

# SCHS Studies

A Special Report Series by the State Center for Health Statistics  
1908 Mail Service Center, Raleigh, N.C. 27699-1908  
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No. 127

November 2001

## An Investigation of the Characteristics of Mothers and their Very Low Birth Weight Babies Referred to North Carolina's Infant Toddler Program

by

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### ABSTRACT

**Objectives:** This study compares the prevalence of high neonatal risk among very-low-birth-weight babies (VLBW) referred to North Carolina's Infant/Toddler Program and those VLBW babies not referred to the program. The study also compares demographic and socioeconomic characteristics of mothers with VLBW babies referred and not referred to the program.

**Methods:** The sample for this study was obtained from the North Carolina Pregnancy Risk Assessment Monitoring System (PRAMS). The study design incorporates a case-control approach. High neonatal risk includes birth weight less than or equal to 800 grams, gestational age less than or equal to 28 weeks, and extended infant hospitalization after birth (75+ days). For the study period, July 1997 through December 1999, there were 616 VLBW PRAMS babies. The case group consisted of 200 of these infants whose birth certificate name and date of birth matched to the Infant/Toddler service records, leaving 416 infants in the control or non-Infant/Toddler group.

**Results:** No significant demographic differences were found among mothers with VLBW babies in the Infant/Toddler and non-Infant/Toddler groups. The prevalence rates for extreme low birth weight, extreme preterm birth, and extended infant hospitalization after birth were all significantly higher in the Infant/Toddler group. Among the four low socioeconomic indicators, two were significantly elevated in the Infant/Toddler group: Medicaid payment for prenatal care and annual household income below \$12,000.

**Conclusion:** The study confirms that high neonatal risk is strongly associated with an infant being referred to North Carolina's Infant/Toddler program. Monitoring program coverage rates for extremely low birth weight and extremely preterm babies over time will help assess program efforts to enhance coverage of this high risk population.



## Introduction

In 1986 Public Law 99-457 (Part H of the Education of the Handicapped Act Amendments) established the national Early Intervention Program for Infants and Toddlers with Disabilities. The Federal law required that all states begin serving children from birth to three years old diagnosed with certain conditions and those experiencing developmental delays in one or more areas of cognitive development, physical development, social-emotional development, or adaptive development.<sup>1</sup> When crafting its Infant/Toddler Program, North Carolina elected to add to this target population the group of infants and toddlers “at-risk” for delay, which was considered an optional service category under Part H (now called “Part C” of the Individuals with Disabilities Education Act [IDEA]). For North Carolina, the inclusion of this at-risk category substantially expanded the number of children potentially eligible for Infant/Toddler services.

In the 22<sup>nd</sup> *Annual Report to Congress on State Implementation of Individuals with Disabilities Education Act*<sup>1</sup>, the authors contend, in reference to the growth of the Part C program over the past decade, that much remains unknown “about the characteristics of these children or their families, about the services they receive, or about the outcomes they achieve.” The same is true of North Carolina’s Part C population. Namely, we know of no previous studies examining the characteristics of mothers and their medically fragile babies being served by the state’s Infant/Toddler Program.

In this study, we focus on the “at-risk” or potential high risk group of infants referred to North Carolina’s Infant/Toddler Program. For the study period (1997-1999), potential high risk referrals accounted for about 18 percent of all Infant/Toddler referrals with known eligibility status. To be eligible for this type of referral, the program requires that there be at least three documented risk factors from one or more domains of risk: parent/family, neonatal, or postneonatal. Parent/family risk is comprised of 14 indicators encompassing conditions likely to impact the quality of parenting,

such as “maternal age less than 15” or “difficulty in parent/infant bonding.” Neonatal risk is defined by a set of four indicators: (1) birth weight less than 1500 grams (3 pounds, 5 ounces), (2) gestational age less than 32 weeks, (3) respiratory distress, and (4) asphyxia. Postneonatal risk consists of six indicators, ranging from suspected visual impairment to suspected abuse/neglect.

Our study population consisted of very-low-birth-weight (VLBW) babies referred to the Infant/Toddler program. By using the definition of VLBW (<1500 grams), constructed from birth certificate data, we were able to identify a comparison group of VLBW babies not in the Infant/Toddler program. VLBW babies represent about 45 percent of all potential high risk referrals, i.e., at least three documented conditions of parent/family, neonatal, or postneonatal risk. Ninety-five percent of babies with one or more neonatal risk indicators were VLBW. In addition, we estimate that about 20-25 percent of all children enrolled in the Infant/Toddler program were VLBW.

Among these high-risk infants referred to the Infant/Toddler program, a referral is usually preceded by the family first being enrolled in the Child Service Coordination (CSC) Program. The North Carolina CSC Program was developed in concert with the NC Infant/Toddler Program to ensure outreach and identification of young children with special needs, and ensure service coordination for all families in the early intervention system. The CSC target population consists of children birth to age three with potential high risk conditions, and children ages three to five with at least one diagnosed condition.

The CSC Program assumes primary responsibility for early identification of high-risk infants who may be eligible for Infant/Toddler services. For the CSC coordinator, identification of these infants is facilitated by partnerships with and referrals from Maternity Care Coordinators (providing prenatal service coordination for mothers with high-risk pregnancies). Early identification is also facilitated

by partnerships with and referrals from hospital medical teams responsible for the infant's assessment and treatment while in the neonatal intensive care unit (NICU).

Once the family has accepted CSC services, the coordinator's first step is to build a relationship with the family and verify the risk status of the infant/child. An important part of this process involves an initial CSC assessment of the home environment and strengths and needs of the family and child, accompanied by a service delivery plan. If the CSC provider and parents agree that therapeutic or early intervention services would be beneficial to the child's development, the child may then be referred to the Infant/Toddler program. Enrollment in the Infant/Toddler program begins with a multi-disciplinary evaluation (mandated by Part C) to determine the child's physical and psychological developmental status and need for specialized services.

## Study Objectives

The objectives of this study are twofold. We compare the prevalence of high neonatal risk, such as *extremely* low birth weight, among the group of VLBW infants referred to Infant/Toddler services with that of VLBW infants not referred to the program. Secondly, we compare the demographic and socioeconomic characteristics of mothers with VLBW babies referred to Infant/Toddler services with the corresponding characteristics found among mothers with VLBW babies not referred to the program.

We anticipate two important factors associated with a high-risk infant being referred to Infant/Toddler. First, we can reasonably assume that the most medically fragile babies, for example, survivors of *extremely* low birth weight, would be referred to the program at a significantly higher rate than heavier babies in the VLBW group, who may be progressing more normally. Secondly, we expect that mothers with VLBW babies referred to Infant/Toddler services to be of lower socioeconomic status than non-referrals, considering the adverse

consequences of family poverty on infant development.

## Study Design

The study design incorporates a case-control approach. Very low birth weight babies referred to the Infant/Toddler program, based on a match to the Infant/Toddler program data files, comprised the case group. Very low birth weight babies from the same birth years who did not match to the Infant/Toddler database comprised the control or non-referral group.

The sample for this study was obtained from the North Carolina Pregnancy Risk Assessment Monitoring System (PRAMS). PRAMS is an ongoing monthly survey of North Carolina mothers with recent deliveries. Data from PRAMS allow us to measure various infant and maternal indicators, such as length of NICU hospitalization or household income, which are not available on the infant's birth certificate. In addition, NC PRAMS oversamples VLBW babies at a very high rate: approximately 1 in 4 of all VLBW babies born each month are randomly selected for the survey. The oversampling of these babies has produced a large number in NC PRAMS within a few years.

The study period included the first three years of PRAMS survey data, beginning with July 1997 births and continuing through December 1999 births, the latest year of available PRAMS data. For this 2 ½ year period, there was a total of 4,428 NC PRAMS mothers with completed questionnaires.

In constructing the analysis file, we began with 823 PRAMS mothers who had delivered VLBW babies. We eliminated 207 babies who had reportedly died by the survey date; we did so to avoid including babies who died in the first hours or days of life, who would not have had an opportunity to be referred to Infant/Toddler. Using a unique identifier, constructed from the infant's name and date of birth from the birth certificate, we matched the remaining 616 VLBW PRAMS babies to the HSIS (Health Services Information Systems) Patient Master Files,

which is comprised of encounter data from North Carolina public health departments. These master files contain patient identifiers and HSIS ID numbers. The ID number was used for linking to Infant/Toddler service records. In the final step, 200 of the 616 babies were matched to the Infant/Toddler Program records, leaving 416 VLBW babies in the non-Infant/Toddler group.

## Analysis

High neonatal risk was defined based on two indicators derived from the infant's birth certificate: extremely low birth weight (< or = 800 grams) and extreme preterm birth (< or = 28 weeks gestational age). From PRAMS, we used an indicator for extended hospitalization, i.e., infants reportedly hospitalized for 75 or more days after birth. Low socioeconomic status was defined based on four indicators from PRAMS: (1) maternal report of Medicaid reimbursement for prenatal care, (2) total household income less than \$12,000/year, (3) receipt of food stamps during pregnancy, and (4) receipt of Work First (TANF) during pregnancy.

Descriptive statistics are presented on the number and percentage of infants and mothers with the selected risk indicators, comparing the Infant/Toddler and non-Infant/Toddler groups. The Chi-square test was used to test for differences in the frequency of the event occurring in the Infant/Toddler group, compared to the frequency of the event occurring in the non-Infant/Toddler group.

Among the VLBW infants referred to the Infant/Toddler program, we also calculated the time between the referral date and infant's date of birth, tabulated by the infant's eligibility status reported in the Infant/Toddler service record. These calculations provide an indication of how soon these babies were identified and referred to the program, according to eligibility status.

## Results

### Maternal Demographics

Comparing mothers in the Infant/Toddler and non-Infant/Toddler groups, the distributions by age, race, and education were similar (Table 1). For example, the percentage of teenage mothers (less

**Table 1. Maternal demographic characteristics for VLBW infants (1997-1999 NC PRAMS Survey) by referral to NC Infant Toddler program**

Maternal Demographics		Referred to Infant/Toddler % (n)	Not Referred to Infant/Toddler % (n)
<b>Age</b>	Less than 18 years	9.0% (18)	8.2% (34)
	18 – 25 years	42.0% (84)	40.1% (167)
	26 – 35 years	40.0% (80)	39.7% (165)
	Age 36 and older	9.0% (18)	12.0% (50)
	<i>Total</i>	100% (200)	100% (416)
<b>Race</b>	White	51.5% (103)	53.9% (224)
	African American	45.5% (91)	43.0% (179)
	Other	3.0% (6)	3.1% (13)
	<i>Total</i>	100% (200)	100% (416)
<b>Education</b>	Less than high school	25.0% (50)	22.9% (95)
	High school (12 yrs.)	39.5% (79)	35.7% (148)
	More than high school	35.5% (71)	41.4% (172)
	<i>Total</i>	100% (200)	100% (415)

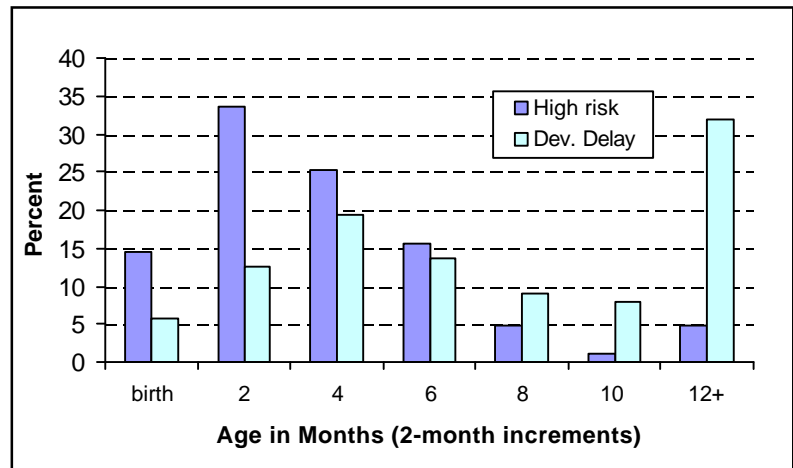
than 18 years) in both groups varied by less 1.5 percentage points. The percentage of mothers age 36 and older varied by only 3 percentage points. The percentage of African American mothers for children in the Infant/Toddler program (45.5%) was only slightly higher than in the comparison group (43.0%). A slightly lower percentage of white mothers was found in the Infant/Toddler program. The distribution by maternal education was also similar between the two groups, with mothers of children in the Infant/Toddler program having a somewhat lower educational level.

### Age at Referral

The Infant/Toddler service records provide four indicators of the infant’s eligibility risk status: (1) potential high risk, (2) established high risk, (3) developmental delay, and (4) atypical development. For the 200 VLBW Infant/Toddler infants in the study, eligibility status was recorded for 182 infants: 83 with potential high risk, 88 with developmental delay, and 11 with established high risk. No infants were given the diagnosis of atypical development.

Overall, more than 60 percent of Infant/Toddler infants were referred to the program by six months of age. In Figure 1, for the two largest eligibility groups, we show the age distribution of infants at the time of their program referral date. The results

**Figure 1. Age of VLBW infants at date of referral to NC Infant/Toddler Program, by reasons for eligibility**



indicate that infants with potential high risk for delay were referred to the program much sooner than infants with a developmental delay. Over 80 percent of potential high risk infants were referred by six months of age, compared to about 45 percent of infants with a developmental delay. At 12 or more months of age less than 5 percent of potential high risk infants were referred, while almost 32 percent of those with a developmental delay were referred after 12 months of age.

### High Neonatal Risk

Table 2 shows that the percentages for extremely low birth weight (ELBW) births, extremely preterm (EP) births, and extended infant hospitalizations were all significantly higher in the referral group.

**Table 2. High neonatal risk among VLBW infants (1997-1999 NC PRAMS Survey) by referral to NC Infant Toddler Program**

High Neonatal Risk	Referred to Infant/Toddler % (n)	Not Referred to Infant/Toddler % (n)	Chi-square P value
Extremely low birth weight (less than/equal to 800 grams)	34.0% (68)	15.4% (64)	p < 0.001
Extremely preterm (less than/equal to 28 weeks gestational age)	66.5% (133)	44.5% (185)	p < 0.001
Extended infant hospitalization 75+ days (mothers’ self-report: PRAMS Survey)	41.5% (83)	25.5% (106)	p < 0.001

A little more than one-third of Infant/Toddler infants were born ELBW and slightly more than two-thirds were EP, or born more than two months before term. Furthermore, 40 percent of babies in the study group required extended hospitalization, compared to about one-fourth of the babies in the comparison group.

### Low Socioeconomic Status

Differences between the Infant/Toddler and non-Infant/Toddler groups, in terms of low socioeconomic status, were statistically significant for two of the four indicators (Table 3). Almost half of mothers in Infant/Toddler (47.9%) reported household incomes of less than \$12,000 in the year before delivery, compared to 35.8 percent of non-referral mothers. Mothers in Infant/Toddler were also significantly more likely to report that Medicaid had paid for their prenatal care. With respect to the receipt of food stamps during pregnancy or the receipt of Work First services, there was no significant difference between the two groups. In addition, the reliability of these estimates is diminished by small cell sizes (n<50).

### Discussion

We found that there were no substantial differences in the demographic characteristics between mothers

with VLBW births in Infant/Toddler program and those with VLBW infants not in the program.

With respect to the timing of referrals, we found that by six months of age, more than 60 percent of all study infants had been referred to the Infant/Toddler program. By eligibility category, the group of babies identified with potential high risk status were referred, on average, about 2-3 months sooner than the group of babies with a developmental delay. The latter points to the fact that a diagnosed condition during infancy requires more time to establish than does the identification of infants who may be at risk for delay.

Findings from this study confirm our hypothesis that high neonatal risk is strongly associated with an infant being referred to North Carolina's Infant/Toddler program. Infants born at the margin of viability will have the greatest risk for subsequent developmental problems.<sup>2</sup> We found that within the VLBW births referred to Infant/Toddler services, about one-third of these babies were extremely low birth weight (< or = 800 grams), about two-thirds were extremely preterm (< or = 28 weeks), and about 40 percent required 75 or more days of hospitalization after birth.

Based on previous studies, we expect as many as half of all ELBW babies at 12 months of age (corrected

**Table 3. Low socioeconomic status among mothers of VLBW infants (1997-1999 NC PRAMS Survey) by referral to NC Infant Toddler Program**

Low socioeconomic status	Referred to Infant/Toddler % (n)	Not Referred to Infant/Toddler % (n)	Chi-square P value
Medicaid paid for prenatal care	58.6% (112)	47.5% (190)	p < 0.05
Reported household income from all sources in year before delivery less than \$12,000	47.9% (89)	35.8% (142)	p < 0.01
Mother received food stamps during pregnancy	19.5% (39)	19.7% (82)	p=0.95
Mother in Work First Program during pregnancy	13.5% (27)	9.4% (39)	p=0.12

for gestational age) to have suspect or abnormal neurological examinations.<sup>3</sup> At 18 months corrected age, we expect as many as one-third of all ELBW babies to exhibit poor motor or cognitive development,<sup>4</sup> while as many as one-fourth may have some type of major neurosensory abnormality.<sup>5</sup> This research indicates that the need for early intervention services among ELBW infants in the first year of life may be as high as 50 percent. In this study, the Infant/Toddler program referral rate for the ELBW sample was 51.5 percent (68 ELBW referrals/132 total ELBW births), suggesting that program coverage of these medically fragile babies is in line with what would be expected from the research.

Poverty has long been associated with a variety of detrimental effects on children's development. Poverty that occurs early in children's lives and extends over more years has been found to be the most detrimental.<sup>6</sup> In this study, there was some indication that mothers with VLBW infants referred to the Infant/Toddler program had lower incomes than those not in the program. Mothers of children in the Infant/Toddler program were more likely to report annual household incomes below \$12,000, and they were more likely to report that Medicaid had paid for their prenatal care. The higher reported rate of Medicaid reimbursement for prenatal care among mothers with children in the Infant/Toddler program may reflect a high number of these mothers also being enrolled in Maternity Care Coordination during pregnancy, which targets Medicaid-eligible mothers with high-risk pregnancies.

## Conclusion

Given the relatively small number of Infant/Toddler infants in this study and limitations of the PRAMS survey data (e.g., recall bias), these results should be viewed as a preliminary assessment of the socio-demographic characteristics of mothers and the birth characteristics of their infants referred to North Carolina's Infant/Toddler Program. These results should be replicated using population-based data files, such as the North Carolina Composite

Matched Birth File. Through linking to Infant/Toddler service records, similar results could be generated for the statewide population of VLBW babies, including ELBW and EP births. In addition, it would be possible to identify mothers enrolled in Maternity Care Coordination during pregnancy and the extent to which their infants are subsequently referred to the Infant/Toddler Program. However, in such a statewide study the information from PRAMS would not be available.

One of the issues facing the North Carolina Infant/Toddler Program today concerns the need to improve the referral and transition process for preterm infants moving from the NICU to the community.<sup>7</sup> In response to this need, the Director of the Wake County Infant Toddler Program and staff from Wake County Medical Center collaborated to secure grant funds for developing partnerships between NICU medical staff (predominantly in Level III hospitals), Child Service Coordinators, Infant/Toddler Program staff, and parents to help improve the state's early intervention response to the needs of very preterm infants and their families. Currently, there are eleven such partnerships across the state. It is hoped that their presence will have the effect of increasing the number of referrals made from the NICU, thereby increasing enrollment at an earlier age. Our results indicate that, among extremely preterm births, about 42 percent were referred to the Infant/Toddler program. Monitoring program coverage rates for EP and ELBW babies over time will help assess program efforts to enhance coverage of this high risk population.

### ***Acknowledgments:***

For their valuable contributions to this study, the author thanks Patti Beardsley, Director of Wake County Infant/Toddler Program, Laurie Thompson, Director of Wake County Child Service Coordination Program, and Paul Buescher, Chief of Statistical Services, State Center for Health Statistics, Raleigh, North Carolina.

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