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Factors Influencing the Enrollment of Eligible Extremely-Low-Birth-Weight Children in the Part C Early Intervention Program

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Abstract

Objective—To determine whether eligible extremely-low-birth-weight children (<1000 g) were enrolled in the federally enacted, state-coordinated Early Intervention (EI) program intended to help children with developmental delay or disability regardless of parental income, and the factors associated with enrollment.

Methods—Retrospective analysis of 884 EI-eligible ELBW children born in South Carolina with birth weight 401 to 999 g, gestation ≥24 weeks, and survival for the first 120 days of life. We created a linked data set with data from Early Intervention (1996–2001), Vital Records (1996–1998), death certificates, and Medicaid. Each child was followed from birth to 3 years old, the program eligibility period.

Results—A total of 54% of ELBW children were enrolled in EI at any time from birth to 36 months. Even among children ever enrolled in Medicaid (83% of all ELBW children), only 63% were enrolled in EI. Being born in a multiple gestational birth, having heavier birth weight (750 to 999 g), and having ever enrolled in Medicaid were positively associated with EI enrollment. Among Medicaid patients for whom perinatal data were available, additional risk adjustment showed that EI enrollment was more likely with birth in level 3 hospitals, birth weight 750 to 999 g, Neonatal Medical Index severity level V (most severe), and longer initial length of hospital stay.

Conclusions—Only about half of eligible ELBW children in South Carolina were enrolled—much lower than reported elsewhere. Efforts are needed to understand why eligible infants are not being enrolled and to develop strategies to remedy the situation.

Keywords

early intervention; low birth weight

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In the past 2 decades, medical advances have reduced the mortality of extremely-low-birth-weight (ELBW; <1000 g) premature infants;[1] however, morbidity remains high among this population.[2,3] Although many of these children successfully transition into adulthood,[4] others face persistent health and development problems.[5,6] Because of ELBW children's high developmental risk, all automatically meet the Social Security Supplemental Security Income disability definition.[7]

In addition to trying to prevent preterm births, we must also try to improve outcomes for ELBW children.[8] However, high-risk follow-up clinics for premature infants typically do not follow children past 1 year of age, and primary care clinicians, many of whom see few ELBW children (<1% of births), may lack experience treating these children and need additional support.

In 1986, Congress established a program encouraging states to develop comprehensive Early Intervention (EI) programs for children <3 years old with disabilities or suspected developmental delays. Today, this program is administered as Part C under the 2004 Individuals with Disabilities Education Act.[9] This legislation was intended to provide a range of services (eg, hearing and vision services, physical therapy, occupational therapy) to these children regardless of family income. EI functions include identification (eg, screening and referral), diagnosis, service coordination, and direct interventions. Both the Institute of Medicine[10] and the American Academy of Pediatrics[11] support use of comprehensive follow-up and EI services for premature infants. Additionally, EI enrollment for ELBW children during the first year of life has been shown to be positively associated with receipt of a needed follow-up ophthalmologic examination.[12]

Despite the documented benefits of EI and its adoption nationwide, data about referral and enrollment for ELBW infants are limited. A study from Massachusetts that used linked data showed that 93% of infants born weighing <1200 g during 1998–2000 were referred to EI; however, the percentage enrolled was not reported.[13] Another study showed that only 10% of children in the United States classified as having delays at 24 months received EI services; the latter study included all children born <1500g as well as other children who fit the criteria of delay.[14]

In this study, we developed a data set linking multiple service programs in South Carolina to investigate EI enrollment among ELBW infants born in the state during 1996–1998. We focused on South Carolina in particular because it was 1 of 2 states with linkable, population-level data for all relevant services available for release at the time (Massachusetts was the other). South Carolina has a low overall EI enrollment rate (1.98% of population births enrolled, compared with Massachusetts, 6.41%),[15] and is among the poorer states within the United States. Therefore, we assessed rates and characteristics of EI enrollment within this population.

Methods

Data Sources and Study Population

Our data set linked Vital Records, Medicaid files, death certificate files, and EI claims data for the first 3 years of life (the EIeligibility period) for children born in South Carolina between January 1, 1996, and December 31, 1998. Inclusion criteria were a birth weight of 401 to 999 g,[16] gestation of ≥24 weeks, and survival for at least 120 days, which increased the likelihood that a child survived initial hospitalization and had the opportunity to benefit from EI services during follow-up (N = 884).[17] Our key outcome measure was EI enrollment at any time from birth to 36 months, measured by using 1996–2001 EI enrollment data. The University of California–Los Angeles and RAND institutional review boards approved the study.

South Carolina's EI Program

South Carolina has an established list of diagnoses associated with developmental delay that result in automatic EI qualification, including ELBW. With parental permission, a hospital discharge coordinator, social worker, or physician can submit a referral form to the EI coordinator in the patient's resident county. The EI coordinator then contacts and visits the family to discuss the program. During the study period, if the parent or parents agreed to participate, their child was enrolled until age 36 months, with no need for annual reenrollment.

Predictor Variables

Analysis included child and maternal sociodemographic variables (eg, maternal age, race, education, child gender) and birth characteristics (eg, birth weight, single vs multiple birth) from the child's vital records. We used a variable indicating whether the mother's residential zip code had >50% urban composition (based on 2000 census data). Additionally, we used dummy variables for ordinal birth hospital levels (3 being the most sophisticated and 1 the least) and for each of the 3 counties (of 46), with the highest numbers and proportions of ELBW children born in level 3 hospitals because regionalization of care in these counties may facilitate referral. We also created a variable for those who were ever enrolled in Medicaid from age 0 to 3.

Additional Risk Adjustment for Medicaid Children

For ELBW children enrolled in Medicaid at hospital discharge (65% of data set), we performed additional neonatal severity adjustments using the Neonatal Medical Index[18] (NMI) and neonatal length of stay information available in Medicaid administrative claims data. The NMI, a score calculated with data from initial hospitalization, has been validated and predicts later cognitive and motor development during infancy and childhood.[19] Factors used in the calculation include birth weight, days on assisted ventilation, major surgeries, and other complications such as meningitis, seizures, and periventricular leukomalacia. NMI scores range from I to V; NMI V characterizes infants with the most serious complications and is associated with poor neurodevelopmental outcomes.[20] Apgar scores were not used for risk adjustment because they are not considered a valid measure for ELBW infants, most of whom are intubated immediately after birth.[21]

Statistical Analyses

We calculated descriptive statistics for the overall sample and by subgroup for sample characteristics and EI enrollment variables. In addition, we conducted bivariate and multivariate logistic regressions to investigate factors that predict EI enrollment. Stata 9.0 software was used for all analyses (StataCorp, College Station, Tex).

Treatment of Missing Data

For maternal and child variables, missing responses per item averaged 1% and never exceeded 2%. Zip codes and information derived from them were missing for 4% of ELBW children. Missing values were imputed by the multiple imputations by chained equations (MICE) approach in Stata.[22]

Results

Sample Characteristics

Characteristics of the sample are provided in Table 1.

Mothers of ELBW infants(N = 884) were on average 25 years old when they gave birth (range, 12–43 years) and had an average of 12 years of education. Sixty-three percent were black, and 34% were non-Hispanic white. Sixty-two percent lived in an urban zip code. The median family income in all zip codes averaged $41,399.

Fifty-one percent of ELBW children were boys, with 82% born in level 3 hospitals and 15% born in multiple gestational births. Mean birth weight was 784 g. Sixty-five percent of children were enrolled in Medicaid by the time of hospital discharge, and an additional 18% were enrolled before age 3.

Among those infants enrolled in Medicaid at hospital discharge (N = 574), the length of initial hospital stay averaged 9.5 weeks (standard deviation, 6), and 59% were classified as NMI V.

EI Enrollment and Factors Associated With Enrollment

Fifty-four percent of ELBW children (57% of blacks and 49% of whites) enrolled in EI. Among children who were ever enrolled in Medicaid, only 63% were enrolled in EI; only 74% of Medicaid-enrolled children with NMI V. were enrolled in EI.

Multivariate analysis of all ELBW children showed that children born in a multiple gestational birth (odds ratio [OR] = 1.78; P=.011), who had birth weight of 750 to 999 g (OR = 1.38; P=.037), and who had ever enrolled in Medicaid (OR = 15.67; $P < .001$) were more likely to enroll in EI, whereas those with maternal residence in county 1 were less likely to enroll (OR = .60; P=.045) (Table 2). In multivariate analysis of the subset of ELBW children with Medicaid at hospital discharge (for whom we could perform additional risk adjustment), we found that EI enrollment was positively associated with birth in a level

3 hospital (OR = 2.14; *P* =.042), birth weight 750 to 999 g (OR = 2.07; *P* < .001), NMI V classification (OR = 1.88; *P* =.004), and longer neonatal length of stay (OR = 1.13 for each additional week; *P* < .001). EI enrollment was negatively associated with maternal residence in county 1 (OR =0.49; *P* =.028).

Discussion

ELBW children are known to be at high risk of developmental delay and disability.[5,23,24] EI can potentially provide an important developmental safety net for ELBW children regardless of family income. However, we found that only 54% of ELBW children were enrolled by age 3. Among children who were ever enrolled in Medicaid, only 63% were enrolled in EI; only 74% of Medicaid-enrolled children with NMI V were enrolled in EI. These results indicate underenrollment in EI of even the sickest, most financially disadvantaged children.

EI underenrollment of ELBW children may be a function of low rates of referral, lack of family or program follow-through, or both. Deficiency in clinician knowledge may contribute to suboptimal referral rates. It is also possible that families shy away from the stigma of special services for their children and that clinicians may not adequately communicate EI's importance to families. Additionally, lack of coordination among clinicians may contribute to low referral rates; effective neonatal intensive care unit discharge planning, as well as coordinated care after the immediate neonatal period, may increase referrals.

We found that enrollment rates varied on the basis of several important characteristics. First, consistent with results about EI referral in Massachusetts,[13] enrollment in South Carolina was more likely among multiple-birth infants. Our findings also indicate that NMI V is independently correlated with enrollment; however, the heavier of these infants (750 to 999 g) were also more likely to be enrolled. It may be that the heavier infants of this group are perceived as more mature and therefore more able to receive the educational interventions that EI offers. Additionally, we found that EI enrollment was less likely in one particular county, a result that parallels previous findings of county-to-county variability in EI enrollment rates and raises questions about regional differences in barriers to enrollment.[14] We did not find underenrollment of black children in multivariate analysis, a finding that differs from findings of 2 previous studies.[13,14] This may reflect state-specific demographic makeup and efforts to target specific racial/ethnic groups for EI enrollment.

We found that children enrolled in Medicaid are much more likely than other children to enroll in EI. Medicaid's mandated regular developmental assessments may lead to earlier identification of children with developmental problems, which may increase EI referral. It is also likely that some privately insured families had access to alternative early intervention services and opted out of the state-coordinated EI program. Additionally, state EI programs have an option of enrolling children who have environmental risk (ie, physical, social and economic risk factors). Therefore, it is possible that Medicaid-eligible infants were targeted for EI enrollment because they have both biological and environmental risks (ie, they are in so-called double jeopardy).[25] This suggests that social workers and/or discharge coordinators may be important in connecting families to both programs. Nevertheless, the 63% enrollment rate for children with Medicaid leaves considerable room for improvement.

Our study has several limitations. First, our results may not be generalizable because our data cover only South Carolina. EI enrollment policies vary across states, and indeed, findings from Massachusetts during a similar period showed substantially different results, with a 93% referral rate for preterm children weighing <1200 g. Second, the data set did not allow us to determine the reasons for underenrollment; our EI enrollment data did not provide insight into provider-related factors (eg, EI capacity, friendliness of EI staff, convenience of signing up) or parent attitudes that can influence referral and/or enrollment. They also show that the Massachusetts experience is not reflective of the nation at large.

EI can serve as a safety net for all ELBW children regardless of family income, helping to identify their health and developmental problems early and enabling the public health system to coordinate and provide necessary services for these children during a critical period of their development. However, our findings show that many ELBW infants and their families may be missing out on the benefits that EI could provide. Therefore, the results of this study call for a broader examination of EI enrollment of ELBW infants nationwide and an investigation of reasons for nonenrollment so that interventions can be designed to remedy the situation.

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Table 1

Characteristics of 884 ELBW Children Born in South Carolina From January 1996 to December 1998[*]

Characteristics	n (%)
Maternal characteristics	
Race/ethnicity	
Black	561 (63)
Non-Hispanic white	317 (34)
Hispanic white[†]	15 (2)
Other	6 (1)
Age <20 y	196 (22)
Education ≥12 y	654 (74)
Any previous live births	409 (46)
Zip code >50% urban	551 (62)
Maternal county[‡]	
1	89 (10)
2	78 (9)
3	75 (8)
All others	642 (73)
Child characteristics	
Male	449 (51)
Birth hospital level	
3	729 (82)
2	103 (12)
1	52 (6)
Multiple-gestation birth	135 (15)
Birth weight 750–999 g (vs 401–749 g)	541 (61)
Medicaid characteristics	
Ever enrolled in Medicaid during ages 0–3	733 (83)
Enrolled in Medicaid by the time of hospital discharge	574 (65)
NMI I–III[§]	227 (40)
NMI IV[§]	11 (2)
NMI V[§]	336 (59)

[*]ELBW =extremely low birth weight; NMI =Neonatal Medical Index.

[†]All Hispanics also identified themselves as white.

[‡]Three counties (of the 46 counties in the state) with the highest numbers and proportions of ELBW children born in level 3 hospitals.

[§]NMI scores were calculated from the claims data of each infant enrolled in Medicaid during the initial hospitalization period using a set of diagnosis and procedure codes mentioned in the NMI algorithm. The program was run for NMI IV and NMI V because these are the categories that may be clinically important. NMI I–III was the default category for individuals who were not classified as IV or V. Therefore, separate numbers for NMI I–III are not reported.

Table 2

Bivariate and Multivariate Logistic Regressions Predicting Any Early Intervention Enrollment[†]

Predictors[§]	All ELBW Children (N = 884), Odds Ratio Bivariate Analysis	Multivariate Analysis
Maternal characteristics		
Black (vs other races)	1.40*	1.22
Age <20 y (vs ≥20 y)	1.30	0.89
Education ≥12 y (vs <12 y)	0.76	0.89
Any previous live births (vs none)	0.94	0.90
Zip code >50% urban (vs ≤50%)	0.74*	0.84
Maternal county 1 (vs 43 baseline counties)[‡]	0.61*	0.60*
Maternal county 2 (vs 43 baseline counties)[‡]	1.06	1.09
Maternal county 3 (vs 43 baseline counties)[‡]	1.16	0.99
Medicaid status		
Ever enrolled in Medicaid	15.64***	15.67***
Child characteristics		
Male (vs female)	1.01	1.03
Multiple-gestation birth	1.42	1.78*
Birth weight 750–999 g (vs <750 g)	1.49**	1.38*
Hospital characteristics		
Birth hospital level 1 (reference)	Reference	Reference
Birth hospital level 2 (vs level 1)	1.29	1.45
Birth hospital level 3 (vs level 1)	1.43	1.82

* $P<.05$

** $P<.01$

*** $P<.001$

† ELBW = extremely low birth weight.

‡ Counties with the highest number and proportions of ELBW infants born in level 3 hospitals.

§ All predictor variables were used in the multivariate analysis except for birth hospital level 1, which was used as a reference.