILS is part of a program of longitudinal studies funded by the U.S. Department of Education and being conducted by SRI International. Other studies in the program include the Special Education Elementary Longitudinal Study (SEELS) and the National Longitudinal Transition Study-2 (NLTS2). For more information about these studies, see <http://www.seels.net/> or <http://www.nlts2.org/>. The NEILS Web site is <http://www.sri.com/neils/>.

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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). To provide much-needed 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 is being collected repeatedly about participating children and families through their kindergarten year. More information about the study design is contained in Hebbeler and Wagner (1998).¹

NEILS is addressing five key study questions:

- Who are the children and families receiving early intervention services?
- What early intervention services do participating children and families receive?
- What are the costs of the early intervention services?
- What outcomes do participating children and families experience?
- How do outcomes relate to variations in child and family characteristics and services received?

This Report: Birth History and Health Status

This report describes the birth history and health status of the children participating in early intervention. Two earlier reports looked at the demographic characteristics of children and families participating in early intervention. These included child- and family-level descriptors such as gender, race/ethnicity, whether the child was in foster care, family's receipt of public assistance, family structure, household income, and mother's education level (Hebbeler et al., 2001; Hebbeler, Spiker, Mallik, Scarborough, & Simeonsson, 2003).

The federal legislation that created the Part C program under the Individuals with Disabilities Education Act (IDEA) states that services should be provided "to enhance the development of infants and toddlers with disabilities" and "to enhance the capacity of families to meet the special needs of their infants and toddlers" (20 U.S.C. 1431, as amended by the Individuals with Disabilities Education Act Amendments of 1997). The law is premised on the assumption that the provision of high-quality, coordinated, multidisciplinary early intervention services will achieve these objectives. Understanding whether Part C is enhancing the development of infants and toddlers with disabilities and the capacity of families to meet their needs requires information about how the system is being implemented, what services are being provided, and what results are being achieved by those participating in the system.

¹ All NEILS reports are available at www.sri.com/neils.

Providing—and therefore understanding—early intervention services is a complex undertaking. More than 200,000 children receive early intervention in the United States (U.S. Department of Education, 2000). There are many specific reasons for which these children can be eligible for early intervention services. All of these reasons fall within the general categories of developmental delay, diagnosed condition, or risk condition, but there are many types of delays and numerous diagnosed conditions and reasons that children can be at risk for poor development. An initial look at the varied reasons why children are receiving early intervention services was presented in an earlier NEILS report (Hebbeler et al., 2001). Obviously, the nature of the child's condition has significant implications for what services the child and family will receive and the developmental results that can be expected at the conclusion of the child's time in early intervention. Babies born with very serious disabilities, even if provided with the best services available, will still be facing significant developmental challenges when they transition out of early intervention at 36 months of age. By contrast, toddlers with mild delays or infants with risk conditions might no longer need any services.

The amount of progress children will make in early intervention is the result of numerous interacting factors. These include factors related to the child's disability, the child and family's life circumstances, the nature of the services received, and numerous other potential factors whose effects are not well understood. Years of research on the effectiveness of early intervention have shown conclusively that early intervention is effective, but many questions still remain about the specific features of early intervention that result in the best outcomes for certain kinds of children and families (Wolery & Bailey, 2003; Guralnick, 1997).

Understanding how early intervention is working in the United States today and how to make the system more effective requires a detailed understanding of the many parts of the puzzle. The five NEILS study questions listed above are one way of describing this puzzle.

This report is one of four that address the first study question:

- Who are the children and families receiving early intervention services?

The other two reports address demographic characteristics (Hebbeler et al., 2001, 2003) and functional and behavioral characteristics (Spiker et al., in preparation) of children in early intervention.

Describing the birth history and health status of children participating in early intervention is an important first step in an examination of the results the system is achieving. Birth history and health status may be significantly compromised for some children in early intervention but not for others. It is critical to understand this variability since it also affects the services needed, by both the children and their families. We also know that a significant percentage of children in early intervention are from low-income families and are of ethnic minority status (Hebbeler et al., 2003), and these are factors that affect children's birth histories, health status, and access to health care (Chen, Matthews, & Boyce, 2002; Hack et al., 2002). It is highly likely that these factors, associated with poorer health status, also affect the development of infants and toddlers with disabilities, the services they need, and the progress children will make in early intervention.

In this report, the following specific questions are addressed:

- What are the birth weights and birth histories of children entering early intervention?
- What is the overall health status of children entering early intervention?
- What are the early hospitalization experiences of children entering early intervention?
- How many children entering early intervention have health insurance, use medications, or use medical devices?
- How do children in early intervention compare with the general population of young children on their birth histories and health status and care?
- What child and family factors are associated with children's birth history and health status and care?

The remainder of this chapter briefly summarizes the methodology for the study. Findings are presented in the second chapter. The final chapter summarizes what has been learned, discusses the significance of the findings, and highlights next steps in the NEILS analysis agenda.

Data Collection and Analysis

Sample

The findings presented in this report are based on a nationally representative sample of 3,338 children who entered early intervention for the first time between September 1997 and November 1998. Families were recruited through early intervention programs located in 93 counties in 20 states. Local program providers explained the study to families at or near the time of the first Individualized Family Service Plan (IFSP) meeting. All families who met the study criteria (child less than 31 months of age and an adult in the household who spoke English or Spanish) were invited to participate. If a family had more than one child entering early intervention, only one child was selected for the study. Programs invited 4,653 families to participate in the study, and 3,338 (71%) agreed.

Data Collection

The findings in this report are based primarily on telephone interviews conducted within 16 weeks of enrollment in early intervention. Some data were taken from additional telephone and/or mail surveys for those who could not be interviewed within 16 weeks of enrollment. A 40-minute telephone interview was conducted with "the person best able to answer questions about the child and the child's program." Fourteen percent of the interviews were conducted within 2 weeks of the initial IFSP meeting, 36% within 2 to 4 weeks of the IFSP, 18% within 4 to 6 weeks of the IFSP, and 25% within 6 to 16 weeks of the IFSP. Telephone interviews were completed with 89% of the families (n = 2,974). Families who could not be reached by phone were sent a questionnaire in the mail. Some families who could not be

contacted for the initial interview were successfully contacted for the next scheduled interview a year later. These families were asked some of the questions from the first interview (e.g., information about the child's birth history) during this interview. Interview or mail survey data were available for 3,200 children, or 96% of the sample. Some data, such as date of the IFSP meeting, were available for 100% of the sample. Individual items will have fewer respondents because of missing data. Additional information about the study's methodology is presented in Javitz et al. (2002).

Most (83%) of the respondents to the telephone interview were the child's biological mother. Other respondents included foster mothers (5%), grandmothers (4%), adoptive mothers (3%), and biological fathers (4%). Six percent of the interviews were conducted in Spanish. Since most of the children were being cared for by their biological mothers, we generally will use the term "mothers" throughout the report to refer to the primary female caregivers.

Analysis

All data presented in this report are weighted, which means that numerical weights have been applied to the raw data. The procedures for calculating the weights are described in detail in Javitz et al. (2002). Because of the nature of the sample selection procedures employed and the weights applied to the data, the data presented in this report represent national estimates. The percentages and means are 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 the estimate, researchers use a statistic called "standard error." To aid the reader in determining the precision of the estimates, tables in Appendix A present the approximate standard error for each percentage or mean and the unweighted number of cases on which the statistic is based.

The tables in Appendix A also show p-values from chi-square analyses or the analysis of variance testing the relationship between the items of interest and a set of key child and family characteristics. These analyses address questions about whether or not the items vary as a function of variations in characteristics of children and families (e.g., whether the child's health was related to when the child began early intervention).

Finally, throughout the report, wherever possible, we present comparison information from national data on the general U.S. population of families with infants and toddlers. Many of the comparison data are available for families with children birth to age 3, but some are based on the birth to age 5 population or other age groups. To the extent possible, we attempted to make comparisons with the birth to age 3 general population.

Limitations

Every effort was made to recruit and enroll all eligible families in the 93 counties in the study. However, in some counties, some programs declined to participate in the study. This occurred very infrequently, but it is possible that the families who would have been enrolled

by the refusing programs would be different from those enrolled by the participating programs in a county.

We also have reason to believe that not all early intervention personnel at participating programs invited all eligible families to participate in NEILS. Some staff misunderstood the directions, and others reported excessive workloads, which resulted in their completing enrollment forms for (and recruiting into the study) some families but not all. SRI worked with sites throughout the recruitment period to minimize these problems, but we strongly suspect that there were some families for whom data forms were not completed. 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. To the extent that no such difference exists, there should be no bias introduced by the incompleteness of information that results from this second limitation.

Finally, some of the families who agreed to participate in the study are not included in the findings presented here because they could not be located, declined to be interviewed, or did not return the mail questionnaire. A comparison of the weighted family characteristics available at the time of enrollment (described in Hebbeler et al., 2001) and those for the interviewed sample (available for this report) showed comparable population estimates for all variables. This result suggests that the population estimates reported here reflect accurate estimates for the entire population of children and families entering early intervention during the enrollment period who were eligible to be enrolled into NEILS.

FINDINGS

This chapter presents findings on the following health-related characteristics of children at the time they began receiving early intervention (EI) services:

- Birth weight and gestational age
- General health status, including hospitalizations
- Health insurance
- Medications and medical devices.

Each section begins with the findings on the characteristics listed above, and then the data are examined with regard to other key child and family characteristics. These other characteristics examined include:

- Reason for eligibility for early intervention (i.e., developmental delay, diagnosed condition, risk condition)
- Age at entry into early intervention
- Gender
- Race/ethnicity
- Education level of primary caregiver

- Household income
- Receipt of public assistance.

These additional analyses answer questions such as “Does the percentage of children born at low birth weight differ for children with developmental delays and those with diagnosed conditions?” or “Does general health status differ for children from households with different income levels?” In addition, some of the birth history and health variables are examined in relation to each other (e.g., “Do children of different birth weights have different health status?”).

If the relationship between the variable of interest and another characteristic is statistically significant and large enough to be meaningful, it is described in the text and sometimes in a graph. Generally, nonsignificant relationships are not described. The reader interested in additional analyses is referred to Appendix A. This appendix presents the data for all of the birth history and health characteristics discussed in the report in relation to each of the other key characteristics examined.

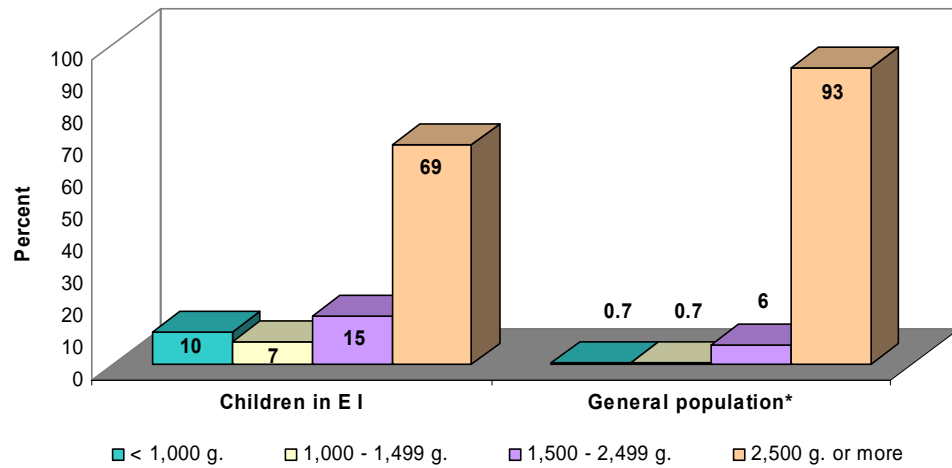
Birth History of Infants and Toddlers

Children who are born at low birth weight (LBW²) and prematurely are at risk for a variety of developmental and health problems, both early in life and over the long term (Botting, Powls, Cooke, & Marlow, 1998; Bregman, 1998; Hack et al., 2002). The developmental and health consequences of low birth weight are most apparent for those born at very low birth weight (VLBW) and include developmental delays and behavioral difficulties in the first 3 to 5 years of life, with continuing behavioral problems and academic difficulties at later school ages (Hack et al., 2002; Saigal, 2000). Furthermore, a significant body of research indicates that the negative outcomes experienced by many LBW children are exacerbated by family environments characterized by poverty, low educational attainment of caregivers, and poor parental stimulation and interactions with the children (Hack, Klein, & Taylor, 1995; Hollomon, Dobbins, & Scott, 1998; Taylor, Klein, Schatschneider, & Hack, 1998).

A substantial proportion of babies and toddlers in early intervention had compromised birth histories (Figure 1). Approximately one-third of children (32%) in early intervention were born at low birth weight, four times the percentage of LBW births in the general population (7%) (Ventura, Martin, Curtin, & Mathews, 1999). Furthermore, 17% had birth weights considered to be VLBW, an estimate that is 12 times the rate in the general population (1.4%) (Ventura et al., 1999). Girls in early intervention were slightly more likely to be LBW than were boys (35% versus 29%) ($p < .01$). As expected given this rate of LBW children, nearly one-third of children (31%) in early intervention were born prematurely (less than 37 weeks gestational age), more than twice the prematurity rate in the general population (13%) (Ventura et al., 1999).

² Children who are born weighing less than 2,500 grams are termed low birth weight (LBW), and those weighing less than 1,500 grams are referred to as very low birth weight (VLBW).

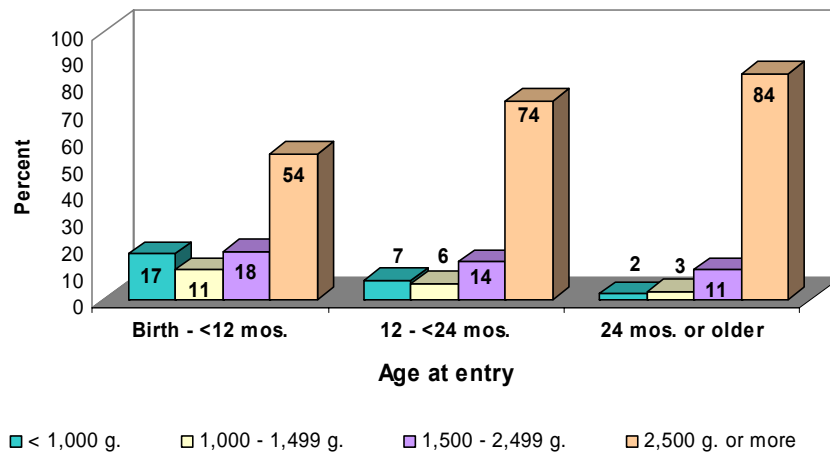
Figure 1
PERCENTAGE DISTRIBUTION OF BIRTH WEIGHTS OF CHILDREN IN EARLY INTERVENTION (EI), COMPARED WITH GENERAL POPULATION



*Source for general population: Ventura, Martin, Curtin, and Mathews (1999).

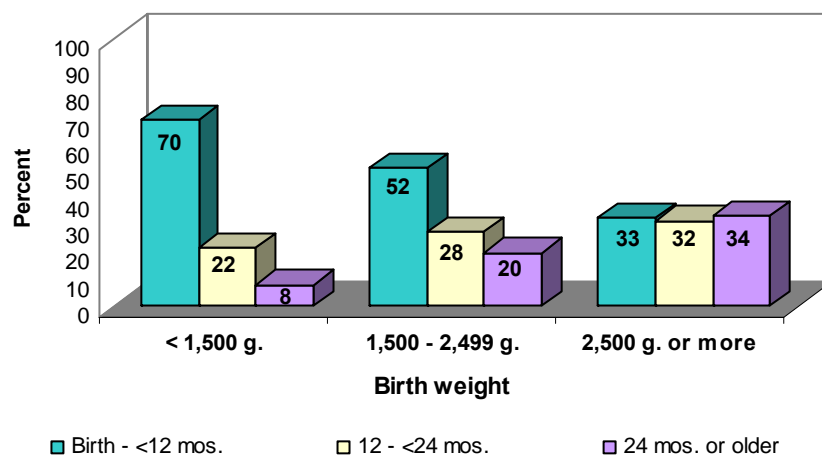
More of the children who entered early intervention at younger ages were LBW ($p < .001$). Nearly half (46%) of infants who entered early intervention in the first year were LBW, whereas only 16% of those who entered after age 2 were LBW (Figure 2). As was true for birth weight, nearly half (46%) of the children who entered early intervention in the first year were born prematurely.

Figure 2
PERCENTAGE DISTRIBUTION OF BIRTH WEIGHTS OF CHILDREN IN EARLY INTERVENTION, BY AGE AT ENTRY INTO EARLY INTERVENTION



Another way to examine the relationship between birth weight and the age at which children enter early intervention services is to look at the age at entry within each of the birth weight groups (Figure 3). Of the infants who weighed less than 1,500 grams, nearly three-fourths (70%) entered in the first year, whereas about half (52%) of those with birth weights from 1,500 to 2,499 grams did so. In contrast, children with birth weights of 2,500 grams or more entered early intervention approximately equally in each of the first three years of life. It is somewhat surprising that although the majority of children with birth weights under 1,500 grams entered early intervention before age 12 months, 8% of the tiniest LBW children entered at 24 months or older and another 22% entered between 12 and 24 months. This pattern is important to note because these are children who are at substantial risk for health and developmental problems for which the earlier monitoring and services from early intervention are warranted.

Figure 3
AGE AT ENTRY INTO EARLY INTERVENTION, BY BIRTH WEIGHT GROUP

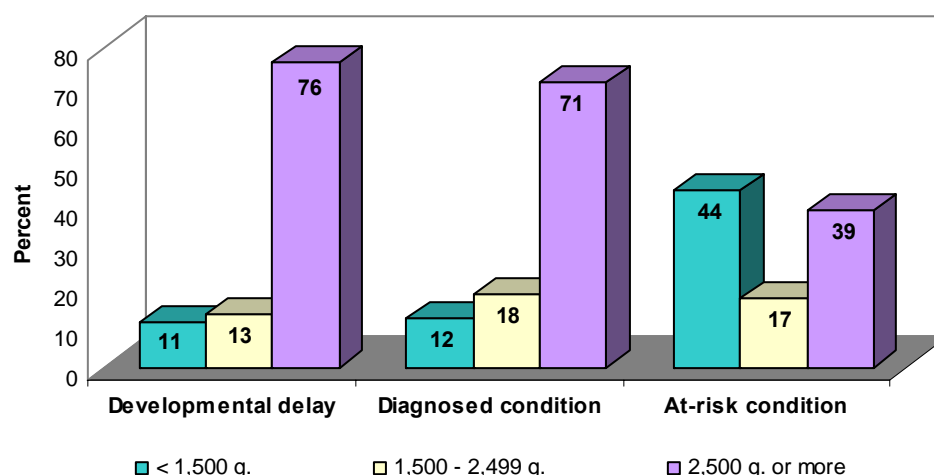


Reasons for eligibility for early intervention were associated with birth weight ($p < .001$) (Figure 4). Children who were eligible because of at-risk status were most likely to have been born at low birth weight. This finding is due in part to the coding system used by the study to classify reasons for eligibility. If a provider indicated LBW as the only reason for eligibility for early intervention, the child would have been classified as at risk for study purposes (see Hebbeler et al., 2001, for more information). Most (61%) of the children eligible because of at-risk status were LBW, whereas 30% of those eligible because of a diagnosed condition and 24% of those eligible because of developmental delay were LBW. This association also holds for prematurity, which is closely related to birth weight. The association between LBW, prematurity, and reasons for eligibility for early intervention is not surprising since low birth weight and prematurity (and their sequelae) are included in some states' eligibility definitions

as a diagnosed condition or, in a few states, as a factor defining risk status (Shackelford, 2002).

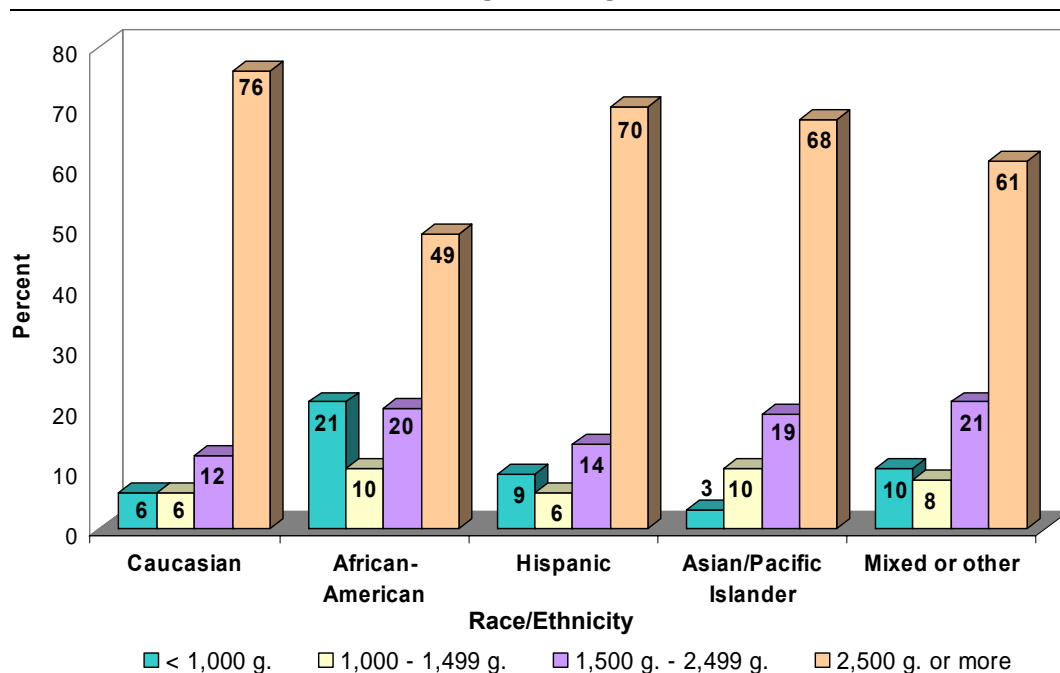
Of those children in EI who were low birth weight, a quarter (25%) had no other apparent conditions that made them eligible for early intervention, other than being LBW. These children accounted for only 8% of the children entering early intervention, overall. Most (88%) of these children entered early intervention in their first year; 12% entered EI at 12 months or older. Furthermore, 43% of these children were under 1,000 grams at birth, 28% from 1,000 to 1,499 grams, and 30% from 1,500 to 2,499 grams.

Figure 4
REASONS FOR ELIGIBILITY FOR EARLY INTERVENTION SERVICES, BY BIRTH WEIGHT GROUP



As also seen in the general population, ethnicity was associated with LBW and prematurity of children in early intervention ($p < .001$) (Paneth, 1995). Data from the general population of births in 1999 indicate that about 13% of African-American children were LBW, compared with about 7% of Caucasian and 6.5% of Hispanic children (Ventura et al., 2001). Among children in early intervention, we find that although significant percentages of children from all ethnic groups were LBW, children from minority ethnic groups were more likely than those of Caucasian backgrounds to be LBW (Figure 5). Half (51%) of African-American children in early intervention were LBW, as were 32% of those of Asian or Pacific Islander backgrounds, 30% of those of Hispanic backgrounds, and 39% of those of mixed or "other" race. This contrasts with just under one-fourth of Caucasian children (24%). Similarly, African-American children in early intervention were more likely to be born prematurely than were children in other ethnic groups, with nearly half being born prematurely. Thus, African-American infants and toddlers in early intervention were most likely to be small at birth and to be born early.

Figure 5
BIRTH WEIGHTS OF CHILDREN IN EARLY INTERVENTION, BY CHILD'S RACE/ETHNICITY



Household income also was associated with LBW and prematurity ($p < .001$). Again, although at least one-quarter of children in all income brackets in early intervention were born at low birth weight, greater proportions of children from low-income families were LBW. For example, 37% of children in families with annual incomes of \$15,000 or less were LBW, whereas 25% of children in families with annual incomes over \$75,000 were LBW. Likewise, greater proportions of children in the lowest income brackets were born prematurely, compared with those in higher-income families: 35% of children in the lowest-income families (\$15,000 or less per year), compared with 24% of those in the highest-income families (over \$75,000 per year).

The education level of the mothers or primary caregivers was associated with LBW ($p < .05$) or prematurity status of children in early intervention ($p < .001$), with more children who were LBW having mothers or primary caregivers with lower educational attainment. This pattern is to be expected because mother's education level and household income are positively correlated.

Birth History and Demographic Risk Status

In an earlier report (Hebbeler et al., 2003), we examined the occurrence of multiple demographic risk factors and found that more than half of children in early intervention had two or more demographic risk factors. To explore the occurrence of multiple demographic risk factors among children entering early intervention, a demographic risk index was constructed. The index allotted one point to a child for each of the following:

- Being a member of a minority group
- Being in foster care
- Being in a low-income household (\$25,000 or less annually)
- Having a primary female caregiver with less than a high school education
- Having a primary female caregiver who was 17 years old or less at the time of the interview
- Living in a household with only one adult present
- Living in a household with one or more other children with special needs
- Living in a household with four or more children
- Adequacy of housing was rated as fair or poor
- Adequacy of transportation was rated as fair or poor.

A child with all of the risk factors would have a score of 10, and a child with none would have a score of 0.

Using this risk score to compare children in different birth weight groups, children in early intervention with LBW had significantly more risk factors than children with normal birth weight ($p < .001$) (Figures 6 and 7). This combination of both biological and socioenvironmental risk has been shown in numerous studies to be particularly detrimental to children's early development (Escalona, 1982; Hollomon et al., 1998; Hack et al., 2002).

Figure 6
AVERAGE NUMBER OF DEMOGRAPHIC RISK FACTORS FOR CHILDREN RECEIVING EARLY INTERVENTION, BY BIRTH WEIGHT GROUP

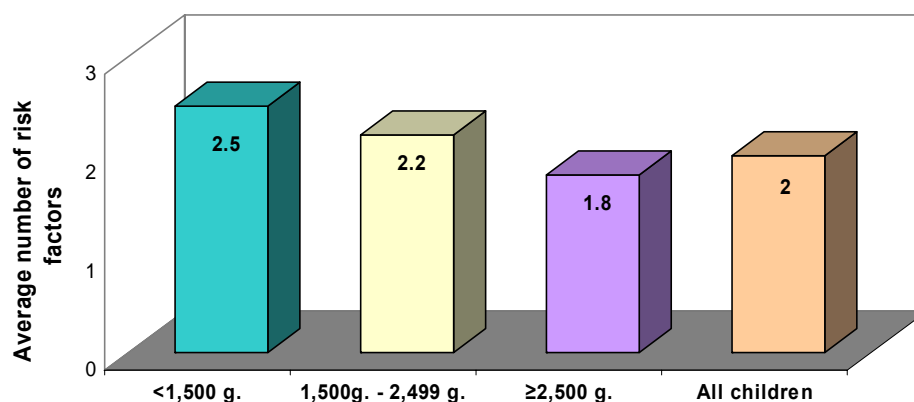
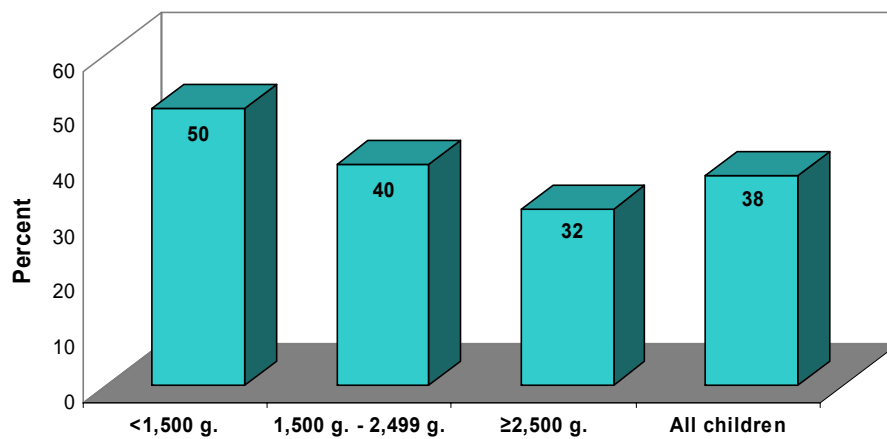


Figure 7
PERCENTAGE OF CHILDREN RECEIVING EARLY INTERVENTION WITH 3 OR MORE
DEMOGRAPHIC RISK FACTORS, BY BIRTH WEIGHT GROUP



General Health Status of Infants and Toddlers

Parents were asked several questions about the 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 problems per se.

As might be expected, many children in early intervention experienced difficulties and health problems at or immediately after birth, particularly those who were LBW (Table 1). Whereas about 6 in 10 children in early intervention (61%) stayed in the hospital less than 4 days after birth, indicating an uneventful birth experience, nearly 2 in 10 (19%) stayed for more than 1 month, suggesting significant birth and perinatal difficulties. One important indicator of birth problems and possibly later developmental difficulties is whether the child was hospitalized in a neonatal intensive care unit (NICU) after birth. Nearly 4 in 10 (38%) spent some time in an NICU after birth; this is 10 to 20 times more frequent NICU use than in the general population, estimated at 2% to 4% (U.S. Congress, Office of Technology Assessment, 1987).

As would be expected, the children born at low birth weight were also premature, and they were more likely to spend time in an NICU after birth and to be hospitalized longer after birth (Table 1). For instance, almost all of the children born at less than 1,500 grams spent some time in an NICU after birth. However, it is notable that 2 in 10 (20%) of the normal birth weight children in early intervention also spent some time in an NICU after birth. Another indication that the LBW children were less healthy than their normal birth weight peers is that those children born at the lowest birth weights were more likely to be rehospitalized after birth than those of normal birth weight, as discussed later in the chapter.

Table 1
NICU STAYS OF CHILDREN IN EARLY INTERVENTION,
BY BIRTH WEIGHT GROUP

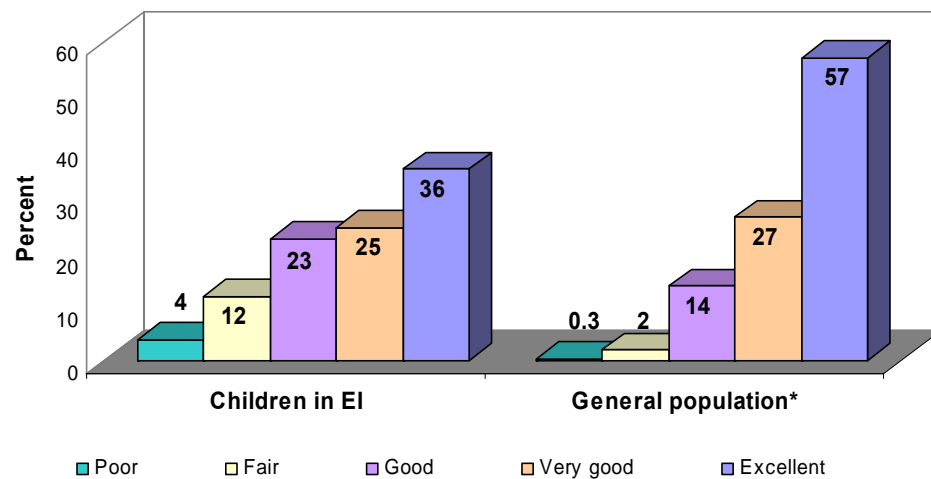
Birth weight	Less than 1,000 g.	1,000 – 1,499 g.	1,500 – 2,499 g.	2,500 g. or more	All Birth weights
In NICU after birth					
Yes	98	93	63	20	38
Nights in hospital after birth					
0	0.2	3	27	73	55
1-4	0.2	1	5	8	6
5-14	0.4	3	26	12	12
15-30	4	14	21	4	7
31-61	18	56	14	2	9
62-91	39	16	2	0.45	5
92-121	14	3	0.2	0.2	2
>121	24	3.0	4	0.4	3

Other factors related to NICU use and extended hospitalization after birth were gender and race/ethnicity. Girls had longer hospital stays after birth than boys did ($p < .001$) and spent time in an NICU ($p < .05$). Interestingly, diagnosed conditions were more frequent among girls than boys. African-American children were more likely than those from other ethnic groups to have been in an NICU ($p < .01$), reflecting their higher rate of being LBW.

Many national surveys use an overall rating of health status because it has been found to be a valid and reliable indicator of other objectively obtained measures of health status and health care use (Federal Interagency Forum on Child and Family Statistics, 2002). Furthermore, other national data indicate that ratings of fair, or poor health are quite uncommon, but are associated with many indicators of poor health and frequent use of health services (Krause & Jay, 1994; Montgomery, Kiely, & Pappas, 1996).

In NEILS, parents or primary caregivers were asked to rate their child's overall health as excellent, very good, good, fair, or poor at the time the child began early intervention services. The vast majority of the parents of children in early intervention rated their children's overall health status as good to excellent (84%) (Figure 8). However, 16% of the children in early intervention were rated as having fair or poor overall health, and far fewer were rated as in excellent health, compared with general population estimates (36% versus 57%). The percentage of children rated in fair or poor health is eight times that in the general population, for which only about 2% of all children birth through 4 years are described as being in fair or poor health (Bloom & Tonthat, 2002). This difference shows that a sizeable minority of children in early intervention have special health needs, and they may be at risk of not receiving necessary early intervention services on a regular basis because they may be frequently sick.

Figure 8
GENERAL HEALTH STATUS OF CHILDREN IN EARLY INTERVENTION, COMPARED
WITH NATIONAL ESTIMATES

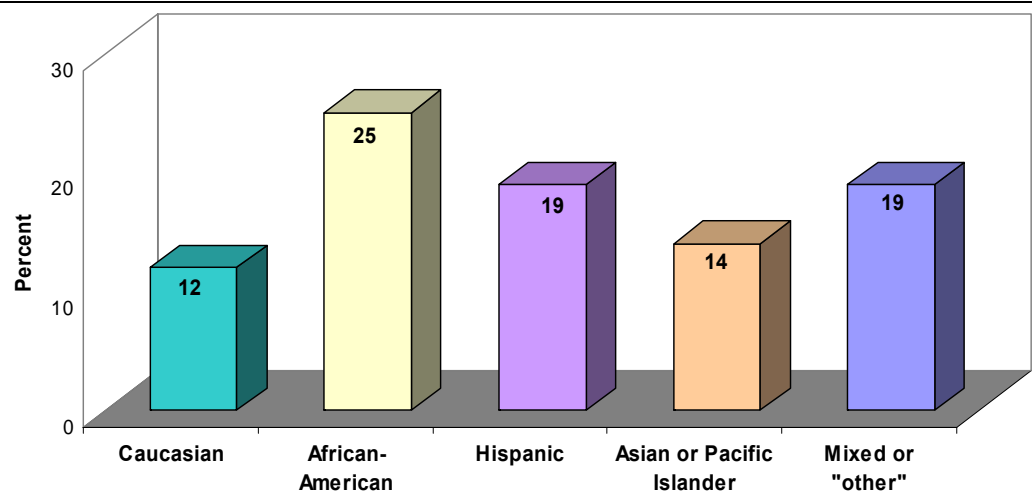


*Source for general population (birth to age 5) for 1997 estimates: Bloom and Tonthat (2002).

What other factors are associated with poorer health status for children in early intervention? Compared with children in the general population, more children in early intervention in all racial/ethnic groups had fair or poor health. However, more of the non-Caucasian children in early intervention were rated as having fair or poor health (25% for African-American, 19% for Hispanic, 19% for mixed race or “other”) (Figure 9). In the general population of children birth to age 5 years, only about 2% of Caucasian children and 4% of African-American children are described by parents as having fair or poor health (Adams, Hendershot, & Marano, 1999).

Not surprisingly, more of the children who entered early intervention in the first year were described to be in fair or poor health (22%), compared with children who entered early intervention when they were 2 years and older (11%) ($p < .001$). This pattern probably reflects the fact that those who enter earlier have diagnosed or risk conditions and are more likely to have been LBW. As further support for this speculation, children eligible because of developmental delay were more likely to have better health ratings. They also were more likely to enter services at later ages ($p < .05$).

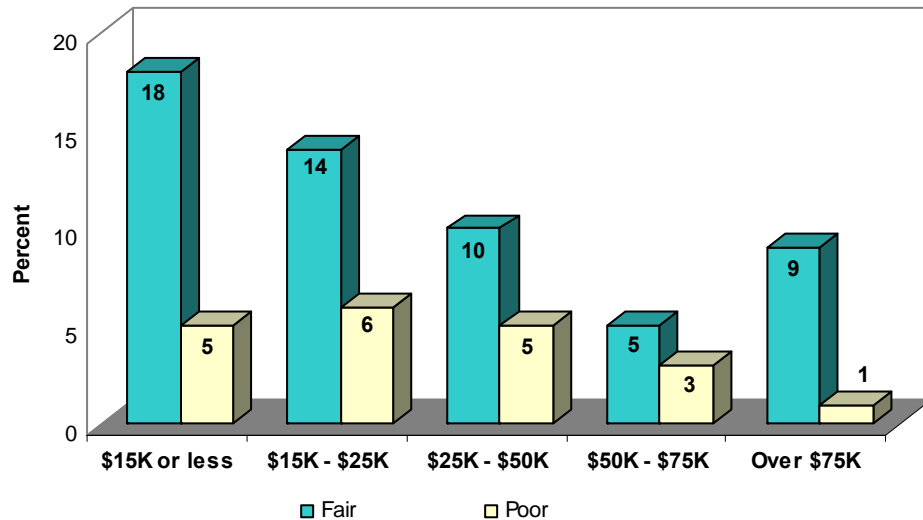
Figure 9
PERCENTAGE OF CHILDREN IN EARLY INTERVENTION WITH FAIR OR POOR HEALTH STATUS, BY CHILD RACE/ETHNICITY



In national data for the general population (Montgomery, Kiely, & Pappas, 1996), indicators of family socioeconomic status, such as family income, are significantly related to ratings of child health status. Children in low-income households are rated as having poorer health (Adams et al., 1999). Not unexpectedly, more children in early intervention from families in the lowest income bracket were rated as having fair or poor health (23%). Only 10% of those in the highest-income bracket were described as having fair or poor health, ($p < .001$) (Figure 10). Alternatively, nearly three-fourths of children in the highest-income households (71%) were described as having excellent or very good health, compared with only about half of those in the lowest-income households (51%).

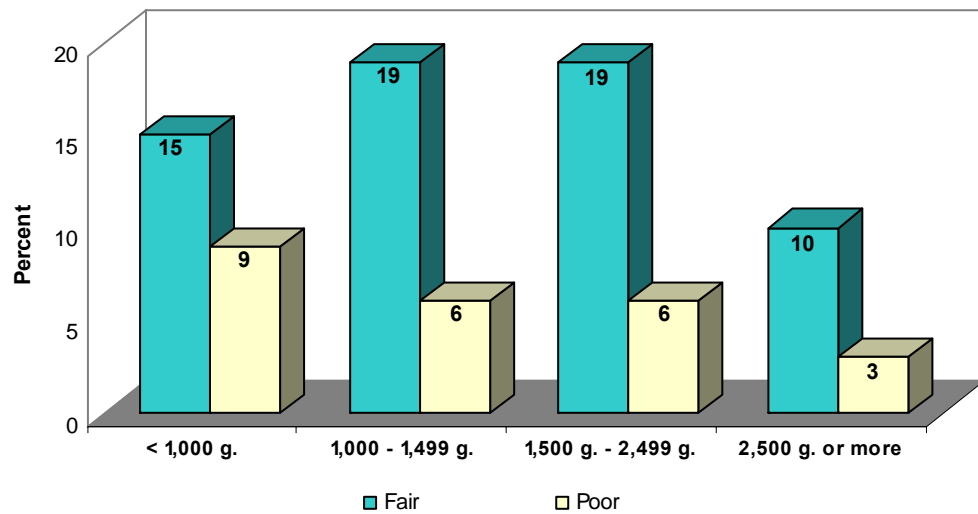
As might be expected from the positive association between education level of mothers and level of household income described earlier, health ratings also were associated with mothers' education levels. Children whose mothers had less than a high school diploma were more than twice as likely to be rated with fair to poor health (25%) as children whose mothers had a college degree or higher (10%) ($p < .001$).

Figure 10
PERCENTAGE OF CHILDREN IN EARLY INTERVENTION WITH FAIR OR POOR
HEALTH STATUS, BY HOUSEHOLD INCOME



Health status was related to other indicators of the children's birth and early hospitalization experiences. More of the LBW children were described as having fair or poor health: about one-fourth of each of the three LBW categories were described as being in fair or poor health at entry to early intervention. By contrast, only one in eight of the normal birth weight children (13%) were rated as having fair or poor health ($p < .001$) (Figure 11). Alternatively, twice as many of the normal birth weight children as those with the lowest birth weights were rated as having excellent health (40% versus 22%). As would also be expected, children who were born the most prematurely were more likely to have poorer health, as were those who spent time in an NICU after birth. Furthermore, children who had longer hospital stays after birth were rated as having poorer overall health when they began early intervention.

Figure 11
PERCENTAGE OF CHILDREN IN EARLY INTERVENTION WITH FAIR OR POOR
HEALTH STATUS, BY BIRTH WEIGHT GROUP



Other indicators of health status are rehospitalization and the amount of time children spend in a hospital after going home after birth. Approximately one-third (34%) of the children were reported to have been hospitalized at least once after they went home from the hospital after birth (see Table 2). Seven percent of the children in early intervention had spent more than 2 weeks in the hospital since coming home. More of the children who were African-American or of mixed race or “other” ethnicity were rehospitalized, compared with white children (40% versus 31%) ($p < .001$). Children who entered early intervention services in the first year (the youngest infants) were more likely to be rehospitalized than were those who entered in the third year of life (38% versus 28%) ($p < .001$). Children who were eligible for early intervention services because of a diagnosed condition were more likely to have been rehospitalized, compared with those who entered early intervention because of developmental delays or at-risk conditions, although all three groups had relatively high rates of rehospitalization (41% versus 32% and 31%, respectively) ($p < .001$). Children who were born LBW (especially those under 1,000 grams) were more likely to be hospitalized after going home, compared with their normal birth weight counterparts. As in the general population, hospitalization in the first years of life was more common for children in early intervention who lived in poorer households. Table 3 summarizes general health status ratings of children in EI by certain birth history variables. Children born at 24 weeks gestational age or less were more likely to be rated as having fair or poor health (27%) compared to those born at 37 weeks or more (13%) ($p < .001$). In terms of hospitalization both after birth and since coming home after birth, it was evident that children with longer hospital stays were more likely to be rated as having fair or poor health relative to their counterparts with shorter or no hospital stays after birth (see Table 3). Taken together, the findings indicate that there are some vulnerable young infants in early intervention who have

a combination of biological and social-environmental risk factors that place them in significant developmental jeopardy.

Table 2
EARLY HOSPITALIZATION OF CHILDREN IN EARLY INTERVENTION,
BY BIRTH WEIGHT GROUP

	Less than 1,000 g	1,000 – 1,499 g	1,500 – 2,499 g	2,500 g. or more	All children
Days in hospital since coming home after birth					
0	57%	60%	64%	68%	66%
1-4	22%	18%	20%	17%	17%
5-14	12%	10%	13%	10%	11%
15-30	4%	4%	4%	3%	4%
> 30	5%	4%	3%	2%	3%
Has been hospitalized since birth	0.8%	0.0%	0.2%	0.0%	0.1%

Percentages describe a nationally representative weighted sample and may not add to 100 because of rounding and/or missing data.

Table 3
GENERAL HEALTH STATUS RATINGS OF CHILDREN IN EARLY
INTERVENTION, BY BIRTH HISTORY VARIABLE

	Excellent	Very good	Good	Fair	Poor
Gestational age					
24 weeks or less	13%	18%	42%	22%	5%
25-28 weeks	21%	26%	28%	16%	9%
29-32 weeks	29%	22%	27%	16%	6%
33-36 weeks	37%	23%	20%	15%	5%
37 weeks or more	39%	24%	22%	10%	3%
In NICU after birth					
Yes	27%	37%	45%	51%	64%
Nights in hospital after birth					
0	44%	25%	20%	9%	2%
1-4	30%	23%	33%	9%	4%
5-14	31%	26%	23%	14%	6%
15-30	25%	22%	29%	17	7%
31-61	28%	23%	29%	14%	6%
62-91	27%	25%	30%	14%	5%
92-121	14%	29%	17%	22%	18%
>121	7%	17%	33%	30%	13%
Days in hospital since coming home after birth					
0	43%	26%	21%	8%	2%
1-4	32%	26%	26%	13%	3%
5-14	20%	20%	27%	25%	7%
15-30	13%	24%	26%	24%	13%
> 30	9%	8%	24%	38%	21%
Has been hospitalized since birth*	0%	0%	51%	17%	32%

*Infant was still in hospital at time of interview.

Health Insurance and Health Care

Overall, 95% of the children had health insurance when they began early intervention. This is a higher rate than estimates for the general population (88% for children under 18 years of age) (Health Resources and Services Administration, 2002). It is possible that this higher

rate of insurance coverage for children in early intervention occurs because children with health insurance are more likely to be screened and referred than those without insurance. Thus, there may be a group of young children, those without health insurance, who are not receiving the early intervention services they need, possibly because they do not regularly see a health care provider. Alternatively, uninsured children who are eligible for publicly supported health insurance may be referred for that coverage as part of the process of beginning early intervention.

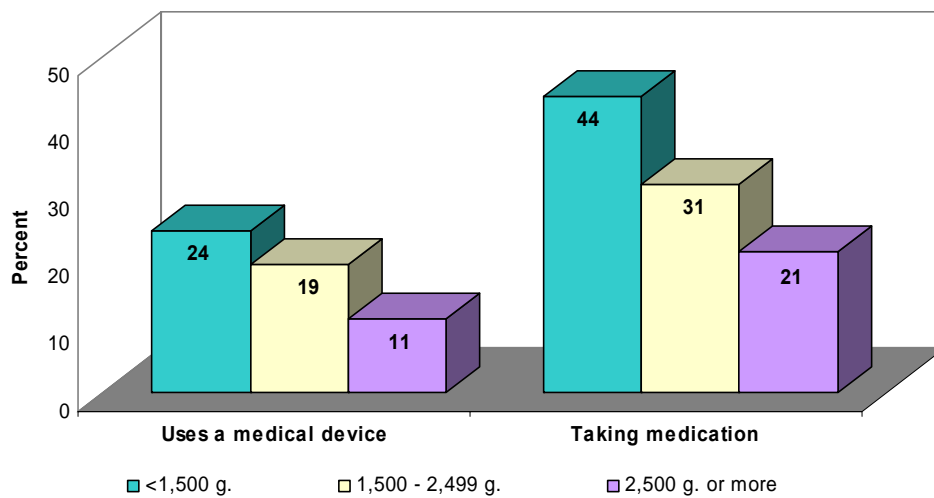
Despite this overall high rate of coverage, children in low-income families and those whose mothers had less than a high school education had lower rates of coverage. For instance, 90% of children of mothers who did not finish high school were covered, whereas 99% of children with mothers who had graduated from college were covered.

Almost all children in early intervention had a regular place for health care (97%). This level of coverage is comparable to that of the general population of children birth to 4 in 1998, when 97% had a regular place for health care (Blackwell & Tonthat, 2002). More children (4%) in the lowest-income families (\$15,000 or less per year) did not have a regular place for health care, compared with 1% of those in the highest-income families (over \$75,000 per year) ($p < .001$). Those children in early intervention with no regular place for health care were not more likely to be in poor health or to be LBW than those who did have a regular place.

Medical Devices and Medications

Parents or caregivers were asked about medical devices the children were using and any medications they were taking. One in six children (16%) receiving early intervention services were reported to be using some kind of medical device. These devices include apnea monitors, respirators, nebulizers, feeding tubes, and catheters. Such use was not related to gender or ethnic background. Children from the lowest-income families were more likely to use a medical device ($p < .01$). Age at entry into early intervention services and eligibility category were related to use of medical devices ($p < .001$). Children who entered in the first year of life were three times as likely to use a medical device (25%) as were those who entered at 24 months of age or older (8%). Children who were eligible because of risk conditions were more than twice as likely to use a medical device as were those who entered early intervention because of a developmental delay (27% versus 11%). This difference is probably related to the fact that the children who enter early intervention as young infants have the most compromised birth histories and health or have diagnosed conditions that may have significant health-related sequelae. Indeed, sicker children were more likely to use such devices; 37% of those in fair or poor health used medical devices, whereas only 9% of those in very good or excellent health did so ($p < .001$). Low birth weight infants were more likely than their normal birth weight counterparts to use a medical device (see Figure 12). Nearly a quarter (24%) of children under 1,500 grams at birth used a medical device, compared with 11% of those who were 2,500 grams or more at birth.

Figure 12
USE OF MEDICAL DEVICES AND MEDICATIONS BY CHILDREN IN EARLY INTERVENTION, BY BIRTH WEIGHT GROUP

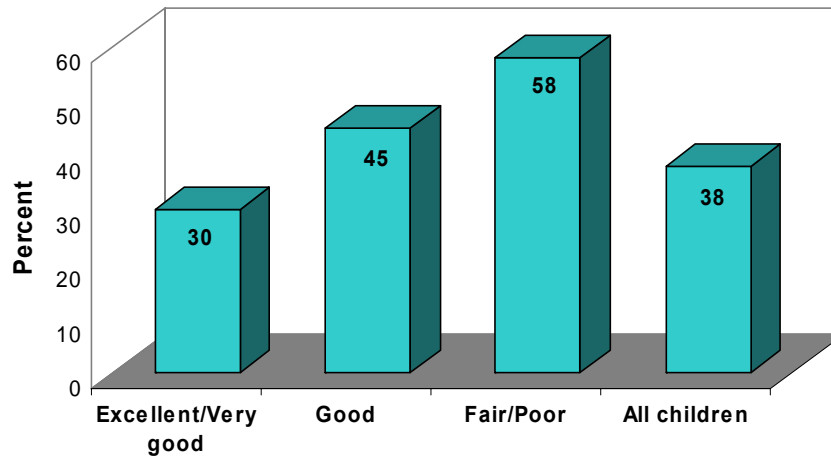


Use of medications was reported for one-quarter of all children receiving early intervention services (26%). Families were not asked what kind of medication their child was taking. Medication use was similar for boys and girls. However, children from the lowest-income families and African-American children were more likely to use medications ($p < .001$). Children who entered early intervention in the first year were more than twice as likely to use some kind of medication (36%) as were those entering in the third year of life (16%). Children who were eligible for early intervention services because of diagnosed conditions were more likely to use medications (39%) than were those eligible because of developmental delay (21%) or risk conditions (28%). Here again, sicker children would be more likely to be taking prescription medication, and these children would be younger and more likely to have a diagnosed condition as the reason for eligibility for early intervention. More than half (57%) of children in fair or poor health were taking medications, whereas only 14% of those in very good or excellent health were taking medications ($p < .001$). Finally, children with lower birth weights were more likely to be taking medications ($p < .001$) (Figure 12).

Overall Health Status and Demographic Risk Status

We examined the children's overall health status in relation to the demographic risk index described earlier. Children in early intervention with health status described as fair or poor had a higher risk index, on average, and more of them had three or more risk factors, compared with children described as having better health (Figure 13) ($p < .001$). Twice as many of the children with fair or poor health status had three or more risk factors (58%), compared with 30% of children with excellent or very good health status. This again shows that there is a group of children in early intervention with a combination of biological and socioenvironmental risk that dramatically increases their developmental vulnerability.

Figure 13
PERCENTAGE OF CHILDREN IN EARLY INTERVENTION WITH 3 OR MORE
DEMOGRAPHIC RISK FACTORS, BY HEALTH STATUS GROUP



CONCLUSIONS

This report has presented a descriptive picture of the birth history and health status of early intervention participants. Birth history and health status at entry into early intervention services were examined by demographic characteristics including the gender and race/ethnicity of the child, the education level of the mother, and household income. To provide a more unified description of co-occurring demographic factors, a demographic risk index described in an earlier report (Hebbeler et al., 2003) was used to examine relationships between demographic risk and birth history and health variables. The report also looked at differences in birth history and health status with regard to two child characteristics related to the receipt of early intervention, the child's age at first IFSP and the reason the child was eligible for early intervention. The relationships of birth history to health status and care also were examined. This chapter summarizes the findings on the birth histories and health status of children entering early intervention services and discusses their implications for services delivered under Part C of IDEA.

Overview

With regard to birth history, a sizable proportion of children in early intervention had significantly compromised birth histories, with low birth weight, prematurity, an early history of care in a neonatal intensive care unit, or some combination of these. Others were full term, with normal birth weight. With regard to health status, most children in early intervention had health that was reported as generally good to excellent, but a significant minority were reported to be in relatively poor health. As was noted previously, there is no

“typical” child in early intervention (Hebbeler et al., 2003; Scarborough et al., in press). More specifically, what can be said about the birth histories, health status, and early health care of children as they enter early intervention services?

Summary of Birth History

Many children in early intervention had compromised birth histories, including significant percentages of children with LBW and prematurity. Not surprisingly, the lowest birth weight infants and toddlers, those less than 1,500 grams at birth, were particularly overrepresented in early intervention, and they were most likely to begin early intervention at younger ages. LBW children in early intervention also demonstrated greater demographic risk.

- Approximately one-third (32%) of children in early intervention were born at low birth weight (LBW, <2,500 grams), which is four times the percentage of LBW in the general population (7%).
- Only 8% of children entering early intervention, or 25% of those who were LBW, were eligible for services solely on the basis of being low birth weight.
- Nearly 2 in 10 infants and toddlers in early intervention (17%) were born at very low birth weight (VLBW, <1,500 grams), which is 12 times the percentage of LBW in the general population (1.4%).
- Nearly half (46%) of infants who entered early intervention in the first year were LBW, compared with only 16% of those entering after 24 months of age.
- Children in early intervention in all ethnic/racial groups were more likely to be LBW, compared with their peers in the general population. However, the percentages of LBW children were higher for non-Caucasian children. Half of all African-American children in early intervention (51%), 32% of Asian or Pacific Islander children, 30% of Hispanic children, and 24% of Caucasian children in early intervention were LBW.
- Children in early intervention from families with lower household incomes and mothers with lower educational attainment were more likely to be LBW.
- Children in early intervention who were LBW had significantly higher levels of demographic risk factors than those with normal birth weight.

The findings presented in this report indicate that the proportion of children entering early intervention who had been born at low birth weight is high (32%), as is the percentage of very low birth weight children (10%). An unanswered question is what proportion of children nationally who are born at low birth weight are served in early intervention programs, or, asked another way, are there children born at low birth weight who are not receiving early intervention services? National data indicate that approximately 7% of all births each year, or 300,000 infants, are LBW, with 60,000 being very low birth weight. In the national population of birth to 3-year-olds, therefore, there are approximately 900,000 LBW children, 180,000 of whom are very LBW. In 1998, 298,000 LBW infants were born in the nation, with 56,976 of them being born VLBW. During the time when the sample was drawn for

this study, a total of 190,000 children were served through Part C early intervention programs. If 10% of these children were VLBW, that would amount to only 19,000 children. Even allowing for some LBW or VLBW children who may begin and end early intervention before their third birthday, it is clear that there are an enormous number of LBW (more than 800,000) and even VLBW (more than 150,000) children in the birth to 3 population who are not receiving early intervention services.

Summary of Health Status and Health Care

The vast majority of children in early intervention had health that was generally good to excellent (84%). However, many children in early intervention had poor health status, and this was particularly true for children who were LBW, from poor families, or African-American.

- Compared with national data for children from birth to age 3, more children in early intervention had fair or poor health status (16% versus 2%).
- Children of color in early intervention and those in poor families were more likely to have fair or poor health status than were Caucasian children in early intervention.
- Not surprisingly, children in early intervention who were LBW were more likely to have fair or poor overall health status.

Many children in early intervention spent time in a neonatal intensive care unit (NICU) after birth, and many were rehospitalized after leaving the hospital after birth. The findings show increased NICU use and rehospitalizations by children in early intervention who were born at LBW, which is a pattern found in many studies of LBW children (Hack et al., 2002; McCormick, 1985; Saigal, 2000). Similarly, the higher rates of early rehospitalizations among children from poorer families have been well established in studies of the general population of young children (Chen et al., 2002). Among the major findings are the following:

- Nearly 4 in 10 children in early intervention (39%) spent some time in a neonatal intensive care unit after birth, which is 10 to 20 times as frequent as the 2% to 4% NICU use estimated for the general population.
- Not surprisingly, children in early intervention born at LBW were more likely than those born at normal birth weight to spend time in an NICU after birth.
- The percentage of children in early intervention who spent time in an NICU after birth reflects the large percentage born at low birth weight, but even 2 in 10 (20%) of the normal birth weight children in early intervention spent time in an NICU after birth.
- About one-third of children in early intervention (34%) had been rehospitalized between leaving the hospital after birth and beginning early intervention.
- LBW children in early intervention were more likely to be rehospitalized after leaving the hospital after being born than were the normal birth weight children in early intervention.

- Children in early intervention from poorer households were more likely to be rehospitalized after leaving the hospital after birth.

Certain aspects of health care show interesting results for children in early intervention. These include the following:

- Compared with the general population of children (under 18 years of age), children in early intervention were more likely to have health insurance (95% versus 88%).
- Nearly all children in early intervention were reported to have a regular source of medical care (97%).
- One in six of children in early intervention (16%) were using some kind of medical device (e.g., apnea monitors, respirators, catheters) when they began early intervention.
- Children in low-income families, with at-risk conditions, who were LBW, or who entered early intervention earlier were more likely to use medical devices.
- Slightly more than one-quarter of children in early intervention (26%) were taking some type of medication.
- More of the children who used medications were from low-income families, were LBW, or were African-American.

It is possible that children in early intervention are more likely to have health insurance because those with insurance are more likely to have screenings or be seen by a medical professional and then be referred for early intervention services. Alternatively, when families, particularly poor families, go through the process of seeking a diagnosis or referral for developmental concerns, they may be found eligible for publicly funded health coverage and enrolled into those health insurance programs.

These findings cannot tell us whether there are children without health insurance who are not getting into early intervention services they are eligible to receive. These findings also do not address an important issue raised by recent research on managed health care about the kind of health services children receive: are these children receiving the types and quality of health care they need? Recent research on managed care indicates that children with disabilities and special needs who have special health needs, regardless of their health insurance status, have more difficulty gaining access to the more specialized health care that they need (Krauss, Gulley, Sciegaj, & Wells, 2003; Krauss, Wells, Gulley, & Anderson, 2001; Newacheck et al., 1998). Clearly, however, these findings show that there is a group of infants and toddlers in early intervention who have poor health status and who quite likely have a need for more intensive and specialized health services.

The approximately one-fourth of children in early intervention (26%) who use some type of medication is identical to recent national data for school-age children with disabilities receiving special education services, which show that 26% of those children are taking some kind of prescription medication (Blackorby, Levine, & Wagner, 2002). For children in early intervention, children who were LBW were significantly more likely to be taking medications,

another indication of the more vulnerable health status of this group of children. Nearly one-fifth of children in early intervention were also using medical devices. Again, the LBW children were more likely to be using some type of medical device (about one in four of them). Data about use of medical devices in the general population of infants and toddlers are not available for comparison purposes.

Relationships between Characteristics

Previous NEILS findings have shown that the age when the child began early intervention (under 12 months of age, 12 to 24 months of age, and 24 to 31 months of age) and reason for receipt of early intervention (developmental delay, diagnosed condition, risk condition) were related to each other, with children who were younger at entry being more likely to be eligible for early intervention because of a diagnosed condition or a risk condition (Hebbeler et al., 2003). This report documents that children who began early intervention at younger ages also were more likely to be born at low birth weight, spend time in an NICU after birth, spend more nights in the hospital after birth, be rehospitalized, use a medical device, use some type of medication, and have poorer overall health status. These younger children were more often eligible because of risk conditions, of which LBW is one, or a diagnosed condition.

The findings show that the reason for eligibility for early intervention (developmental delay, diagnosed condition, risk condition), as well as the demographic characteristics of the children and families, were related to birth history, health status, and health care. Not surprisingly, children eligible because of risk conditions were most likely to be born LBW, but many of the children eligible because of developmental delays and diagnosed conditions also were LBW. Within the increased vulnerability of this LBW group in early intervention, there is variation in the degree of both biological and demographic risk, and the degree and combination of risks is related to future developmental outcomes (Escalona, 1982; Hack et al., 2002; Saigal, 2000).

The previously reported NEILS findings also show that a significant percentage of children receiving early intervention were economically disadvantaged families, with a larger percentage being African-American children than in the general population (Hebbeler et al., 2003). Furthermore, minority families were far more likely to be poor; 49% of the families of African-American children receiving early intervention were living in households with incomes of \$15,000 or less. The results here extend those findings to show that many of these poorer African-American children are also disadvantaged early in life because of compromised births and early poor health status. A remarkable half (51%) of African-American children in early intervention were born at low birth weight. The analyses of demographic risk scores showed that this LBW group had significantly more risk factors than the normal birth weight children in early intervention, including a greater chance of having mothers with less education and families with lower incomes.

It might be argued, on the basis of current empirical data about the developmental and health consequences of LBW (e.g., Bregman, 1998), that most or all LBW children below a

certain birth weight, perhaps 1,500 grams, should be eligible for early intervention. Participation in early intervention might be recommended for a period of time after birth so that developmental and health monitoring can occur and the consequences of the compromised birth history can be assessed. The potential negative impact of LBW on development has been recognized by states that include LBW in their eligibility definition for receipt of early intervention. The fact that some but not all states consider LBW a diagnosed condition with a high probability of resulting in delay probably explains why so many LBW children are not receiving early intervention. Furthermore, recent research shows that the chance of later special education placement is particularly elevated for those children born at LBW who have mothers with low education levels (Hollomon et al., 1998). These national data show that this particularly vulnerable LBW group make up a substantial percentage of the children enrolled in early intervention. There are many more such children who are not being served.

In the earlier report about the demographic characteristics of children and families at entry into early intervention, we reported on the interrelated nature of the demographic factors. Differences were found for race/ethnicity with respect to nearly every other demographic factor. Overall, minority children in early intervention were more likely to have the demographic characteristics associated with poor developmental outcomes, such as lower level of mother's education, lower family income, and only one adult in the household. Similarly, low income was related to the other demographic variables.

In this report, we expand that picture to show that many of these poor and minority children also have more compromised birth histories and poorer health status than their economically more privileged peers. These unfortunate relationships mirror well-established patterns found in many studies about the health of young children (Chen et al., 2002). Taken together, these findings show that there is a significant group of young children in early intervention (16%) with a distressing combination of high biological and demographic risk, who were LBW and in fair or poor health or with three or more demographic risk factors, or both. Subsequent NEELS data on outcomes at 36 months of age and in kindergarten will address the question whether children in early intervention with such multiple risk factors do in fact experience poorer developmental outcomes.

Because of the range of health status and needs of children in early intervention, early intervention service systems must be flexible in the ways they work with families. The form and type of services and supports needed will be quite different for an infant or toddler with serious health problems than for one with relatively good health. Furthermore, the impact on the family of having a seriously ill infant or toddler can be quite different for families with different resources. The data presented in this report confirm just how diverse the children and families receiving early intervention are and reinforce the need for the individualized, family-centered services that are a cornerstone of the Part C early intervention system. The findings also indicate that health status is a critical variable that must be considered in understanding the service needs and the potential outcomes of early intervention for both the children and their families.

REFERENCES

- Adams, P. F., Hendershot, G. E., & Marano, M. A. (1999). Current estimates from the National Health Interview Survey, 1996. *Vital and Health Statistics, 10*(200). Hyattsville, MD: National Center for Health Statistics.
- Blackwell, D. L., & Tonthat, L. (2002). *Summary health statistics for U.S. children: National Health Interview Survey, 1998. Vital and Health Statistics, 10*(208). Hyattsville, MD: National Center for Health Statistics.
- Blackorby, J., Levine, P., & Wagner, M. (2002). *Behind the label: The functional implications of disability*. Menlo Park, CA: SRI International.
- Bloom, B., & Tonthat, L. (2002). Summary health statistics for U.S. children: National Health Interview Survey, 1997. *Vital and Health Statistics, 10*(203). Hyattsville, MD: National Center for Health Statistics.
- Botting, N., Powls, A., Cooke, R. W. I., & Marlow, N. (1998). Cognitive and educational outcome of very-low-birthweight children in early adolescence. *Developmental Medicine and Child Neurology, 40*, 652-660.
- Bregman, J. (1998). Developmental outcome in very low birth weight infants. *Pediatric Clinics of North America, 45*, 673-690.
- Chen, E., Matthews, K. A., & Boyce, W. T. (2002). Socioeconomic differences in children's health: How and why do these relationships change with age? *Psychological Bulletin, 128*(2), 295-329.
- Escalona, S. (1982). Babies at double hazard: Early development of infants at biologic and social risk. *Journal of Pediatrics, 70*, 670-676.
- Federal Interagency Forum on Child and Family Statistics. (2002). *America's children: Key national indicators of well-being, 2002*. Washington, DC: Author.
- Guralnick, M. (1997). Second-generation research in the field of early intervention. In M. Guralnick (Ed.), *The effectiveness of early intervention* (pp. 3-20). Baltimore: Paul Brookes.
- Hack, M., Flannery, D., Schluchter, M., Cartar, L., Borawski, E., & Klein, N. (2002). Outcomes in young adulthood for very-low-birth-weight infants. *New England Journal of Medicine, 346*, 149-157.
- Hack, M., Klein, N., & Taylor, H. G. (1995). Long-term developmental outcomes of low birth weight infants. *Future Child, 5*, 176-196.
- Health Resources and Services Administration. (2002). *Child Health USA 2002*. Vienna, VA: HRSA.
- Hebbeler, K., & Wagner, M. (1998). *The National Early Intervention Longitudinal Study (NEILS) design overview*. Menlo Park, CA: SRI International.
- Hebbeler, K., Wagner, M., Spiker, D., Scarborough, A., Simeonsson, R., & Collier, M. (2001). *A first look at the characteristics of children and families entering early intervention services*. Menlo Park, CA: SRI International.
- Hebbeler, K., Spiker, D., Mallik, S., Scarborough, A., & Simeonsson, R. (2003). *Demographic characteristics of children and families entering early intervention*. Menlo Park, CA: SRI International.
- Hollomon, H. A., Dobbins, D. R., & Scott, K. G. (1998). The effects of biological and social risk factors on special education placement: Birth weight and maternal education as an example. *Research in Developmental Disabilities, 19*, 281-284.
- Javitz, H., Spiker, D., Hebbeler, K., & Wagner, M. (2002). *National Early Intervention Longitudinal Study: Sampling and weighting procedures: Enrollment form, family interview, service records*. NEILS methodology report. Menlo Park, CA: SRI International.

- Krause, N. M., & Jay, G. M. (1994). What do global self-rated health items measure? *Medical Care*, 32, 930-942.
- Krauss, M. W., Gulley, S., Sciegaj, M., & Wells, N. (2003). Access to specialty medical care for children with mental retardation, autism, and other special health care needs. *Mental Retardation*, 41, 329-339.
- Krauss, M. W., Wells, N., Gulley, S., & Anderson, B. (2001). Navigating systems of care: Results from a national survey of families of children with special health care needs. *Children's Services: Social Policy, Research, and Practice*, 4, 165-188.
- McCormick, M. C. (1985). The contribution of low birth weight to infant mortality and childhood morbidity. *New England Journal of Medicine*, 312, 82-90.
- Montgomery, L. E., Kiely, J. L., & Pappas, G. (1996). The effects of poverty, race, and family structure on U.S. children's health: Data from the NHIS, 1978 through 1980 and 1989 through 1991. *American Journal of Public Health*, 86, 1401-1405.
- Newacheck, P. W., Strickland, B., Shonkoff, J. P., Perrin, J. M., McPherson, M., McManus, M., Lauver, C., Fox, H., & Arango, P. (1998). An epidemiologic profile of children with special health care needs. *Pediatrics*, 102, 117-123.
- Paneth, N. (1995). The problem of low birth weight. *The Future of Children*, 5, 19-34.
- Saigal, S. (2000). Follow-up of very low birth weight babies to adolescence. *Seminars in Neonatology*, 5, 107-118.
- Scarborough, A., Spiker, D., Mallik, S., Hebbeler, K. M., Bailey, D. B., & Simeonsson, R. J. (in press). A national picture of children and families entering early intervention. *Exceptional Children*.
- Shackelford, J. (2002). State and jurisdictional eligibility definitions for infants and toddlers with disabilities under IDEA. *NECTAC Notes, Issue 11*. Chapel Hill: The National Early Childhood Technical Assistance Center.
- Spiker, D., Scarborough, A., Mallik, S., Simeonsson, R., Hebbeler, K., & McWilliam, R. (2004) *Functional and behavioral characteristics of children beginning early intervention*. Menlo Park, CA: SRI International. Manuscript in preparation.
- Taylor, H. G., Klein, N., Schatschneider, C., & Hack, M. (1998). Predictors of early school age outcomes in very low birth weight children. *Developmental and Behavioral Pediatrics*, 19, 235-243.
- U.S. Congress, Office of Technology Assessment. (1987). *Neonatal intensive care for low birthweight infants: Costs and effectiveness*. Health Technology Case Study 38. OTA-HCS-38. Washington, DC: OTA.