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The impact of race on participation in Part C early intervention services

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Abstract

Objective—To quantify racial differences in receipt of early intervention (EI) services among children ages birth to three.

Methods—We conducted multivariable analyses of a nationally representative sample of children eligible for EI services using data from the Early Child Longitudinal Study, Birth Cohort. Birthweight <1000 grams, genetic and medical conditions associated with developmental delay, or low scores on a standardized measure of developmental performance defined EI eligibility. Receipt of EI services was ascertained from parent self-report. The effect of race on receipt of EI services was examined in main effect models and models stratified by EI qualifying condition, which was defined as either established medical condition or developmental delay in the absence of an underlying medical diagnosis.

Results—At 9 months of age, among the 1000 children eligible for EI services, 9% of children received services; there were no Black-white racial differences in receipt of services. At 24 months of age, among the 1000 children eligible for EI services, 12% received services; Black children were 5 times less likely to receive services than white children (aOR 0.19; 95% CI 0.09, 0.39). In models stratified by qualifying condition, Black children who qualified for services at 24 months based on developmental delay alone were less likely to receive services (aOR 0.09; 95% CI 0.02, 0.39); there were no differences by race among children who qualified based on established medical conditions (aOR 0.56; 95% CI 0.18, 1.72).

Conclusions—Racial disparities in EI service receipt, which were not present during infancy, emerged as children became toddlers. These disparities were found most consistently among children who qualified for services based on developmental delay alone.

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INTRODUCTION

Children birth to three who are identified as having, or being at risk for, developmental delay are eligible for services through early intervention (EI) programs under Part C of the Individuals with Disabilities Educational Act (IDEA). In 2009, almost 340,000 infants and toddlers received EI services. This number, which represents 3% of US children birth to three, has almost doubled over the past 10 years.[1, 2] Despite an increase in the percentage of children obtaining services, however, studies suggest that many young children who have or are at risk for developmental delays fail to receive EI services. Even more concerning, recent US Department of Education data show a relative decrease in the proportion of Black children receiving EI services, from 18% in 1998 to 13% in 2007, raising a possibility of a disparity in access to services.[2] Studies of children presumed eligible for EI services support this observation.[3, 4] Existing research about why Black children are less likely to receive EI services is contradictory. Poverty and lack of health insurance, which disproportionately affect Black children, have been shown to predict service receipt in some studies[5] and have no impact in others.[4]

Children who qualify for EI services based on developmental delay but do not have an easily recognizable established medical condition appear less likely to receive services than children with established medical conditions such as extreme prematurity or sensory impairment.[3, 4, 6] This finding reflects two distinct pathways of referral and entrance into EI services, which could differentially affect Black children. In the first pathway, a child qualifies for EI by virtue of an obvious and easily recognized condition; the second pathway requires active screening and surveillance to identify a child’s delays. Thus, we examined enrollment in EI among a nationally representative sample of children who were followed longitudinally from birth to 24 months to further understand how a child’s qualifying condition contributes to racial differences in receipt of EI services. Analyses of the relationship between a child’s qualifying condition and service receipt could provide a new paradigm through which to understand racial disparities in receipt of EI services.

METHODS

Data Source

This study used data from the Early Child Longitudinal Study, Birth Cohort (ECLS-B). The ECLS-B draws from a nationally representative sample of the nearly 4 million US children born in 2001. It includes data from face-to-face parent interviews, direct cognitive and developmental assessments, and information from birth certificates.[7] Details of the ECLS sampling strategy are available at http://nces.ed.gov/ecls/birth.asp (last accessed November 14, 2010). Data used in this analysis were collected during the 9-and 24-month rounds of data collection, the period when children would be eligible to receive EI services. The ECLS-B cohort included 10700 infants at 9 months and 9850 children at 24 months. [i]

We included in our sample children who were identified as non-Hispanic Black or non-Hispanic white, had parent interviews and developmental assessments at the 9 and 24 month

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[i] All unweighted N’s are rounded to the nearest 50 subjects in accordance with the ECLS-B restricted data use license.

time points, and met the eligibility criteria for EI services, which was determined independently at 9 and 24 months to reflect changes in a child's developmental status.

Measures

Qualifying conditions and eligibility for early intervention services under Part C of IDEA—Children ages birth to 3 years with demonstrated developmental delays or a diagnosed physical or mental condition known to increase risk of developmental delay are entitled to EI receive services under Part C of IDEA. However, determining definitions of developmental delay and criteria for service eligibility has been a major challenge to states responsible for delivering these services. Although states have developed methods to define developmental delay and developmental risk, there is wide variability in the relative breadth or restrictiveness of state eligibility policies[8] and the specific tools and the quantitative criteria used to determine eligibility.[9] We defined eligibility for EI services to be consistent with the major existing study that used ECLS-B data to examine participation in EI.[4] The published eligibility algorithm was validated using data from 44 states and the District of Columbia and demonstrated 94% sensitivity and 68% specificity in appropriately classifying eligible children. We made changes to the algorithm, with the aim of increasing its specificity. Based on documented state eligibility policies, we decreased birthweight eligibility from 1500 to 1000 grams and included children with medical conditions that automatically qualify children for EI services.[10]

The four criteria used to determine eligibility were 1) birthweight < 1000 grams; 2) medical conditions associated with developmental delay, such as blindness and deafness, determined from parental self-report at the 9 month and 24 month interviews; 3) genetic and congenital conditions associated with developmental delay, such as Down syndrome and fetal alcohol syndrome, and major congenital anomalies such as cleft lip and palate, ascertained based on information from the birth certificate; and 4) developmental delay, evaluated through direct assessment separately at the 9 and 24 month interviews using the Bayley Short Form Research Edition (BSF-R) Mental Scale and Motor Scales. The BSF-R includes a subset of items from the Bayley Scales of Infant Development, 2nd Edition (BSID-II);[11] scores are similar to those obtained from the full BSID-II.[12] We used the BSF-R Scale Scores based on guidance from the ECLS-B study team[13] and defined as eligible children who scored > 1.5 SD below the mean on the Mental Scale or > 1.5 SD below the mean on the Motor Scale, or > 1 SD below the mean on both scales. For analyses, eligibility criteria were dichotomized as having an established medical condition (with or without evidence of delay on BSF-R scores) versus having developmental delay alone. Children who qualified for services based on developmental delay alone did so based on BSF-R scores, in the absence of an underlying medical condition associated with developmental delay.

Child and Family Characteristics—Child race was coded as Black non-Hispanic, or white non-Hispanic according to US Census categories based on maternal self-report.[14] We extracted additional sociodemographic characteristics (Table 1) based on their documented or theoretical relevance to the outcome of interest, receipt of EI services.[3, 4, 15–17]

Outcome Measure: Receipt of Part C early intervention services—Receipt of EI services was determined based on parent response at the 9 and 24 month interviews. At each assessment, respondents were asked whether or not their child was participating in an early intervention program or regularly receiving services to help with their child's special needs from their local school district, state, health or social service agency, health care provider, or some other source. Receipt of services was coded as yes or no independently at 9 and 24 months.

Data Analyses

In two serial cross-sectional analyses, we studied associations between a child's race and receipt of EI services among the 1000 children who met inclusion criteria at 9 months; and then independently among the 1000 children who met inclusion criteria at 24 months. To further understand how a child's qualifying condition contributed to racial differences in receipt of EI services we performed analyses stratified by whether a child had an established medical condition or developmental delay alone. We elected to stratify eligible children on this basis because of the hypothesized pathways by which children with and without established medical conditions enter EI services. Specifically, we hypothesized that the racial disparity in receipt of services would be accentuated for children with developmental delay alone, who require active screening and surveillance to determine eligibility for EI services.

We used individual level weights from ECLS-B to account for the study's complex sampling design and to yield valid national estimates. On weighted data we used the chi-square test to describe sample characteristics and eligibility and receipt of services by race. We used multivariable logistic regression models to examine associations between race and receipt of EI services at 9 and 24 months, employing Taylor series estimation[18] to accommodate ECLS-B's sampling design and arrive at valid confidence intervals. All models were adjusted for socioeconomic status (SES quintile), insurance type (none or public versus private), maternal nativity (US versus foreign born), and place of residence (urban versus rural). The 24 month models were further adjusted for prior receipt of EI services.

We performed all analyses using SAS v9.1.[19] The Boston University Medical Center Institutional Review Board reviewed the study and deemed it exempted this study from review. Pursuant to the terms of the ECLS restricted data use license, this manuscript was reviewed by the National Center for Educational Statistics prior to publication.

RESULTS

Population

Based on the 9 month assessment, among the 10700 children in the ECLS-B cohort, 1000 children (18% Black, 82%white) met our eligibility criteria and were presumed eligible for EI services (Table 1). Across racial groups, there were no significant differences in the percentage of eligible children by child gender, maternal employment, or household size. Compared to white children, eligible Black children were significantly more likely to live in urban, single parent, poor households and to have public insurance. Their mothers were more likely to be foreign born and have lower educational attainment. The children, who were assessed at 9 months, were assessed again at 24 months. At 24 months, 1000 (27% Black, 73% white) of the 9,850 children in the ECLS-B cohort met eligibility criteria and were presumed eligible for EI services. Of these children, 72% were newly eligible based on their developmental performance. The remaining children(28%of those eligible)were eligible at 9 months and continued to be eligible based on either developmental delay or having an established medical condition. The demographics of the children eligible at 24 months were similar to those of the children eligible at 9 months with the exception that Black children were less likely to be first born and their mothers were younger.

Race, receipt of EI services, and eligibility reason among children at 9 months

Of the children presumed eligible to receive EI services at 9 months, 9% received such services. Of these,41% qualified for services based on having an established medical condition and59% based on developmental delay alone. In bivariate analyses (Table 2a), there were no significant differences in service receipt by race. We found that significantly more Black children qualified for services based on established medical conditions (25% Black,12% white, p<.0001), reflecting the higher rates of low birthweight in this nationally representative sample. Among children actually receiving services, 66% of Black children qualified based on established medical conditions compared to 36% of white children (p<. 01).

In multivariable models comparing Blacks to whites that adjusted for sociodemographic characteristics and qualifying condition, race was not a predictor of service receipt (aOR 0.63; 95% CI 0.29, 1.36)(Table 2b). In analyses stratified by qualifying condition (established medical condition or developmental delay alone), race continued not to be a predictor of service receipt.

Race, eligibility reason, and receipt of EI services among children at 24 months

Of the children presumed eligible to receive EI services at 24 months, 12% received such services. Of these, 27% received services based on having an established medical condition and 73% based on developmental delay alone. In bivariate analyses (Table 3a), Black children were less likely to receive services than whites (5% Black,15% white, p<.0001). Unlike at 9 months, the majority of children, regardless of race, qualified for services based on developmental delay alone (87% Black,89% white, p>.05). Among children actually receiving services, 66% of Black children who received services were eligible based on established medical conditions versus 22% of white children (p=.01).

In multivariable models comparing Blacks to whites that adjusted for sociodemographic characteristics, prior receipt of services, and qualifying condition(Table 3b), race was a significant predictor of service receipt (aOR 0.21; 95% CI 0.11, 0.41). We conducted analyses stratified by qualifying condition. We found that Black children who qualified for EI services based on developmental delay alone were more than 8 times less likely to receive services (aOR 0.09; 95% CI 0.03, 0.32); there were no racial differences in the likelihood of service receipt among children who qualified based on established medical conditions (aOR 1.23; 95% CI 0.46, 3.30).

We conducted two exploratory analyses(full results from exploratory analyses are available from authors upon request). First, to determine if differential drop out of Black children contributed to disparities in receipt of EI services observed at 24 months, we examined continuity of service among the subgroup of children who were eligible for EI at the 9 and 24 months and received services at 9 months. Of the children who received services as infants(N=150), 79% continued to receive services at 24 months. At 24 months there were no significant differences in service receipt by race in bivariate or multivariable analyses (72% Black, 80% white, $p > .05$; aOR 0.43; 95% CI 0.11, 1.75). Second, to test the stability of study findings, we reran all final multivariable models using more restricted eligibility criteria to determine developmental delay (> 2 SD below the mean on the Mental Scale or > 2 SD below the mean on the Motor Scale, or > 1.5 SD below the mean on both scales). In the 9 month models, we found no significant differences in receipt of services by race in the main effect model and in the model stratified by established medical condition. In the 9 month stratified model that included only children who qualified based on developmental delay alone, Black children were significantly less likely to receive services (aOR 0.16; 95% CI 0.05,0.51), a difference from what we observed using more generous eligibility criteria to determine developmental delay. In all 24 month models, estimates did not differ when using the more restrictive eligibility criteria.

DISCUSSION

Among a nationally representative cohort of Black and white children followed longitudinally during early childhood, our analyses revealed 3 important findings. First, at 9 months of age, only 9% of children eligible for EI services received such services and there were no racial differences in receipt of services. Second, at 24 months of age, 12% of children eligible for EI services received services and differences between Black and white children emerged, with Black children being almost 5 times less likely to receive services. Third, racial differences in receipt of EI services appeared more consistently among children who qualified for EI services based on developmental delay alone compared to children who qualified based on an established medical condition.

Our results are consistent with and extend the findings from previous research, which have reported low levels of EI service receipt among eligible young children, racial differences in receipt of services, and increased participation of children with established medical conditions.[3, 4, 17] We believe we are the first study to explore the evolution of racial disparities in EI service receipt, documenting the absence of racial differences among infants receiving services and emergence of such differences by the time children are 24 months old. Such differences could be attributable to differential dropout among children who were receiving services or differential uptake among those who were eligible but had not received services previously. Our findings do not support differential dropout as a contributor to the racial disparities observed at 24 months. First, children who were presumed eligible for services at both 9 and 24 make up only a small proportion (28%) of the total number of children eligible at 24 months. Second and more important, over three quarters of the Black and white children eligible for services at 24 months who received services at 9 months continued to receive services. Instead, our findings suggest that Black children without established medical conditions that cued parents and health care providers to actively assess developmental risk were less likely to receive EI services.

Receipt of EI services is the outcome of a process that requires identification of developmentally at-risk children, referral, and confirmation of eligibility. Given that all children in our study are presumed eligible, we focused on differences in identification and referral as possible explanations for differences in service receipt between Black and white children. Previous studies have documented that children without a diagnosed medical condition are less likely to be identified and referred to services.[3, 20] Detection of at-risk children requires proactive identification by the child's parents or a clinician. It is possible that clinicians, who play a major role in identifying children with developmental delay and referral to EI services, are less likely to identify such delays in Black children. Studies of racial differences in the identification of children with specific developmental disabilities, such as autism, offer support for this hypothesis.[21] There is additional evidence that clinicians respond differently to patients based on gender, clinical training, and child's behavior, which could influence identification and referral patterns.[22, 23]

Another possible explanation is that variation in family beliefs and cultural values may underlie differences in what triggers a concern about atypical development. A strong literature exists supporting the sensitivity of parental concerns to detect developmental delays among young children.[24–27] Only one of the studies considered racial differences in parental concerns and reported no differences between non-white and white subjects in the likelihood of reporting concerns or discussing such concerns with their child's pediatric provider.[28] Studies of Black mothers identify factors such as stigma, fear of blame and child protective services involvement as factors affecting the willingness of such mothers to discuss their own emotional health concerns with their child's health care provider.[29, 30] Future studies are needed to determine if these same factors influence the willingness of Black parents to discuss concerns related to their young children.

The study has several limitations. First, the study relies on parent report of receipt of early intervention services. Given the varied models of early intervention service delivery, parents may be unclear of whether they are receiving Part C services or developmental services provided through other mechanisms. The second limitation relates to determination of EI eligibility. Eligibility for EI services is determined by each state individually and changes in response to budgetary concerns. Previous studies have documented variations in EI participation based on the relative breadth or restrictiveness of EI eligibility criteria.[8] It was not possible to assign eligibility on a state-by-state basis given ECLS sample characteristics. Thus, the study's inclusion criteria presume, but cannot definitively confirm, eligibility. It is possible that our eligibility criteria may overestimate the number of eligible children. We selected the eligibility criteria, which had reasonable sensitivity and specificity characteristics, to be consistent with the existing published study of EI participation using ECLS-B data.[4] When we tested study findings using more restrictive eligibility criteria, overall, results were similar. The exception was the 9 month stratified model that showed that Black children who qualified for EI services based on developmental delay alone were less likely to receive services. This finding, while suggesting a need for further investigation about the relationship between child age, racial disparities and eligibility criteria, provides additional support for our hypothesis that racial differences in receipt of EI services are accentuated among children without established medical conditions that alert parents and health care providers to the potential for delay. It is also possible that we may have underestimated the number of children eligible to receive EI services. We did not include children who would be eligible based on delays in social-emotional and adaptive functioning. Third, some of our analyses were limited by the small number of children who received services, preventing us from conducting more detailed multivariable analyses. Fourth, as is typical of cohort studies, the associations reported in this study are not necessarily causal, and residual confounding may exist. Finally, we limited the study's focus to the experience of non-Hispanic Black and white children born in 2001. Our study needs to be replicated to include Hispanic children, with particular attention to the role English language proficiency, acculturation, and nativity play as potential effect modifiers. Relative to secular changes that may have occurred, it is possible that with new American Academy Pediatrics (AAP) guidelines regarding developmental screening,[31] enrollment in early intervention services has changed during the intervening period. However, US Department of Education data showed relative decrease in the proportion of Black children receiving EI services since the publication of the new guidelines.[2]

These limitations notwithstanding, we believe our study provides new information about racial disparities in receipt of EI services. The study benefited from use of a rigorously tested, nationally representative data set, which allowed us to track EI participation longitudinally through early childhood. In the study population, we found wide variation in service receipt based on whether a child qualified for EI services based on having an established medical condition or developmental delay alone. However, disparities in service receipt did not emerge until 24 months after birth and were observed more consistently among Black children who did not have an established medical condition and qualified for services based on developmental delay alone. Clinicians, who work with young children, may wish to be more alert to development delays, particularly in Black children. Clinicians play a critical role in assisting families whose children demonstrate developmental delays to secure appropriate services. For children birth to three, such services are delivered through EI programs that exist in every state. These data can be used to inform current efforts to increase developmental screening of young children and support their participation in EI programs.

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Table 1

Characteristics of children eligible for Early Intervention services at 9 months, by race

	Total (n=1000)	Black (n=300)	White (n=700)
Population estimate based on 2001 birth cohort, weighted n	**227831 Weighted %**	**40312 Weighted %**	**187519 Weighted %**
Child Characteristics			
Child Male	52	57	50
Firstborn Child *	30	18	33
Maternal Characteristics			
Maternal Age at Birth *			
<20 years	3	10	2
20–29 years	45	58	43
30–39 years	45	30	49
40+ years	6	3	6
Mother Born in USA	93	89	94
Maternal Education *			
<High School	13	31	9
>=High School Degree	30	32	29
>=Some College	57	37	62
Mother Employed	48	54	47
Family Characteristics			
Urban Residence *	84	93	82
Insurance Type *			
None or Public	31	65	23
Private	69	35	77
Household Income < 100% Federal Poverty Limit *	20	53	12
Household SES *			
Lowest quintile	13	35	8
Middle three quintiles	57	59	57
Highest quintile	30	5	36
Number in household (mean, +/−SD)	4.37 (0.07)	4.67 (0.10)	4.30 (0.08)

Unweighted N’s, weighted percentages. Percentages may not add to 100 due to rounding.

*Differences between racial groups significant at p<.05

Table 2a

Eligibility reasons and receipt of services among children eligible for Early Intervention services at 9 Months, by race

	Total N=1000 weighted %	Black N=300 weighted % 18	White N=700 weighted % 82	Chi-Square p value
Service receipt at 9 months				0.80
Yes	9	8	9	
No	91	92	91	
Qualifying condition among eligible				< 0.0001
Established medical condition	14	25	12	
Developmental delay alone	86	75	88	
Qualifying condition among children receiving services				< 0.01
Established medical condition	41	66	36	
Developmental delay alone	59	34	64	

Table 2b

Association of race and qualifying condition with child receipt of Early Intervention services at 9 Months

Main effect models			Stratified models	
	Race[†] OR (95% CI)	**Qualifying condition[‡] OR (95% CI)**		**Race[†] OR (95% CI)**
			Established medical condition	
Unadjusted point estimate	0.94 (0.56, 1.57)		Unadjusted point estimate	0.77 (0.41,1.45)
Race adjusted for sociodemographic characteristics	0.75 (0.37, 1.53)		Race adjusted for sociodemographic characteristics	0.75 (0.35,1.59)
Race + qualifying condition, adjusted for sociodemographic characteristics	0.63 (0.29, 1.36)	0.16 (0.09, 0.29)[*]	**Developmental Delay**	
			Unadjusted point estimate	0.57 (0.20,1.58)
			Race adjusted for sociodemographic characteristics	0.48 (0.13,1.77)

Sociodemographic characteristics included in models: household socioeconomic status, insurance type, maternal nativity, and place of residence.

[†] Black vs. white (reference)

[‡] Developmental delay alone vs. established medical condition (reference)

[*] p<.05

Table 3a

Eligibility reasons and receipt of services among children eligible for Early Intervention services at 24 Months, by race

(n=1000)	**Total N=1000 weighted %***	**Black 350 weighted % 27**	**White 650 weighted % 73**	**Chi-Square p value**
Service receipt at 24 months				< 0.0001
Yes	12	5	15	
No	88	95	85	
Qualifying condition among eligible				0.38
Established medical condition	11	13	11	
Developmental delay alone	89	87	89	
Qualifying condition among children receiving services				0.01
Established medical condition	27	66	22	
Developmental delay alone	73	34	78	

Table 3b

Association of race and qualifying condition with child receipt of Early Intervention services at 24 Months

Main effect models	Race† OR (95% CI)	Qualifying condition‡ OR (95% CI)	Stratified Models	Race† OR (95% CI)
			Established medical conditions	
Unadjusted point estimate	0.28 (0.18, 0.44)*		Unadjusted point estimate	0.72 (0.28,1.80)
Race adjusted for sociodemographic characteristics	0.24 (0.12, 0.48)*		Race adjusted for sociodemographic characteristics	0.76 (0.25,2.38)
Race + qualifying condition, adjusted for sociodemographic characteristics	0.22 (0.11, 0.45)*	0.27 (0.14, 0.53)*	Race adjusted for sociodemographic characteristics and service receipt at 9 months	1.23 (0.46,3.30)
Race + qualifying condition, adjusted for sociodemographic characteristics and service receipt at 9 months	0.21 (0.11, 0.41)*	1.91 (0.76, 4.80)	**Developmental Delay**	
			Unadjusted point estimate	0.13 (0.04, 0.41)*
			Race adjusted for sociodemographic characteristics	0.10 (0.03, 0.40)*
			Race adjusted for sociodemographic characteristics and service receipt at 9 months	0.09 (0.03, 0.32)*

Sociodemographic characteristics included in models: household socioeconomic status, insurance type, maternal nativity, and place of residence.

[†] White (reference)

[‡] Developmental delay alone vs. established medical condition (reference)

[*] p<.05