

The Effect of State Early Intervention Eligibility Policy on Participation Among a Cohort of Young CSHCN

abstract

OBJECTIVE: This purpose of this study was to describe differences in early intervention (EI) participation according to state among a cohort of young children with parent-reported developmental delays and disabilities.

METHODS: Data were obtained from the 2005–2006 National Survey of Children With Special Health Care Needs to describe state differences in EI participation. Multilevel modeling was used to estimate the relative contributions of child sociodemographic and developmental characteristics, and state EI eligibility policy on EI participation.

RESULTS: The overall rate of EI participation was 45.7% (23.1%–83.3% across the states). EI participants were less likely to be Hispanic, live in a multiracial family, be poor, have a developmental delay, or have a less severe condition/delay. The predicted probability of receiving EI was lower for children who lived in states with more strict EI eligibility criteria than those with liberal criteria (.43 vs .52). Poverty influenced this association, with the adjusted probabilities of receiving EI for poor (<100% federal poverty level) and nonpoor (>185% federal poverty level) children being .18 and .36, respectively ($P < .05$). Among nonpoor children, those who lived in states with strict eligibility criteria were nearly as likely as poor children who lived in states with liberal eligibility criteria to receive EI (.33 vs .36; $P < .05$).

CONCLUSIONS: The results of this study reveal marked disparities and unmet needs in EI participation as a function of both characteristics of the child and the state program. Improving developmental services for vulnerable populations requires addressing these sources of disparity. *Pediatrics* 2009;124:S368–S374

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KEY WORDS

early intervention, state policy, multilevel modeling

ABBREVIATIONS

IDEA—Individuals With Disabilities Education Act

EI—early intervention

NS-CSHCN—National Survey of Children With Special Health Care Needs

CSHCN—children with special health care needs

FPL—federal poverty level

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The Individuals With Disabilities Education Act (IDEA) Part C was promulgated to create state early intervention (EI) programs. According to the IDEA, states are required to provide EI services to children who experience or are at risk of developmental delay.¹ Risk may manifest as a diagnosis (eg, cerebral palsy), developmental delay, biological risk factors (eg, low birth weight), or environmental risk factors (eg, child abuse). Approximately 2% of children have a recognized physical or mental disability,² and 40% are at increased risk for developmental delay overall³ and, thus, could be potentially eligible for these services. However, considerable variation is seen across the states in EI enrollment, varying from 0.91% in Nevada to 9.4% in Hawaii.⁴ Moreover, evidence⁵ suggests that EI enrollment in many states falls substantially below the proportion of children in need.

The reasons for this variation are not clear. One source might be differences in the proportion of children with conditions that make them eligible for EI. The proportion of children with moderate or severe health conditions ranges nearly twofold across states (6.1%–11.5%).⁶ In addition, other studies have shown that EI enrollment varies according to child and family characteristics, with poorer children more likely to enroll and mixed results for enrollment of minority children.^{5,7} Thus, 1 source of variation would arise from the differences in distributions according to developmental risk, race/ethnicity, and poverty among the states.

Less frequently examined than individual-level predictors of EI use is the role of state policy.⁸ Although specific diagnoses are mandated by the legislation, states have considerable flexibility in establishing criteria for developmental delay and at-risk categories.⁹ One study⁴ documented that

states with broader eligibility criteria (targeting at-risk children and having less restrictive performance standards on formal assessments) have higher rates of EI enrollment compared with states with narrow criteria (serving only children with established conditions and having stricter limits on standardized assessment).³ This previous study was limited in that it included only children enrolled in EI, and the authors had no information on the underlying risk of the population in terms of relevant individual sociodemographic and neurodevelopmental characteristics.

We have examined the enrollment in EI of a cohort of infants and toddlers at high risk for poor developmental outcomes to ascertain (1) if between-state variability in EI participation exists and (2) if variability exists, the extent to which it can be explained by individual sociodemographic factors and state EI eligibility policy.

METHODS

Participants

To create a cohort of children at risk for neurodevelopmental delay from the 2005–2006 National Survey of Children With Special Health Care Needs (NS-CSHCN),^{10,11} we selected children younger than 3 years who had a diagnosis or parent report of developmental difficulty that affected their function at least some of the time. To be eligible for the study, children also had to meet 1 of the following definitional criteria to identify children with special health care needs (CSHCN)¹²: required more medical, educational, or behavioral services; or received or needed physical, occupational, or speech therapy or had functional limitations; or had behavioral or developmental difficulties. Analyses were restricted to cases with complete data for all covariates with the exception of poverty status (see below).

Data Sources and Definition of Variables

The dependent variable was parent report of EI services in response to the following question: “Did [child’s name] receive services from a program called Early Intervention Services? Children receiving these services often have an Individualized Family Service Plan.”

The primary child-level exposure was the presence of established risk or developmental delay. To correspond to diagnoses specified in the legislation, children were defined to have an established risk if their parents answered positively to questions regarding specific diagnoses including cerebral palsy, mental retardation, vision condition/delay, hearing condition/delay, autism spectrum disorder, muscular dystrophy, Down syndrome, heart defect, cystic fibrosis, and arthritis.¹³ In the absence of a specific diagnosis, developmental delay was considered present if the parent reported that the child has difficulty with physical, fine motor, social, cognitive, or language development.

The primary state-level variable was Part C eligibility policy. The Office of Special Education Programs (OSEP) within the Department of Education designates state Part C eligibility criteria as broad, moderate, or narrow (Fig 1).¹⁴ We used the definitions described by the OSEP, the categorization of states according to the IDEA Infant and Toddler Coordinator’s Association,¹⁵ and the most recent eligibility criteria for each state.⁶

We also included several sociodemographic and developmental covariates to determine variability in EI according to child and family factors: poverty status; race and ethnicity; parental education; severity of condition/delay; gender of the child; and having a usual source of health care. For those missing poverty data, we used the imputed poverty file and multiple imputation methods described by Pedlow et al.¹⁶

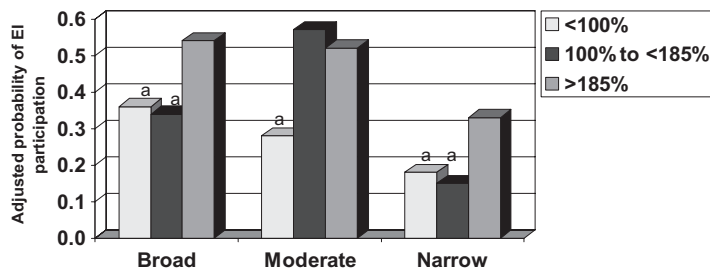


FIGURE 1

Probability (adjusted for race/ethnicity, severity of condition/delays, and neurodevelopmental risk) of EI participation according to FPL and state EI eligibility category for a cohort of children ($N = 900$) at risk for adverse neurodevelopment (model 4). State EI eligibility categories are broad, moderate, and narrow based on extent of developmental delay required to receive EI services. Specifically, developmental delay requirements are 25%, 33%, and 50% for broad, moderate, and narrow states, respectively. For more information, on these state EI eligibility categories, please refer to ref 12. ^a $P < .05$.

Analysis

Preliminary analyses (data not shown but available from the authors) first involved a comparison of those with complete data versus the entire sample. Then, for the study sample, bivariable analyses examined the association of EI participation with all the covariates listed above and according to state. These results were further assessed and summarized in a series of multilevel models.

To examine the relative contribution of characteristics of children within states and state EI eligibility policy to state differences in EI participation, we used multilevel modeling¹⁷ to account for the fact that individuals within states share a similar social and political milieu, which makes them more alike than individuals between states.

We fit 4 multilevel logistic regression random-intercept models:

- model 1 describes the overall between-state variability in EI participation;
- model 2 adjusts for the individual sociodemographic and neurodevelopmental covariates;
- model 3 further adjusts for state eligibility policy; and
- model 4 further examines the interaction between individual poverty status and state eligibility policy on EI participation.

For each model, we reported the β coefficient for each individual- and state-level variable, which indicates if each is a significant predictor of EI participation. Then, to further estimate the effect of the covariates included in each model, we calculated the state-level variance and proportion of variance explained by the model covariates. Because the β coefficients for logistic random-intercepts models do not readily convert to a population odds ratio, we calculated the adjusted probability of EI participation under the conditions imposed by each multivariable model.

All analyses were conducted in SAS 9.1.¹⁸ Multilevel models were calculated in the SAS 9.1 macro “proc glimmix.”¹⁹

RESULTS

Of the NS-CSHCN population, 2350 were children younger than 3 years, and 900 children met our criteria. The distributions of sociodemographic covariates before and after complete case ascertainment revealed no substantial differences.

The overall rate of EI participation in the study cohort was 45.7% (Table 1), with substantial variation, according to state, in EI participation rates that ranged from 23.1% (Maryland and Delaware) to 83.3% (Rhode Island). The unadjusted probability of EI participation across all 3 eligibility categories ranged from 42% in states

with narrow eligibility criteria to 53% in states with broad eligibility criteria (data not shown).

Multilevel Analyses

State variation was reflected in the first model (Table 2), with a statistically significant between-state variation in the log odds of EI participation ($\sigma^2 = .4028$; SE: .10).

The individual-level variables included in model 2 were race/ethnicity, poverty, severity of condition/delays, and developmental delay versus established condition. Gender of the child, having a usual source of care, and parental education were omitted, because they were not statistically significant in either the bivariable or multivariable models. Greater poverty levels were associated with less EI participation ($P < .001$), whereas there was a positive association between EI participation and severity of condition/delays (Table 2). Children with a developmental disability were more likely to receive EI than children with developmental delay not associated with a diagnosis (Table 2). Hispanic and multiracial children were least likely to receive EI (Table 2). The addition of the individual-level covariates to the model (model 2), however, did little to further explain differences in EI participation between states when compared with the null model (model 1) (Table 2), resulting in a 4% decrease in the between-state variability in EI participation ($\sigma^2 = .3880$; SE: .11).

The addition of the state EI-eligibility-policy category in model 3 substantially reduced the between-state variance ($\sigma^2 = .2481$; SE: .11) when compared with model 2, with combination of the individual sociodemographic and neurodevelopmental and state-level variables together explaining 38% of the state variance in EI participation.

State eligibility criteria and poverty operated together to influence enroll-

TABLE 1 Distribution of EI Participation, State EI Eligibility-Policy Category, and Sociodemographic and Developmental Covariates, According to State, in a Cohort of 900 Families of Infants and Toddlers With Special Health Care Needs

State	n	% in EI ^a	Eligibility Policy ^b	Race/Ethnicity of EI Participants, %				Income of EI Participants, % FPL			Developmental Status of EI Participants	
				Non-Hispanic White	Non-Hispanic Black	Hispanic	Other	<100	100 to <185	>185	Established Risk ^c	Developmental Delay ^d
Alaska	14	57.1	B	62.5	—	—	37.5	37.5	25	27.5	75	25
Alabama	23	39.1	B	66.7	22.2	—	11.1	33.3	11.1	55.6	88.9	11.1
Arkansas	21	47.6	B	70.0	10.0	—	20.0	10.0	40.0	50.0	100.0	—
Arizona	16	75.0	M	66.7	8.3	8.3	16.7	33.3	25	41.7	83.3	16.7
California	20	30.0	B	33.3	16.7	50.0	—	16.7	16.7	66.7	83.3	16.7
Colorado	17	29.4	M	60.0	—	—	40.0	20.0	20.0	60.0	60.0	40
Connecticut	14	57.1	M	75.0	—	12.5	12.5	—	—	100.0	100.0	—
District of Columbia	18	44.4	N	50.0	50.0	—	—	12.5	37.5	50.0	75.0	25.0
Delaware	13	23.1	N	100.0	—	—	—	—	33.3	66.7	33.3	66.7
Florida	18	61.1	B	45.5	18.2	18.2	18.2	27.3	27.3	45.5	90.9	9.1
Georgia	21	38.1	M	50.0	37.5	—	12.5	25.0	25.0	50.0	75.0	25.0
Hawaii	24	70.8	B	6.3	6.3	6.3	81.3	11.8	23.5	64.7	82.4	17.7
Iowa	19	36.8	B	100.0	—	—	—	—	42.9	57.1	100.0	—
Idaho	16	56.3	M	77.8	11.1	11.1	—	33.3	44.4	22.2	100.0	—
Illinois	15	46.7	M	85.7	—	—	14.3	—	14.3	85.7	85.7	14.3
Indiana	17	58.8	M	80.0	—	20.0	—	10.0	20.0	70.0	90.0	10.0
Kansas	18	38.9	B	71.4	—	28.6	—	—	28.6	71.4	85.7	14.3
Kentucky	18	38.9	M	100.0	—	—	—	—	42.9	57.1	71.4	28.6
Louisiana	17	47.1	M	62.5	12.5	—	25.0	37.5	12.5	50.0	87.5	12.5
Massachusetts	17	70.6	B	58.3	8.3	25.0	8.3	25.0	8.3	66.7	83.3	16.7
Maryland	13	23.1	B	66.7	—	33.3	—	—	—	100.0	100.0	—
Maine	8	62.5	M	80.0	—	—	20.0	20.0	40.0	40.0	100.0	—
Michigan	18	55.6	B	50.0	30.0	10.0	10.0	40.0	30.0	30.0	90.0	10.0
Minnesota	22	45.5	M	90.0	10.0	—	—	—	10.0	90.0	90.0	10.0
Missouri	20	25	N	80.0	20.0	—	—	20.0	20.0	60.0	100.0	—
Mississippi	22	65.0	B	53.9	30.8	7.7	7.7	30.8	7.7	61.5	100.0	—
Montana	12	33.3	N	100.0	—	—	—	—	—	100.0	75.0	25.0
North Carolina	20	40.0	M	62.5	12.5	—	25.0	25.0	12.5	62.5	100.0	—
North Dakota	12	58.3	N	71.4	—	—	28.6	—	28.6	71.4	100.0	—
Nebraska	14	42.9	M	83.3	—	16.7	—	50.0	16.7	33.3	100.0	—
New Hampshire	12	58.3	B	100.0	—	—	—	—	—	100.0	85.7	14.3
New Jersey	25	52.0	M	42.6	7.7	7.7	38.5	—	38.5	61.5	76.9	23.1
New Mexico	24	75.0	B	27.8	5.6	27.8	28.9	16.7	33.3	50.0	77.8	22.2
Nevada	23	60.9	N	71.4	—	7.1	21.4	28.6	21.4	50.0	85.7	14.3
New York	17	64.7	M	54.6	9.1	27.3	9.1	18.2	18.2	63.6	72.7	27.3
Ohio	13	38.5	B	100.0	—	—	—	—	20.0	80.0	100.0	—
Oklahoma	10	50.0	N	80.0	—	—	20.0	60.0	—	40.0	60.0	40.0
Oregon	21	42.9	M	88.9	—	11.1	—	55.6	22.2	22.2	77.8	22.2
Pennsylvania	15	73.3	B	72.7	27.3	—	—	18.2	18.2	63.6	90.9	9.1
Rhode Island	18	83.3	B	46.7	6.7	6.7	40.0	13.3	20.0	66.7	86.7	13.3
South Carolina	20	45.0	M	62.5	12.5	25.0	—	44.4	22.2	33.3	77.8	22.2
South Dakota	28	32.1	M	100.0	—	—	—	—	11.1	88.9	66.7	33.3
Tennessee	18	33.3	N	66.7	—	—	33.3	16.7	33.3	50.0	83.3	16.7
Texas	21	57.1	B	66.7	—	25.0	8.3	33.3	16.7	50.0	75.0	25.0
Utah	21	57.1	M	91.7	—	8.3	—	25.0	41.7	33.3	83.3	16.7
Virginia	14	35.7	B	40.0	20.0	20.0	20.0	—	20.0	80.0	80.0	20.0
Vermont	11	27.3	M	66.7	—	—	33.3	—	33.3	66.7	100.0	—
Washington	11	45.5	B	40.0	—	20.0	40.0	—	20.0	80.0	80.0	20.0
Wisconsin	23	60.9	B	71.4	14.3	7.1	7.1	21.4	21.4	57.1	85.7	14.3
West Virginia	18	27.8	B	100.0	—	—	—	—	40.0	60.0	80.0	20.0
Wyoming	20	25.0	B	100.0	—	—	—	40.0	40.0	20.0	100.0	—
Total	900	45.7	—	62.9	11.3	15.1	10.7	23.1	20.1	56.8	84.1	15.9

^a The proportion of study cohort with parent-reported participation in EI.

^b State EI eligibility category: B indicates broad; M, moderate; N, narrow. Source: 2004 Child Count Data Charts, IDEA Infant and Toddler Coordinator's Association¹³ and Shakelford et al¹⁹ (2006).

^c Establish risk: parent-reported diagnosis that corresponds to the IDEA mandates for EI service delivery.

^d Developmental delay: parent-reported child difficulty with physical, fine motor, cognitive, or language skills.

TABLE 2 Parameter Estimates (β), SE of β , State-Level Variance (σ^2), and SE of σ^2 for Each Logistic Regression Random-Intercept Multilevel Model of Participation in EI Among a Cohort of 900 Families of Children at Risk for Adverse Neurodevelopment

	Model 1 (Null)	Model 2 (Individual Covariates)	Model 3 (Individual + State Covariates)	Model 4 (Cross-Level Interactions)
Intercept		-.1316 (.2529)	-.07786 (.2802)	-.02652 (.2921)
Race				
White, non-Hispanic		Reference	Reference	Reference
Black, non-Hispanic		.1061 (.2274)	1.069 (.2291)	.1691 (.2339)
Hispanic		-.2399 (.2555)	-.2469 (.2593)	-.2109 (.2617)
Other		-.4195 (.2354)	-.4231 (.2375)	-.4102 (.2405)
Income, % FPL				
<100		-.7831 (.1884) ^a	-.7862 (.1895) ^a	-.7366 (.2522) ^a
100 to <185		-.5088 (.1953) ^a	-.5084 (.1964) ^a	-.8397 (.2690) ^a
>185		Reference	Reference	Reference
Severity of condition				
Mild		Reference	Reference	Reference
Moderate		.9446 (.1824) ^a	1.9450 (.1834) ^a	.9551 (.1866) ^a
Severe		1.6726 (.2015) ^a	1.6679 (.2028) ^a	1.6909 (.2502) ^a
Neurodevelopmental risk				
Established condition		Reference	Reference	Reference
Developmental delay		-.3060 (.0974) ^a	-.3072 (.0980) ^a	-.3224 (.0995) ^a
Policy				
Broad			Reference	Reference
Moderate			-.05141 (.2416)	-.07751 (.4672) ^a
Narrow			-.2376 (.3603)	-.2740 (.2993) ^a
Policy*poverty				
Broad*<100% FPL				Reference
Moderate*<100% FPL				-1.206 (.3913) ^a
Narrow*<100% FPL				-.8969 (.6754)
Broad*100% < 185% FPL				Reference
Moderate*100% < 185% FPL				.04805 (.3827)
Narrow*100% < 185% FPL				-1.1381 (.7201) ^a
Level 2 variance	.4028 (.10) ^a	.3880 (.11)	.2481 (.11)	.2399 (.11)
Explained variance, % ^b	4	38	39	

^a $P < .05$.

^b To determine the relative contribution of each model to the between-state variance in EI participation, we used the formula: $(V_0 - V_i)/V_0$, where V_0 is the state-level variance in the null model and V_i is the state-level variance of the adjusted model.²⁵ Statistical significance of state-level variance ($P < .05$) was determined if σ^2 was > 1.96 times the estimate of the SE of σ^2 . A substantial reduction in the state-level variance across models indicates that the covariates included in the model explain the observed differences in EI participation across states.²⁷

ment. The adjusted probability (Fig 1) of receiving EI for poor children (<100% federal poverty level [FPL]) was 18 percentage points lower in states with a narrow versus broad EI eligibility policy (.18 vs .36). In addition, although nonpoor children generally had a higher probability of receiving EI, nonpoor children (>185% FPL) who lived in states with strict eligibility criteria (adjusted probability of .33) were nearly as likely as poor children who lived in states with liberal eligibility criteria to receive EI (adjusted probability of .36).

DISCUSSION

Although on average EI participation in our study population of potentially eligible children was 46%, individual state participation rates ranged from 23% to >80%. Some of this variability can be attributed to characteristics of the children who lived within states. Factors most significantly associated with lower EI participation seem to be being poor, mild severity of condition/delays, and not having a diagnosis. Hispanic ethnicity and being from a multi-racial family seem influential but did

not reach statistical significance in these analyses, likely because of the small subgroup sample size.

Our findings related to poverty are somewhat inconsistent with previous data,⁶ which suggests that poor children are overwhelmingly represented in EI. One reason for our disparate finding is that previous research was based on children enrolled in EI, whereas we created a cohort of infants and toddlers at high risk for adverse neurodevelopment for which EI use was not universal. We found socio-demographic disparities in EI use suggesting unmet need among minority and poor children with developmental delays and disabilities.

In this study, children with established risk were more likely than those with developmental delay to participate in EI. This is not surprising, because children who received a diagnosis presumably have had contact with the medical system and may have been more likely to be referred to follow-up services. Although current practice recommendations are that all young children be screened for developmental delays, studies have shown that this practice occurs ineffectively and inconsistently.²⁰ As a result, many young children who present with developmental delay may not receive a diagnosis until school entry and are not referred for earlier services.

The racial and ethnic patterns of EI participation we found are consistent with the National Early Intervention Longitudinal Study (NEILS) data,⁷ in which it was shown that non-Hispanic black children were more likely to participate in EI than white children and children from other minority groups. However, our findings differ from the Early Childhood Longitudinal Study (ECLS) data, which suggest that non-Hispanic black children have lower EI participation than their white peers. Previous data^{6,7} related to Hispanic

children have been mixed but suggest that this population is nearly as or more likely to receive EI than non-Hispanic white children. However, neither previous study included a comparison group of similar children with developmental delays and disabilities. Moreover, our findings are consistent with previously reported ethnic disparities in developmental risk²¹ and access to health services for Hispanic children more generally.²² Contributing factors are multifactorial and likely include a lack of bilingual and culturally sensitive providers and disparate provision of family-centered care.²³ Future research should explore these barriers in the context of EI.

Although differences in child characteristics did account for some state variation in EI participation, the overwhelming factor seemed to be state policy. States with a more lenient EI eligibility policy had higher rates of EI participation. Similar results were observed in a cohort of children enrolled in EI⁶ and State Children's Health Insurance Programs.²⁴ Although intuitive, this finding has important clinical and policy implications. For example, a 24-month-old boy with a 6-month developmental delay in his cognitive skills, which most clinicians would argue is substantial enough to warrant intervention, would not receive EI in a state in which a 12-month developmental delay in cognitive skills is needed to receive developmental intervention through EI.

State policy does not affect children equitably across income groups. Although the average probability of receiving EI for poor children was .34 (<100% FPL) and .40 (100% to <185% FPL), EI participation rates for these children were .18 and .15, respectively, in states with narrow eligibility criteria.

We acknowledge several limitations to the present study. The data were cross-sectional, and we acknowledge the possibility of reverse causation, that is, low

EI enrollment rates influence more restrictive eligibility policy. In addition, there may be unmeasured factors at the individual state level that contributed to the results. Examples include maternal awareness of development, state regulations for developmental screening through Medicaid, and Child Find activities²⁵ or outreach to vulnerable populations. Given the complexity of such programming, quantifying this variation is extremely difficult.

Our analyses were limited to only individual- and state-level covariates. For the analyses in this study, we assumed a uniform rate of EI within each state, which previous research³ suggests is unlikely. Future research should include individual, county-level, and state-level data. Furthermore, although the 2005–2006 NS-CSHCN relies exclusively on parent report, previous literature has validated the data-collection methods, in particular the characteristics of CSHCN.²⁶ To our knowledge, the validity of parent report of EI participation has not been measured. If parent report of EI varies across family characteristics (eg, poverty levels), recall bias may be introduced. However, the survey item mentions the program (ie, EI) and a program component (ie, the Individualized Family Service Plan), which is a standard health services research format and improves measurement validity. Last, there may have been selection bias introduced by families who moved from 1 bordering state to another to take advantage of more liberal EI policies. We have no means of identifying the extent to which this may have occurred.

Despite these concerns, several strengths of our study underscore the importance of the findings. To our knowledge, this is the first study to have examined EI rates among a population with diverse risk for adverse neurodevelopment and to compare

those at high risk for poor developmental outcomes who are receiving EI versus those who are not nationally. Previous studies were limited by lack of a control group⁶ or by data being restricted to 1 state⁴ or 1 diagnosis, that is, low birth weight⁴ or very low birth weight.⁷

Furthermore, we were able to control for sociodemographic differences of children within states. Previous authors³ examined state differences without being able to control for individual characteristics of children and is subject to an “ecological fallacy,” that is, erroneous inferences to the individual level while using contextual data.

Last, we were able to discuss patterns in EI related to specific diagnoses and parent report of developmental difficulties. Several authors have described the need for improved developmental screening and follow-up for young children, in particular those whose parents reported concern regarding developmental milestones.²⁰ However, to date, there has been little empirical evidence in the form of large, population-based studies to support these recommendations.

CONCLUSIONS

The results of this study reveal marked social disparities in EI participation among a cohort of young children at increased risk for adverse neurodevelopment. The study highlights areas of unmet need for EI services within vulnerable populations and the contribution of state policies to ameliorating or exacerbating these disparities. It has important policy implications for guiding improved outreach to families of CSHCN.

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