Part C Early Intervention for Infants and Toddlers: Percentage Eligible Versus Served

WHAT’S KNOWN ON THIS SUBJECT: Part C early intervention serves ~2.8% of US children who are younger than 3 years old; however, there is evidence that substantial numbers of infants and toddlers with developmental delays receive no early intervention services.

WHAT THIS STUDY ADDS: Broad eligibility criteria can classify children who have no delays or minimal delays as candidates for Part C services. Despite this, no jurisdiction provides Part C services to all children who have substantial delays.

abstract

OBJECTIVE: Part C early intervention is a nationwide program that serves infants and toddlers who have developmental delays. Previous research has revealed that large numbers of candidates for Part C services do not receive early intervention. Current eligibility criteria for Part C services vary from state to state. This article compares estimates of the percentage of children who are likely to be eligible for early intervention in each state and Washington, DC, with the proportion of children who are served in each of those jurisdictions.

METHODS: Data for this study were obtained from the Early Childhood Longitudinal Survey—Birth Cohort. Using these data, we computed the proportion of children who would be eligible based on the numerical eligibility definitions currently in use across the United States.

RESULTS: This study revealed the proportion of infants and toddlers likely to be eligible for Part C services ranges from 2% to 78% across the United States. The proportion of children enrolled in Part C ranges from 1.48% to 6.96%.

CONCLUSIONS: This research documented substantial variability in the proportion of children who are likely to be eligible for Part C services. Most states have adopted eligibility definitions that make many more children candidates for Part C early intervention than they serve. However, current rates of enrollment are insufficient to serve all children with delays that fall under 2 SDs below the mean on any of the 5 developmental domains that are required to be evaluated by Part C regulations. Pediatrics 2013;131:38–46

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KEY WORDS developmental delay, early intervention, Part C eligibility, Part C enrollment

ABBREVIATIONS

BSF-R—Bayley Short Form-Research Edition
ECLS-B—Early Childhood Longitudinal Survey–Birth Cohort
EI—Part C early intervention

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Part C is the largest of the nation's early intervention programs for children younger than 3 years of age. In 2010, Part C served ~2.8% of the nation's infants and toddlers. Part C early intervention (EI) is available in all the states and several jurisdictions, including Washington, DC. Children who are eligible for Part C services must receive an Individualized Family Service Plan (IFSP). The IFSP specifies child outcomes and services based on a multidisciplinary assessment that addresses the child's functioning, as well as family outcomes based on their priorities and resources identified as important in assisting the family to support their child's development. Part C also requires that each family be provided service coordination. Services provided to children by Part C are most often speech language therapy, followed by occupational therapy, physical therapy, and early childhood education.

The Part C program gives states and other jurisdictions considerable latitude in defining developmental delay for the purposes of determining eligibility for Part C. A developmental delay is any significant lag in a child's development as compared with typical child progress. There is no standard definition of what constitutes a developmental delay. As a consequence, there is considerable variability among the definitions of developmental delay that are used to determine eligibility for Part C services. Part C regulations require that children be evaluated for the presence of delays on 5 domains: (1) cognitive development, (2) motor development, (3) communication development, (4) social or emotional development, and (5) adaptive behavior. In addition, children may also be eligible if they have diagnoses that confer eligibility in the absence of evidence of a delay. Diagnoses granting eligibility are physical or mental conditions that typically result in developmental delays, such as Down syndrome, autism, and cerebral palsy. Jurisdictions also have the option of serving children who show no delay but are considered to be at risk for developmental problems; 4 states (Massachusetts, New Hampshire, New Mexico, and West Virginia) make at-risk children Part C eligible. Finally, eligibility decisions may also be made based on informed clinical opinion.

It is not clear why states have adopted such diverse eligibility criteria. Regulations allow each state to create its own definition, often with input from EI personnel and pediatricians. It is possible that some states want to serve children who are at-risk without declaring them as at risk, because expanding eligibility to include at risk would present additional costs for the state. In other states, it is likely that concerns about the adequacy of funding have led to more restrictive criteria.

There are few studies of the prevalence of delays that are likely to make children eligible for Part C services. One study, which identified a single set of criteria that approximated the definitions of developmental delay used across the United States, revealed that 13% of the nation's infants and toddlers are likely to have delays that would make them eligible for early intervention based on assessments of their cognitive and motor development.

McManus et al used a national sample of children with special health care needs to examine the impact of the restrictiveness of eligibility criteria on enrollment by using a system that classified states' eligibility criteria as broad, moderate, or narrow. They found that living in a state with narrow eligibility criteria was associated with lower likelihood of receiving EI services, particularly for the poorest children. However, these broad categories permit only rough comparisons of the restrictiveness of states eligibility criteria and do not allow us to examine the proportion of children who are likely to be eligible for EI services. At present there are no estimates of the proportion of children who are likely to be Part C eligible in each state and the District of Columbia.

Several studies have revealed that a substantial proportion of children, who are likely to have developmental delays, do not receive EI services. The discrepancy between the prevalence of developmental delays and the rate of participation in Part C warrants exploration. Accurate estimates of the size of the population of children who are likely to be made Part C eligible can help jurisdictions determine whether their eligibility criteria are making the desired proportion of children candidates for Part C. These estimates also allow Part C programs to more accurately gauge the level of resources needed to address the needs of all eligible children.

Currently no national database is available to empirically estimate rates of developmental delays based on all 5 of the developmental domains that are used to determine Part C eligibility. However, it is possible to estimate the proportion of children who are candidates for Part C services based on 5 domains by extrapolating from empirical results obtained from a sample of infants and toddlers who were evaluated on 2 developmental domains. In this situation, probabilistic estimation can be used to compute an estimate for the required 5 domains from the SD of a bivariate distribution that corresponds to that proportion of the population who met eligibility criteria based on 2 domains. The purpose of this study is to estimate the proportion of children who are likely to be Part C eligible under the current definitions of Part C eligibility for the 5 developmental domains.
and to compare that percentage to the percentage of children who receive Part C early intervention.

METHODS

Sample

Data for this study were obtained from the Early Childhood Longitudinal Survey–Birth Cohort (ECLS-B), which was designed to review children’s early development.10 The ECLS-B recruited a representative sample 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.10 These data were collected when children were ~9 and 24 months old. The ECLS-B recruited the parents of 10 700 children who were born in 2001. Child assessments were conducted on a total of 10 200 9-month-olds and 8950 24-month-olds. The sample for this study was limited to full-term infants (n ≈ 7300 at 9 months; n ≈ 6400 at 24 months). Eliminating premature infants from the study sample was done because the ECLS-B’s developmental estimates are adjusted for prematurity at 9 and 24 months10 in ways that are inconsistent with how some states define a developmental delay. For example, Florida does not adjust for prematurity, whereas other states treat prematurity differently than the ECLS-B (Appendix). The characteristics of the study sample at 9 months are summarized in Table 1.

Measures

The ECLS-B database provides normed measures of cognitive and motor skills,2 of the developmental domains that are used to determine children’s Part C eligibility. Children’s cognitive and motor skills were assessed with the Bayley Short Form-Research Edition (BSF-R),11 an abbreviated form of the Bayley Scales of Infant Development, second edition.12 The BSF-R was developed with a core set of items that are appropriate for most of the children in the target age groups. 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 by using the full Bayley Scales of Infant Development, second edition.11

Part C Eligibility

The estimate of the number of children with developmental delays used in this study relied on numerical criteria that are used to define eligibility for Part C services for each of the jurisdictions included in this study. The numerical eligibility definitions for each jurisdiction are provided in the Appendix. Hawaii and Vermont have not adopted numerical criteria and so are not represented in this study. The remaining 48 states and the District of Columbia have adopted 22 unique numerical definitions of eligibility. Approximately one-third of these eligibility definitions make use of 2 alternative criteria: one that is based on an SD score and another that is based on a discrepancy between chronological and developmental age. Eight numerical definitions are shared by 2 or more jurisdictions (Appendix).

Developmental age and the percent delay score, which is derived from developmental age, are often used to define Part C eligibility.2 For norm referenced tests, such as the BSF-R, developmental age scores represent the average chronological age of the children who attained a specific raw score on the test.13 Despite their frequent use, developmental age and percent delay are psychometrically problematic.14 For the purposes of this work, the use of developmental age in eligibility criteria prevents us from generating a purely theoretical estimate of the rate of eligibility because developmental age scores cannot be directly linked to SDs, which are needed to compute an estimate of the proportion of children likely to be made eligible for Part C by a particular eligibility definition. Nevertheless, it is possible to compute an estimate for 5 domains by extrapolating from an empirical result obtained from the ECLS-B’s sample of infants and toddlers who were evaluated on 2 developmental domains.9

Analyses

The proportion of children who met criteria for developmental delay was computed for the Part C eligibility definition of each jurisdiction. Descriptive
analyses of the ECLS-B data were used to
generate estimates of the proportion of
children who met criteria for Part C
eligibility on the cognitive and motor
subscales of the BSF-R at 9 and 24
months by using the entire sample. The
entire sample was used instead of
computing the proportion by using only
the data of each jurisdiction because
some states and the District of Co-
lumbia did not have sufficient cases
participating in the survey to permit an
accurate estimate. SPSS 19 Complex
Samples statistical software (IBM SPSS
Statistics, IBM Corporation, Armonk,
NY), which applies appropriate sample
weights, was used in these analyses.
We obtained the proportion of children
who are candidates for Part C on 5
domains by extrapolating from the SD
obtained from the bivariate normal cu-
mulative distribution function that cor-
responds to the proportion of the
population who met eligibility criteria on
the BSF-Rs cognitive and motor domains.
To do this, we obtained cumulative dis-
tribution functions for 2 and for
5 domains. A cumulative distribution
function is a 2-dimensional relationship
between SDs and probabilities. Hence,
we were able to associate the bivariate
probabilities to the multivariate proba-
TABLES and probabilities based on SDs. The probabilities of
meeting eligibility criteria for 2 and
5 domains were computed by using
mvtnorm (CRAN R-project software,
Available at: http://cran.r-project.org/
web/packages/mvtnorm/index.html).15,16
This procedure has been shown to
accurately estimate rates of developmental
delays among young children.9 We fit
a quadratic function between the bi-
variate and the multivariate probabilities.
We then mapped the probability of
meeting eligibility criteria on 2 domains
to the probability of meeting criteria on 5
domains by using the quadratic function
to estimate the proportion of Part C eli-
gible children for the jurisdictions that
have numerical criteria.

The percentage of children served by
Part C for each state was obtained from
the 2010 annual Part C Child Count.1

RESULTS
Estimates of the percentage of children
likely to be eligible for Part C services
based on 5 domains are presented in
Fig 1. Figure 1 also compares the
proportion of children served in 2010 with
the percentage of children who are
candidates for Part C early inter-
vention. The proportion of children
likely to be eligible for Part C ranges
from ∼2% to 78% of children younger
than 3 years of age. Michigan, with the
broadest definition of delay, made
∼78% and 58% of its children likely to
be Part C eligible at 9 and 24 months,
respectively. In 17 states, over 50% of
children were candidates for Part C at 9
months. The eligibility criteria adopted
by 26 jurisdictions made >20% of their
infants and toddlers candidates for
Part C services. Several states, in-
cluding Minnesota and Ohio, make
children with a delay of 1.5 SD below
the mean in 1 or more areas candi-
dates for services; only 18 states have
adopted more restrictive criteria than
−1.5 SD.
Eligibility definitions in use in most
states also vary in restrictiveness
depending on the age of the child. There
appears to be a tendency for percent
delay criteria to become substantially
more restrictive as age increases,
whereas definitions based on SD scores
become less restrictive with age.
The proportion of children enrolled in
Part C ranges from 1.48% in Georgia to
6.96% in Massachusetts.1 The largest
discrepancies between the percentage
of children who are candidates for Part
C and the percentage enrolled occur in
the states of Washington and Michigan,
which have ∼26 times more candidates
for Part C than they serve. Only Alaska,
Arizona, the District of Columbia, and
Missouri, which have the most re-
strictive eligibility definitions, serve
approximately the same proportion of
children as are estimated to be Part C
eligible.

DISCUSSION
The severity of delays that make chil-
dren candidates for Part C services vary
enormously from state to state. Al-
though the criteria in some juris-
dictions make <3% of children likely
to be Part C eligible, criteria in others
make most infants candidates for early
intervention. Are too many infants
and toddlers candidates for Part C
services? The answer depends on the
eligibility criteria used. The majority of
states have adopted eligibility criteria
that use SD and percent delay scores at
levels that are less restrictive than 1.5
SD below the mean in 1 developmental
domain. The 3 states with the broadest
eligibility definitions make >60% of
9-month-olds and 40% of 24-month-
olds candidates for Part C services.
The criteria of 18 states categorize
>40% of 9-months-olds as delayed.
Criteria that make 40% of the pop-
ulation candidates for Part C create
serious difficulties by classifying chil-
dren who fall within the average range
of abilities as developmentally delayed.
It seems clear that states using the
broadest definitions of delay could mis-
characterize large numbers of children
as delayed and make far too many
children candidates for Part C services.
The impression that children with
minimal delays are enrolled in Part C,
whereas those with more severe
problems go unserved, is reinforced by
recent studies that revealed children
with no delays receiving early in-
tervention.17,18 Clearly, the broadest
definitions of delay make far too many
children candidates for Part C services.
This study also found that, in many
states, only a fraction of the children
who are candidates for services receive
Part C early intervention. Based on the
2010 annual Part C Child Count, Michigan served <5% of the children who were likely to be eligible under its definition.1 But the problem is not just overly broad eligibility criteria. Even if eligibility is limited to the highly restrictive criterion of 2 SD below the mean on 1 of the 5 developmental domains, ~9% of children would still be candidates for Part C early intervention9 (much larger than the 2.8% of the nation’s infants and toddlers who were served in 2010).1 Thus, current rates of enrollment in Part C are less than what would be needed to serve all children who have moderate or severe delays. Are too few infants and toddlers served by early intervention? An answer of “yes” appears warranted.

It will not be easy to provide early intervention to all infants and toddlers with moderate and severe delays. Financial constraints limit Part C’s capacity to serve young children with disabilities.19 A number of Part C programs have revealed difficulty maintaining current service levels.19 In recent years, states have attempted to reduce Part C costs by narrowing enrollment criteria, reducing reimbursement to providers, charging families fees, and obtaining reimbursement from Medicaid and commercial insurance.19 More funding and a better understanding of how best to use those funds are urgently needed. However, efforts to improve the use of Part C funds are hampered by a lack of information about levels of state and local funding, as well as details regarding how those funds are expended.20,21 Additional reasons for children’s failure to enroll in Part C services should also be explored. There is evidence that...

FIGURE 1
Estimated rates of Part C eligibility based on developmental delay. States sharing the same numerical eligibility criteria are grouped within boxes.
a significant number of children with delays receive services outside of the Part C system. A recent study revealed that approximately one-third of candidates for EI services were referred to therapies unconnected to Part C. Children’s patterns of delays may also affect the likelihood that they will participate in EI. For example, children who have persistent delays are more likely to receive EI services than those whose delays are more variable. The possibility that children with delays who are unserved are poor or belong to racial minorities also deserves study.6,7

It would help to know more about how state and community policies and characteristics affect enrollment in Part C. For example, it is unclear why Georgia has a much lower rate of Part C enrollment (1.5%) than Connecticut (3.8%) when they share the same eligibility definition. There is also considerable variability in rates of enrollment within states. Studies reveal wide variations in individual county enrollment rates associated with rates of developmental problems, rurality, and racial makeup of counties. In addition, it would be useful to know how Part C evaluators’ eligibility decisions are influenced by state eligibility guidelines, local financial constraints, parent input, and clinical opinion.

The lack of consistency among the various Part C eligibility definitions makes it difficult to know what the term “delay” means. Perhaps a better understanding of why particular definitions are selected would help the EI field move to more uniform standards for what constitutes delay. More consistent definitions of delay would make eligibility more predictable and increase the likelihood that children who meet well-accepted criteria would be eligible for services when they move from state to state. The use of similar definitions of delay would also facilitate comparisons of the effectiveness of Part C services across states.

This study has a number of limitations. The estimated eligibility rates presented here do not address the proportion of children without delays who are made eligible based on established conditions or clinical opinion. The inclusion of children without delays who could be eligible due to established criteria would increase the estimated proportion of children who are likely to be Part C eligible. The impact of clinical judgment on rates of eligibility is less clear because we have little information about the tendency of Part C evaluators to use their judgment to classify children as eligible or ineligible for services. In addition, the estimates we reported are for full-term infants. Consequently, our results somewhat underestimate the proportion of children who are likely to be eligible for Part C services because preterm infants tend to have higher rates of developmental delays than those who were full term. The estimates for this study were based on only 2 of the 5 domains. Because the 5 developmental domains tend to be moderately correlated, rates of delay in 2 domains should provide a good indication of what is happening in other domains. That said, if cognitive or motor delays occurred at substantially different rates than delays in other domains, these results could under- or overestimate the proportion of children who are likely to be eligible. Finally, states change their eligibility definitions from time to time. For example, Louisiana’s criteria became more restrictive as of May 1, 2012, but this change is not reflected in Fig 1.

CONCLUSIONS

Criteria for Part C eligibility based on developmental delay vary enormously across the nation. Most definitions of developmental delay make many more children candidates for services than are served. There is a pressing need to examine the tendency to adopt criteria that make large numbers of children with minimal delays candidates, while maintaining rates of enrollment that are too small to accommodate all infants and toddlers with significant delays.

APPENDIX: STATE NUMERICAL ELIGIBILITY DEFINITIONS

Alabama, Arkansas, Iowa, Maryland, New Mexico, Texas, and Virginia: 25% delay in 1 or more areas.


Alaska, Arizona, District of Columbia, and Missouri: 50% delay in 1 or more areas.


District of Columbia: http://osse.dc.gov/sites/default/files/dc/sites/osse/


Delaware: 25% delay or 1.75 SD in 1 or more areas.


Idaho: 30% delay or 6-month delay, whichever is less or −2 SD in 1 area or −1.5 in 2 or more areas.


Illinois: 30% delay in 1 area.


Indiana: 25% below chronological age or −2 SD in 1 area or −1.5 SD in 2 areas or 20% delay in 2 or more areas.


Kansas 25% delay or −1.5 SD in 1 or more areas; 20% delay or −1 SD in 2 areas.

Kans 25% delay or −1.5 SD in 1 or more areas or −2 SD in 2 or more areas.


Louisiana, Minnesota, Ohio, South Dakota, and Utah: −1.5 SD below the mean in 1 more areas.


Massachusetts: 30% delay in 1 or more areas or −1.5 SD in 1 or more areas.


Michigan: 20% delay or a score of −1 SD below the mean in 1 or more areas.


Montana, North Dakota, and Nevada: 50% delay in 1 area or 25% delay in 2 areas.

Montana: Shackelford J. State and jurisdictional eligibility definitions for infants and toddlers with disabilities under IDEA. (NECTAC Notes No. 21). Chapel Hill, NC: The University of North Carolina, FPG Child Development Institute, National Early Childhood Technical Assistance Center; 2006.


Nebraska: 2.0 SD below the mean in 1 area or −1.3 SD below the mean in 2 or more areas.


New Hampshire: 33% delay in 1 or more areas.

New Jersey and Rhode Island: 33% delay or −2.0 SD in 1 area; or 25% delay or −1.5 SD in 2 or more areas.


New York: 12-month delay in 1 area, 33% in 1 area, or 25% delay in 2 areas, or −2 SD in 1 area or −1.5 SD in 2 or more areas.


North Carolina: 30% delay or −2 SD in 1 area or 25% delay or −1.5 SD in 2 or more areas.


Oklahoma: 50% delay or −2 SD in 1 area or 25% or −1.5 SD in 2 or more areas.


South Carolina, Tennessee, and West Virginia: 40% delay in 1 area or 25% delay in 2 or more areas.


Wisconsin: 25% delay or −1.3 SD in 1 or more areas.


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WHEN WEIGHT LOSS IS THE GOAL, LESS EXERCISE MAY MEAN MORE: For those trying to lose weight, the well-known mantra “eat less, move more” may not be the entire story. As reported by Time (Health & Family: September 19, 2012), Danish researchers investigating the connection between exercise and weight loss found that more exercise does not necessarily mean greater weight loss. The researchers randomized 61 sedentary, overweight men (BMI of 25-30 kg/m²) between the ages of 25 and 35 into one of three groups: a control group that did not exercise (n = 18); a second group that engaged in moderate aerobic exercise, burning 300 calories each day; and a third group that engaged in more strenuous aerobic exercise, burning 600 calories every day. After 13 weeks, participants’ body weight, fat mass, and energy expenditure were compared to their baseline measurements. Both the moderate and high intensity exercise groups had significant decreases in body weight and fat mass. However, the moderate exercise group showed a larger than expected weight loss, while the high exercise group lost less weight than expected given their caloric expenditure. Researchers aren’t sure how to explain the finding. It may be that the high intensity group ate more than expected or recorded, or that they did not exercise at all between workouts because of fatigue. The moderate intensity exercise group may have continued to engage in modest aerobic activities such as climbing stairs. Regardless, this study supports previous research suggesting a potential ceiling effect on weight and fat loss among exercising individuals. While eating less and exercising more remain important to weight loss, it seems that another classic saying should be kept in mind: all things in moderation.

Noted by Leah H. Carr, BS, MS-III
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