

# PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

## **Prevalence of Developmental Delays and Participation in Early Intervention Services for Young Children**

Steven A. Rosenberg, Duan Zhang and Cordelia C. Robinson

*Pediatrics* 2008;121:e1503-e1509; originally published online May 26, 2008;

DOI: 10.1542/peds.2007-1680

The online version of this article, along with updated information and services, is located on the World Wide Web at:

<http://www.pediatrics.org/cgi/content/full/121/6/e1503>

PEDIATRICS is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. PEDIATRICS is owned, published, and trademarked by the American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, Illinois, 60007. Copyright © 2008 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 0031-4005. Online ISSN: 1098-4275.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



# Prevalence of Developmental Delays and Participation in Early Intervention Services for Young Children

Steven A. Rosenberg, PhD<sup>a</sup>, Duan Zhang, PhD<sup>b</sup>, Cordelia C. Robinson, PhD, RN<sup>c</sup>

<sup>a</sup>Department of Psychiatry and <sup>c</sup>JFK Partners, University of Colorado Denver, Denver, Colorado; <sup>b</sup>College of Education, University of Denver, Denver, Colorado

The authors have indicated they have no financial relationships relevant to this article to disclose.

## What's Known on This Subject

Part C early intervention serves ~2% of US children who are <3 years old; however, we have limited information regarding the number of children eligible for Part C services. National estimates of the number of young children with developmental delays vary and are not based on direct assessments of children.

## What This Study Adds

This study offers a national estimate of the percentage of children who are eligible for Part C services on the basis of direct assessment of the children and provides an estimate of the proportion of young children who are receiving early intervention for developmental problems.

## ABSTRACT

**OBJECTIVES.** The objective of this study was to use a nationally representative longitudinal sample of children born in the United States in 2001 to estimate rates of eligibility for Part C early intervention, to estimate rates of access to services for developmental delays, and to examine factors that are associated with access to services.

**METHODS.** Data for this study were collected as part of the Early Childhood Longitudinal Study, Birth Cohort, which obtained data from participants when children were 9 and 24 months of age. Descriptive analyses were used to generate national estimates of the prevalence of developmental delays that would make children eligible for Part C services and rates of participation in early intervention services. Logistic regression analyses were conducted to examine whether child developmental delay, race, insurance availability, and poverty status were associated with the probability of receiving services.

**RESULTS.** Results indicated that ~13% of children in the sample had developmental delays that would make them eligible for Part C early intervention. At 24 months, only 10% of children with delays received services. Children with developmental delays were more likely to receive services than those who do not have delays; black children were less likely to receive services than children from other ethnic and racial groups.

**CONCLUSIONS.** The prevalence of developmental delays that make children eligible for Part C services is much higher than previously thought. Moreover, the majority of children who are eligible for Part C services are not receiving services for their developmental problems. Strategies need to be developed to monitor patterns of enrollment in early intervention services and reach out to more minority children, particularly black children. *Pediatrics* 2008;121:e1503–e1509

[www.pediatrics.org/cgi/doi/10.1542/peds.2007-1680](http://www.pediatrics.org/cgi/doi/10.1542/peds.2007-1680)

doi:10.1542/peds.2007-1680

### Key Words

developmental delay, early intervention, part C eligibility, epidemiology

### Abbreviations

IDEA—Individuals With Disabilities Education Improvement Act  
ECLS-B—Early Childhood Longitudinal Survey Birth Cohort  
BSF-R—Bayley Short Form—Research Edition  
BSID-II—Bayley Scales of Infant Development, Second Edition

Accepted for publication Dec 20, 2007

Address correspondence to Steven A. Rosenberg, PhD, University of Colorado Denver, Campus Box C268-63, Denver, CO 80262. E-mail: [steven.rosenberg@uchsc.edu](mailto:steven.rosenberg@uchsc.edu)

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275). Copyright © 2008 by the American Academy of Pediatrics

**P**ART C EARLY intervention is specified in the Individuals With Disabilities Education Improvement Act (IDEA) as an interagency program for coordinating efforts within and across community and governmental agencies to address the needs of children who are younger than 3 years and have developmental delays and the needs of their families. Under the Part C program, each participating state is required to establish a definition of eligibility for services that specifies levels of developmental delay and diagnoses associated with developmental conditions that confer eligibility.

In 2002, Part C early intervention served 265 145 infants and toddlers.<sup>1</sup> This number is 2.2% of the nation's children who are younger than 3 years and reflects the US Department of Education's goal of providing Part C services to at least 2% of children who are younger than 3<sup>2</sup>; however it seems that many states have adopted criteria that make far more children eligible than the national goal of 2%.<sup>3</sup> Given the variability in state criteria, it is difficult to know how many children are actually eligible for Part C services or how many Part C–eligible children fail to receive services for their developmental needs.

Most national estimates of the prevalence of developmental problems among infants and young children have been based on survey questions answered by parents, rather than direct assessments of child development. There is

reason to doubt the accuracy of these estimates that range from 17.1% for children up to 17 years of age<sup>4</sup> to 5.6% for children 4 to 59 months<sup>5</sup>; however, in recent years, the Early Childhood Longitudinal Study Birth Cohort (ECLS-B) has directly assessed development in a national sample of children at 9 and 24 months of age, making it possible to estimate accurately rates of developmental delays for the nation's youngest children.

Estimates of service use by young children with developmental delays and disabilities are quite limited. The available information indicates that these children have low rates of participation in early intervention services. Nationally, only 17% of children who are younger than 5 years and whose development was classified as delayed actually received services for those delays.<sup>5</sup> Studies of children who are younger than 3 show that large numbers of presumably eligible children are not enrolled in Part C. Despite high rates of developmental delays among children who receive Early Head Start, <5% of these children were also enrolled in Part C early intervention.<sup>6</sup> Maltreated children also have very low rates of enrollment in Part C.<sup>7</sup>

Factors that have been shown to be associated with children's enrollment in services include race, gender, poverty, and the availability of health insurance. Boys have higher rates of developmental delays than girls<sup>5</sup> and higher rates of Part C enrollment.<sup>8</sup> Poverty is also related to the occurrence of developmental problems.<sup>9,10</sup> Although the availability of health insurance is a powerful factor in determining use of health services,<sup>11</sup> little is known about the relationship of health insurance to Part C services. For example, 1 of the only studies on this topic found that in Hawaii, uninsured children seem to use Part C less than those who have health insurance.<sup>12</sup>

Only a few studies have tried to identify racial and ethnic discrepancies in access to Part C services. These studies have predominantly looked at the relative proportions of different groups of children enrolled in Part C. A study of Part C in Minnesota, for instance, found that counties with higher percentages of black children have lower overall rates of Part C enrollment.<sup>13</sup> In Massachusetts referrals to Part C were lower for birthweight infants of black non-Hispanic mothers than for other racial and ethnic groups.<sup>14</sup> However, work with a national sample found black children to be overrepresented in Part C, whereas white children, in comparison with their representation in the national population, are underrepresented.<sup>8</sup>

This lack of information about the proportion of Part C-eligible children who do not receive services makes clear the need for studies that estimate both the numbers of children who are younger than 3 and have developmental problems and the numbers of children who have delays and do not receive early intervention.<sup>15</sup> In addition, research is needed to address the factors that may affect children's access to early intervention services. This study uses a nationally representative sample to estimate (1) rates of developmental delays that make children eligible for Part C, (2) rates of enrollment in early intervention services by these children, and (3) the relationship of developmental status, race, poverty, and

**TABLE 1 Demographic Characteristics of Study Population**

Characteristic	Children			
	9 mo		24 mo	
	%	SE, %	%	SE, %
Male gender	51.1	0.6	51.1	0.7
Race				
White	53.2	1.8	53.6	1.9
Black	13.7	0.9	13.7	0.9
Hispanic	25.5	1.4	25.2	1.4
Asian	2.8	0.2	2.7	0.2
Other	4.8	0.3	4.9	0.3
Family income				
\$10 000 or less	10.6	0.6	9.4	0.5
\$10 001 to \$25 000	24.7	0.8	22.9	0.9
\$25 001 to \$40 000	20.3	0.6	20.1	0.7
\$40 001 to \$100 000	34.2	0.9	36.6	1.1
\$100 001 or more	10.2	0.7	10.9	0.6
Mother's education				
≤8th grade	6.0	0.4	5.3	0.4
9th–12th grades	21.3	0.9	21.8	0.9
High school diploma or equivalent	21.8	0.8	21.6	0.8
Some college	26.5	0.7	26.6	0.7
Bachelor's degree	15.1	0.8	15.3	0.8
Above bachelor's degree	9.2	0.5	9.4	0.6
Poverty				
Below poverty level	22.9	0.8	21.6	0.9

The unweighted sample size at 9 months was 10 200 and at 24 months was 8950. The percentages reported are population estimates.

insurance status to receipt of services for developmental problems.

## METHODS

### Sample

Data for this study came from the ECLS-B, which was designed to look at children's early development, access to services, and education from birth to kindergarten at the national level. The ECLS-B recruited a probability sample that consisted of children who were representative of all of the children who were born in 2001 in the United States. The ECLS-B data set contains direct assessments of children, caregiver interviews and questionnaires, and information from birth certificates.<sup>16</sup> Data used in this report are from the 9- and 24-month rounds of data collection, conducted from 2001 to 2002 and 2003 to 2004, respectively. The parents of 10 700 children who were born in 2001 participated in the first round of the study when the children were ~9 months of age. Child assessments were conducted on a total of 10 200 of these children. The parents of 9800 children participated in round 2, and child assessments were conducted on 8950 of these children. The characteristics of this sample are summarized in Table 1.

### Measures

#### *Developmental Status*

Children's cognitive and motor skills were assessed with the Bayley Short Form-Research Edition (BSF-R), an abbreviated form of the Bayley Scales of Infant Devel-

opment, Second Edition (BSID-II).<sup>17</sup> The BSF-R was developed with a core set of items that are appropriate for most of the infants in the target age group. The raw score total for these core items was then used to determine whether any specific infant should be administered additional basal or ceiling item sets. The BSF-R diverges from the BSID-II primarily in its use of shortened core, basal, and ceiling item sets. The BSF-R was specially adapted for home administration as part of a household interview survey while replicating, as closely as possible, results that would be obtained using the full BSID-II.<sup>18</sup>

### *Part C Eligibility*

The estimate of the number of children with developmental delays used in this study relied on criteria that are commonly used to determine whether children are eligible for Part C services. Under Part C, each state must provide services to 2 groups of children: those who are experiencing developmental delays and those who have what are known as established risk conditions, such as chromosomal anomalies and low birth weight.<sup>3</sup> Children who have diagnoses of such conditions do not have to have delays to be eligible, because they are presumed to have a very high likelihood of demonstrating developmental delays. Of particular relevance to this study is that each state is required to establish a definition of eligibility for services that addresses delays in 5 developmental domains: motor, communication, cognitive, daily living, and socioemotional. States' criteria for Part C must specify levels of developmental delay and diagnoses that are associated with developmental conditions that confer eligibility. The definitions used across the United States vary. Many jurisdictions use several criteria. Approximately one third use 2 alternative numerical criteria: 1 that is based on an SD score and another that is based on a discrepancy between chronological and developmental age. In addition, ~65% of the states also allow children to be made eligible by informed clinical opinion alone. The ECLS-B database provides normed measures of children's cognitive and motor skills, which can be used to assess the development of children who are younger than 3 years for 2 of the 5 developmental domains that are used to determine children's Part C eligibility. This study's eligibility criteria have been set at  $\geq 1.0$  SD below the mean on the cognitive and motor subscales of the BSF-R or 1.5 SD below the mean in at least 1 of the 2 subscales. In addition, children in this study were defined as eligible when they had a birth weight  $< 1500$  g. These criteria, developmental delay and birth weight, were used to classify children into Part C-eligible and -ineligible groups.

The study criteria for eligibility on the basis of developmental delay were validated by comparing them with the eligibility criteria used by the 44 states and the District of Columbia that have a numerical definition of Part C eligibility. The study criteria demonstrated excellent specificity (0.94) and good sensitivity (0.68) in classifying children.

### *Received Services*

Interviews with current primary caregivers, most of whom were parents, provided information regarding whether a child had received services. These analyses used data that were collected at 24 months, when all caregivers were asked whether their child or family received services to help with their child's special needs.

### *Poverty Status*

Poverty status was assessed at both the 9- and 24-month data collection points. The household-level poverty variable identifies families who are living below 100% of the poverty level on the basis of income and household size. The data collected at 24 months were used in these analyses.

### *Insurance Status*

Caregivers were asked whether their children were covered by any kind of health insurance or health care plan. The data collected at 24 months were used in these analyses.

### **Analyses**

The primary outcomes of interest were children's developmental delay status and whether those with special needs received services. Using the criteria described already, we used descriptive analyses of the ECLS-B data to generate a national estimate of children who meet criteria for Part C eligibility.  $\chi^2$  tests were used to explore bivariate associations among categorical variables, including associations between developmental status and access to services with insurance coverage, race, and poverty. Logistic regression analysis was used to determine whether children with certain characteristics were more likely to have received services. Data analysis was conducted with SPSS 15 Complex Samples statistical software (SPSS Inc, Chicago, IL), which applies appropriate weights for all of the analyses. The results reported here all are population estimates; therefore, these findings are generalizable to the population of children born in 2001 in the United States.

## **RESULTS**

### **Birth Weight**

Very low birth weights ( $< 1500$  g) occurred in 1.3% of the population (SE: 0.1%).

### **Developmental Scores**

The total percentage of children who scored  $\geq 1$  SD below the mean at 9 months was 13.4% on the BSF-R mental scale and 16.0% on the BSF-R motor scale. At 24 months, 14.3% and 14.7% of the children scored  $\geq 1$  SD below the mean on the mental and motor scales, respectively (Table 2).

### **Rates of Developmental Delays**

On the basis of the criteria of a birth weight  $< 1500$  g, or 2 scores  $\geq 1.0$  SD below the mean, or 1 score  $\geq 1.5$  SD below the mean, 12% and 13.8% of children were clas-

**TABLE 2** BSF-R Developmental Assessment and Developmental Delay Status

Parameter	9 mo		24 mo	
	Estimated No. of Children	% of Children (SE)	Estimated No. of Children	% of Children (SE)
Mental scale	<i>N</i> = 10 200		<i>N</i> = 8900	
No delay	3 457 168	86.6 (0.7)	3 389 926	85.6 (0.7)
1.0–1.5 SD below mean	341 194	8.5 (0.6)	297 533	7.5 (0.4)
1.5–2.0 SD below mean	102 726	2.6 (0.2)	147 009	3.7 (0.3)
>2.0 SD below mean	90 084	2.3 (0.2)	123 894	3.1 (0.3)
Motor scale	<i>N</i> = 10 150		<i>N</i> = 8850	
No delay	3 346 973	84.0 (0.7)	3 349 336	85.2 (0.7)
1.0–1.5 SD below mean	378 280	9.5 (0.5)	280 725	7.1 (0.5)
1.5–2.0 SD below mean	160 737	4.0 (0.3)	146 978	3.7 (0.3)
>2.0 SD below mean	99 823	2.5 (0.2)	152 882	3.9 (0.4)
Developmental status	<i>N</i> = 10 200		<i>N</i> = 8950	
No delay	3 515 624	88 (0.5)	3 419 010	86.2 (0.7)
Delay	481 545	12 (0.5)	546 671	13.8 (0.7)

All the *N* presented are unweighted sample sizes; all of the counts in the individual cells are weighted population estimates.

sified as having developmental delays at 9 and 24 months, respectively (Table 2). A significantly greater proportion of these children had delays at 24 months than at 9 months ( $\chi^2 = 14.44$ ,  $P = .016$ ).

### Impact of Poverty

The poverty rates for this population were 22.9% at 9 months and 21.6% at 24 months (Table 1). At 9 months, rates of developmental delays were not different for families above or below the poverty threshold ( $\chi^2 = 1.42$ ,  $P = .391$ ); however, at 24 months, children from families who were living below the poverty level were more likely to have delays than were children from families who were living above the poverty level ( $\chi^2 = 34.94$ ,  $P < .001$ ; Table 3).

### Received Services

At 24 months, all respondents were asked whether their child was receiving services to help with special needs. These reports indicated that 2.8% (SE: 0.3%) of the children received early intervention services. Only 10.1% (SE: 1.1%) of the children who were classified as having delays at 24 months received services. Children with delays were significantly more likely to receive services than were children without developmental delays ( $\chi^2 = 281.58$ ,  $P < .001$ ). Race was also significantly associated with the proportion of children who received services ( $\chi^2 = 9.73$ ,  $P = .013$ ). A smaller proportion of black children received services than did other groups. A significantly higher proportion of children with health

insurance received services (2.9% vs 0.7%;  $\chi^2 = 7.12$ ,  $P = .048$ ; Table 4).

Logistic regression analysis was used to examine how child delay status, race, insurance status, and poverty were associated with receipt of services (Table 5). Poverty and insurance status were not significantly associated with the likelihood of receiving services. Children with delays were 7 times more likely to receive services than were children without delays, and race was significantly related to receipt of services: white children were more than twice as likely as black children to receive services.

### DISCUSSION

Data from the ECLS-B were used to address 3 issues that are central to the design and implementation of Part C early intervention: (1) to estimate the prevalence of developmental delays among children who are younger than 3 that would make them eligible for Part C early intervention; (2) to estimate the number of Part C-eligible children who received services for developmental needs; and (3) to examine the relationship of poverty, race, and insurance coverage to children's participation in developmental services.

### Prevalence of Part C Eligibility

The results of this study indicate that ~13% of children at 9 and 24 months have developmental delays that are likely to make them eligible for Part C early intervention. This percentage is much higher than the 2% figure used as the national goal. It falls between the 5.6% rate of developmental problems found among children aged 4 to 59 months identified in the 1994–1995 National Health Intervention Survey on Disabilities<sup>5</sup> and the 16.7% rate of developmental disabilities for children who are younger than 18.<sup>4</sup> It is important to remember that the data in ECLS-B were obtained by direct assessment of the child, whereas the lower prevalence estimate from the National Health Intervention Survey on Disabilities was based on parent report. The discrepancy between the 2% national goal and the rate of Part C

**TABLE 3** Prevalence of Developmental Delays According to Poverty Status at 24 Months

Parameter	Poverty Threshold ( <i>N</i> = 8950)			
	Below		At or Above	
	Estimated No. of Children	% of Children (SE)	Estimated No. of Children	% of Children (SE)
No delay	704 196	82.1 (1.2)	2 714 813	87.3 (0.7)
Delay	153 400	17.9 (1.2)	393 270	12.7 (0.7)

**TABLE 4 Services Received at 24 Months According to Children's Characteristics**

Parameter	Received Services			
	Yes		No	
	Estimated No. of Children	% of Children (SE)	Estimated No. of Children	% of Children (SE)
Developmental status (N = 8950)				
No delay	54 986	1.6 (0.3)	3 362 913	98.4 (0.3)
Delay	55 004	10.1 (1.1)	491 588	89.9 (1.1)
Race (N = 8900)				
White	66 885	3.1 (0.3)	2 057 864	96.9 (0.3)
Black	8186	1.5 (0.2)	533 122	98.5 (0.2)
Hispanic	26 800	2.7 (0.4)	972 789	97.3 (0.4)
Other	7962	2.8 (0.6)	278 205	97.2 (0.6)
Insurance (N = 8950)				
Insured	108 740	2.9 (0.3)	3 669 455	97.1 (0.3)
Not insured	1249	0.7 (0.5)	183 242	99.3 (0.5)

eligibility found in this study indicates that states must evaluate the appropriateness of their definitions of eligibility and the effectiveness of their child-find strategies.

Poverty was significantly related to prevalence. This finding of higher rates of delays among 2-year-old children in poverty is consistent with reports that show differences on standardized developmental measures favoring children from higher income families becoming apparent by 24 months.<sup>19</sup> This elevated rate of Part C eligibility associated with poverty has important implications for how states design their outreach and child-find strategies.

Part C enrollment in the states varies considerably, with rates of enrollment ranging from a high of 9.4% in Hawaii to a low of 0.9% in Nevada.<sup>1</sup> In addition, there are reports of considerable variability in county rates of enrollment within states, raising questions as to why access is greater in some counties than others.<sup>13</sup> The discrepancy between the prevalence rates found in this study's results and the rates of children's being reported in Part C is an issue that warrants additional exploration. In theory, the proportion of children enrolled in Part C in any given state should depend on the state's eligibility criteria and how those criteria are interpreted and applied in the field; however, it seems that states have adopted eligibility criteria without a clear understanding of the number of children who might be eligible for Part C under those criteria. Until states actually look at the

numbers of children whom their criteria make eligible for Part C, the problem of low rates of enrollment compared with the large numbers of eligible children is not likely to improve.

#### Enrollment in Services

The second question posed in this study concerned the extent to which children are receiving services. This study found remarkably low rates for the receipt of services. Only 10% of children who met criteria for Part C eligibility as defined in this study were reported as receiving services for their developmental needs. Children who did not receive services in this study represent a broad cross-section of society. These data indicate that children who were living in poverty were as likely to receive services as peers from higher income households. This finding is consistent with earlier evidence that children with chronic conditions have unmet health needs across all income levels.<sup>20</sup>

#### Factors Related to Enrollment in Services

The third question concerned the relationship of factors of poverty, race, and insurance coverage to children's enrollment in services. The results of this study indicate that black children were half as likely as were white children to receive services. A recent national study found that black families were less positive about their Part C experience than white families,<sup>21</sup> suggesting that Part C may meet the needs of white families more successfully than for black families. In this study, the availability of insurance was associated with receipt of services for a simple test of proportions but was not statistically significant in the logistic regression. This seemingly contradictory result may be because insurance may have been confounded with other demographic variables. When these confounding variables were taken into consideration in the logistic regression model, insurance did not make enough of a unique contribution to be statistically significant. It may also be that rates of uninsured children and rates of entry into these services are so low that the association of insurance with receipt of developmental services is mini-

**TABLE 5 Logistic Regression of Service Use According to Child Delay, Race, Insurance Status, and Poverty**

Variables	$\beta$ Coefficient (SE)	OR (95% CI)	P
Child developmental delay (reference delayed)	2.00 (0.22)	7.35 (4.74–11.41)	.000
Race (reference white)			.000
Black	0.94 (0.19)	2.56 (1.78–3.71)	
Hispanic	0.40 (0.19)	1.50 (1.03–2.18)	
Other	0.29 (0.22)	1.34 (0.86–2.08)	
Insurance (reference has insurance)	-1.6 (0.82)	4.92 (0.97–25.04)	.055
Poverty (reference below poverty)	-0.10 (0.20)	1.11 (0.75–1.64)	.601

Receipt of services was coded as 1 (not receiving services) or 0 (receiving services). OR indicates odds ratio; CI, confidence interval.

mized. Moreover, the impact of health insurance on children's access to Part C services is minimized because Part C services are available to families regardless of their insurance status. Additional study will be needed to understand the relationship of health insurance coverage and access to Part C early intervention.

In addition, there are reports of considerable variability in county rates of enrollment within states, raising questions as to why access is greater in some counties than in others.<sup>13</sup> The referral practices of health care providers are also likely to be another factor in determining enrollment in early intervention<sup>22</sup>; however, it is not clear what role physicians play in directing families to Part C services or what circumstances prompt practitioners to encourage families to seek early intervention for very young children.

Our findings suggest that many Part C–eligible children do not receive early intervention. Expansion of services through more effective outreach by Part C to sources of referrals and families is necessary. In addition, the creation of programs that can engage families who are underrepresented in Part C will be important.<sup>23</sup> There is evidence that children who are under child welfare supervision are underenrolled in Part C.<sup>7</sup> There is also evidence that children in Early Head Start are underenrolled in Part C.<sup>6</sup> This low rate of enrollment compared with the prevalence of developmental delay should prompt states not only to examine their overall rates of enrollment in Part C but also to examine their enrollment with respect to subsets of children within their state.

### Limitations

Several limitations to this study should be noted. These results may underestimate the true rate of delay and Part C eligibility in this sample because only 2 of the 5 developmental domains that are used to determine eligibility for Part C services (mental and motor functioning) were available to classify children as having delays. This study used parental reports of service use, without an independent assessment of receipt of services; therefore, it is possible that parents overreported or underreported the use of various services for their children. However, previous research indicated relatively strong agreement between parental report and actual services received.<sup>24,25</sup> The reasons for the low level of service use found here are not well understood; it seems likely that many children's delays were either not recognized or judged not to require services. Future research would benefit from assessments that address all 5 of the developmental domains considered when establishing eligibility for Part C services, as well as documenting specific conditions that qualify children for Part C.

Finally, it is likely that the rate of participation in services reported in this study is greater than the rate of enrollment in Part C. This limitation occurs because this study looked at receipt of any developmental services, including developmental services that were provided without being enrolled in Part C.

### Future Research

This evidence of low rates of participation in early intervention suggests that a concerted effort will be needed to overcome barriers to identifying and serving all children who qualify for Part C services. Providing early intervention to large numbers of eligible but currently unserved children will not be easy. To serve the estimated 13% of the population of children who were identified as having delays in this study would require Part C to enroll almost 6 times the number of children currently served. It is doubtful that capacity can be expanded to allow all eligible children to be enrolled; consequently, it will be important to identify groups of underserved children who should be targeted for more aggressive outreach by Part C programs.

Progress toward serving all Part C–eligible children should be monitored in every state. Systems for tracking variations in state enrollment should be implemented to document the identification and use of services by Part C–eligible children. Monitoring should also address how professionals apply their state's enrollment criteria to decide whether a child is eligible. This task will be complicated, in many states, by the use of informed clinical opinion as a means of determining eligibility. Informed clinical opinion of what constitutes delay is not easily defined, making it very difficult to determine how eligibility criteria are being applied. It will also be difficult to monitor the application of eligibility criteria where communities rely on measures that do not provide norm-referenced scores. In states that rely mainly on informed clinical opinion and measures without norms to determine children's eligibility, studies will be needed to assess children with normative measures.

The variability in enrollment rates across states also needs more study.<sup>26</sup> Equally important is the need to understand the reasons for variability across communities within states. The definitions used by the states are only part of the reason for variability. Criteria may not be used consistently. The measures used to evaluate children can vary substantially from place to place. An additional source of variability probably results from differences in Part C agencies' levels of outreach in different communities.

### CONCLUSIONS

This study benefited from access to a nationally representative sample of children in the United States, permitting a national estimate of the number of Part C–eligible children and an estimate of the number of children receiving services for developmental needs. This study substantially expands our knowledge regarding prevalence of developmental needs and service use for young children in the United States. Furthermore, this study finds a high rate of Part C eligibility and suggests that current policies leave many eligible children without service.

### ACKNOWLEDGMENTS

This study was supported by grant R40 MC 05473 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Adminis-

tration, Department of Health and Human Services, and a gift from Paula Jennifer Gumbiner.

We thank Steve Miles, Jennifer Baltz, and Jeannie Losh for invaluable assistance with the preparation of this article.

## REFERENCES

1. US Department of Education, Office of Special Education and Rehabilitative Services, Office of Special Education Programs. *26th Annual (2004) Report to Congress on the Implementation of the Individuals With Disabilities Education Act*. Vol 1. Washington, DC: US Department of Education; 2005
2. US Department of Education. FY 2007 program performance plan; 2006. Available at: [www.ed.gov/about/reports/annual/2007plan/allprogs.pdf](http://www.ed.gov/about/reports/annual/2007plan/allprogs.pdf). Accessed May 08, 2007
3. Shackelford J. *State and Jurisdictional Eligibility Definitions for Infants and Toddlers With Disabilities Under IDEA*. (NECTAC Notes No. 21). Chapel Hill: The University of North Carolina, FPG Child Development Institute, National Early Childhood Technical Assistance Center; 2006.
4. Boyle CA, Decoufle P, Yeargin-Allsopp M. Prevalence and health impact of developmental disabilities in US children. *Pediatrics*. 1994;93(3):399–403
5. Simpson GA, Colpe L, Greenspan S. Measuring functional developmental delay in infants and young children: prevalence rates from the NHIS-D. *Paediatr Perinat Epidemiol*. 2003;17(1):68–80
6. Peterson CA, Wall S, Raikes HA, et al. Early Head Start: identifying and serving children with disabilities. *Top Early Child Spec Educ*. 2004;24(2):76–88
7. Robinson CC, Rosenberg SA. Child welfare referrals to Part C. *J Early Interv*. 2004;26(4):284–291
8. Scarborough AA, Spiker D, Mallik S, Hebbler KM, Bailey DB, Simeonsson RJ. A national look at children and families entering early intervention. *Except Child*. 2004;70(4):469–483
9. Fujiura GT, Yamaki K. Trends in demography of childhood poverty and disability. *Except Child*. 2000;66(2):187–199
10. Emerson E. Poverty and children with intellectual disabilities in the world's richer countries. *J Intellect Dev Disabil*. 2004;29(4):319–338
11. Jeffrey AE, Newacheck PW. Role of insurance for children with special health care needs: a synthesis of the evidence. *Pediatrics*. 2006;118(4). Available at: [www.pediatrics.org/cgi/content/full/118/4/e1027](http://www.pediatrics.org/cgi/content/full/118/4/e1027)
12. Shapiro BJ, Derrington TM. Equity and disparity in access to services: an outcomes-based evaluation of early intervention child find in Hawaii *Top Early Child Spec Educ*. 2004;24(4):199–212
13. Chan B, Obsnorg F. Issues of Part C program access in Minnesota. *Infants Young Child*. 1999;12(1):82–90
14. Barfield WD, Clements KM, Lee KG, Kotelchuck M, Wilber M, Wise PH. Using linked data to assess patterns of early intervention (EI) referral among very low birth weight infants. *Matern Child Health J*. 2008;12(1):24–33
15. Perrin JM. Health services research for children with disabilities. *Milbank Q*. 2002;80(2):303–324
16. Nord C, Edwards B, Andreassen C, Green JL, Wallner-Allen K. *Early Childhood Longitudinal Study, Birth Cohort (ECLS-B), User's Manual for the ECLS-B Longitudinal 9-Month: 2-Year Data File and Electronic Codebook (NCES 2006-046)*. Washington, DC: US Department of Education, National Center for Education Statistics; 2006
17. Bayley N. *Bayley Scales of Infant Development*. 2nd ed. San Antonio, TX: Psychological Corporation; 1993
18. Andreassen C, Fletcher P. *Early Childhood Longitudinal Study, Birth Cohort (ECLS-B), Psychometric Characteristics. Volume 1 of the ECLS-B Methodology Report for the Nine-Month Data Collection (NCES 2005-100)*. Washington, DC: US Department of Education, National Center for Education Statistics; 2005
19. Golden M, Birns B. Social class and infant intelligence. In: Lewis M, ed. *Origins of Intelligence*. New York, NY: Plenum; 1976:299–352
20. Silver EJ, Stein RE. Access to care, unmet health needs, and poverty status among children with and without chronic conditions. *Ambul Pediatr*. 2001;1(6):314–320
21. Bailey DB, Hebbeler K, Spiker D, Scarborough A, Mallik S, Nelson L. Thirty-Six-month outcomes for families of children who have disabilities and participated in early intervention. *Pediatrics*. 2005;116(6):1346–1352
22. Bailey DB, Hebbeler K, Scarborough A, Spiker D, Mallik S. First experiences with early intervention: a national perspective. *Pediatrics*. 2004;113(4):887–896
23. Rosenberg S, Robinson C, Fryer G. Evaluation of paraprofessional home visiting services for children with special needs and their families. *Top Early Child Spec Educ*. 2002;22(3):158–168
24. Bean DL, Leibowitz A, Rotheram-Borus MJ, et al. False-negative reporting and mental health services utilization: parents' reports about child and adolescent services. *Ment Health Serv Res*. 2000;2(4):239–249
25. Hoagwood K, Horwitz S, Stiffman A, et al. Concordance between parent reports of children's mental health services and service records: the services assessment for children and adolescents (SACA). *J Child Fam Stud*. 2000;9(3):315–331
26. Danaher J, Shackelford J, Harbin G. Revisiting a comparison of eligibility policies for infant/toddler programs and preschool special education programs. *Top Early Child Spec Educ*. 2004;24(2):59–67

## Prevalence of Developmental Delays and Participation in Early Intervention Services for Young Children

Steven A. Rosenberg, Duan Zhang and Cordelia C. Robinson

*Pediatrics* 2008;121:e1503-e1509; originally published online May 26, 2008;

DOI: 10.1542/peds.2007-1680

<b>Updated Information &amp; Services</b>	including high-resolution figures, can be found at: <a href="http://www.pediatrics.org/cgi/content/full/121/6/e1503">http://www.pediatrics.org/cgi/content/full/121/6/e1503</a>
<b>References</b>	This article cites 18 articles, 3 of which you can access for free at: <a href="http://www.pediatrics.org/cgi/content/full/121/6/e1503#BIBL">http://www.pediatrics.org/cgi/content/full/121/6/e1503#BIBL</a>
<b>Citations</b>	This article has been cited by 1 HighWire-hosted articles: <a href="http://www.pediatrics.org/cgi/content/full/121/6/e1503#otherarticles">http://www.pediatrics.org/cgi/content/full/121/6/e1503#otherarticles</a>
<b>Subspecialty Collections</b>	This article, along with others on similar topics, appears in the following collection(s): <b>Office Practice</b> <a href="http://www.pediatrics.org/cgi/collection/office_practice">http://www.pediatrics.org/cgi/collection/office_practice</a>
<b>Permissions &amp; Licensing</b>	Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at: <a href="http://www.pediatrics.org/misc/Permissions.shtml">http://www.pediatrics.org/misc/Permissions.shtml</a>
<b>Reprints</b>	Information about ordering reprints can be found online: <a href="http://www.pediatrics.org/misc/reprints.shtml">http://www.pediatrics.org/misc/reprints.shtml</a>

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

