

# Missed Opportunities in the Referral of High-Risk Infants to Early Intervention

**AUTHORS:** Brian G. Tang, MD,<sup>a</sup> Heidi M. Feldman, MD, PhD,<sup>a</sup> Lynne C. Huffman, MD,<sup>a</sup> Kimie J. Kagawa, MD,<sup>b</sup> and Jeffrey B. Gould, MD, MPH<sup>a</sup>

<sup>a</sup>Division of Neonatal and Developmental Medicine, Department of Pediatrics, Stanford University School of Medicine, Palo Alto, California; and <sup>b</sup>State of California, Department of Health Care Services, Systems of Care Division, Children's Medical Services, Program Development Section, Sacramento, California

## KEY WORDS

early intervention, developmental assessment, developmental delay, health service utilization, neonatal follow-up

## ABBREVIATIONS

CCS—California Children's Services  
CLD—chronic lung disease  
CPQCC—California Perinatal Quality Care Collaborative  
DQ—developmental quotient  
EI—early intervention  
NFU—neonatal follow-up

[www.pediatrics.org/cgi/doi/10.1542/peds.2011-2720](http://www.pediatrics.org/cgi/doi/10.1542/peds.2011-2720)

doi:10.1542/peds.2011-2720

Accepted for publication Feb 14, 2012

Address correspondence to Brian G. Tang, MD, Division of Neonatal and Developmental Medicine, Department of Pediatrics, Stanford University School of Medicine, 750 Welch Rd, Suite 315, Palo Alto, CA 94304. E-mail: [bgtang@stanford.edu](mailto:bgtang@stanford.edu)

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Copyright © 2012 by the American Academy of Pediatrics

**FINANCIAL DISCLOSURE:** *The authors have indicated they have no financial relationships relevant to this article to disclose.*

**FUNDING:** This research was supported in part by the Clinical and Translational Science Award 1UL1 RR025744 for the Stanford Center for Clinical and Translational Education and Research (Spectrum) from the National Center for Research Resources, National Institutes of Health, MCHB Grant # 77MC09796-01-00, California Children's Services, and California Perinatal Quality Care Collaborative.



**WHAT'S KNOWN ON THIS SUBJECT:** Neonatal follow-up programs are designed in part to identify developmental delays among high-risk infants after NICU hospitalization and make referrals to state-funded early intervention. Early intervention has been shown to benefit children with developmental delays.



**WHAT THIS STUDY ADDS:** Many high-risk infants demonstrating developmental delays at neonatal follow-up programs are not referred to early intervention. Subspecialty clinics share responsibility with the medical home in referring children from birth through three years with developmental problems to early intervention services.

## abstract

FREE

**OBJECTIVE:** Using a statewide population-based data source, we describe current neonatal follow-up referral practices for high-risk infants with developmental delays throughout California.

**METHODS:** From a cohort analysis of quality improvement data from 66 neonatal follow-up programs in the California Children's Services and California Perinatal Quality Care Collaborative High-Risk Infant Follow-Up Quality of Care Initiative, 5129 high-risk infants were evaluated at the first visit between 4 and 8 months of age in neonatal follow-up. A total of 1737 high-risk infants were evaluated at the second visit between 12 and 16 months of age. We calculated referral rates in relation to developmental status (high versus low concern) based on standardized developmental testing or screening.

**RESULTS:** Among infants with low concerns (standard score >70 or passed screen) at the first visit, 6% were referred to early intervention; among infants with high concerns, 28% of infants were referred to early intervention. Even after including referrals to other (private) therapies, 34% infants with high concerns did not receive any referrals. These rates were similar for the second visit.

**CONCLUSIONS:** In spite of the specialization of neonatal follow-up programs to identify high-risk infants with developmental delays, a large proportion of potentially eligible infants were not referred to early intervention. *Pediatrics* 2012;129:1027–1034

The Individuals with Disabilities Education Act, Part C, provides financial incentives for states to provide early intervention (EI) services to children from birth to 3 years of age who are experiencing developmental delays or have a diagnosed condition with a high probability of resulting in developmental delays. EI encompasses a wide range of state-funded supportive services, such as occupational therapy and educational support. Children benefit from EI with regard to adaptive functioning and quality of life.<sup>1,2</sup> National campaigns and policy statements by the American Academy of Pediatrics have promoted the importance of early screening for developmental delays and referral to EI.<sup>3,4</sup> No studies to our knowledge, however, have evaluated rates of EI referrals in clinical settings specifically geared toward the care of children at high risk for developmental disorders.

Neonatal follow-up (NFU) programs primarily serve children previously hospitalized in NICUs. This patient group is at increased risk for long-term health and neurodevelopmental impairments, including sensory and motor disabilities, intellectual disability, and behavioral problems.<sup>5–8</sup> NFU programs emphasize identifying infants with developmental delays or disabilities early in life by means of standardized developmental testing or developmental screening. The programs also monitor infants with medical problems, such as vision impairment or chronic lung disease (CLD). NFU is not only valuable in assisting children and families with appropriate management plans after NICU discharge but also provides an opportunity to study quality of care outcomes that are of high interest to clinicians, policy makers, and public health officials. Population-based studies are needed to evaluate the effectiveness of NFU programs in addressing the developmental needs of high-risk infants.

The overall goal of this study was to determine EI referral rates among a population of high-risk infants demonstrating developmental delays. Given the responsibility NFU has in providing on-going monitoring of high-risk infants, we hypothesized that high-risk infants with no prior EI, who scored  $\geq 2$  SDs below the mean on a standardized developmental test, or failed a developmental screen would be referred to EI during the same visit. To establish a benchmark, we compared EI referral rates with medical subspecialty referral rates among high-risk infants with known medical conditions. We reasoned that EI referral rates would compare favorably with rates of referrals to ophthalmology among infants with vision impairments and referrals to pulmonology among infants on home oxygen.

## METHODS

### Data Source

The state of California is an important stakeholder in the long-term outcomes of high-risk infants previously hospitalized in the NICU. More than 90% of the NICUs in California are funded in part by California Children's Services (CCS), a statewide program for children with special health care needs. All CCS-funded NICUs are required to provide an NFU service for high-risk infants. Infants eligible for NFU must meet CCS-approved neonatal medical criteria.<sup>9</sup> Children eligible for NFU qualify for a minimum of 3 visits before their third birthday: visit 1 at 4 to 8 months, visit 2 at 12 to 16 months, and visit 3 at 18 to 36 months of age, adjusted for prematurity. CCS has partnered with the California Perinatal Quality Care Collaborative (CPQCC) in quality improvement activities to improve perinatal outcomes in the state. CPQCC is a network of public and private medical providers, health care purchasers, and public health professionals.<sup>10</sup> A High-Risk Infant Follow-up Quality of Care Initiative was formed in

2006 by CPQCC and CCS to identify "quality improvement opportunities" with the goal of reducing long-term morbidity after NICU hospitalization. A real-time data-reporting system was created to track neurodevelopmental, health, and service outcomes of high-risk infants and to evaluate the effectiveness of NFU programs. It contains sociodemographic and child characteristics, service referrals and use (including EI), post-NICU medical history, neurologic examination findings, and developmental status (via a standardized test/screen). Information is abstracted onto standardized forms and entered into a centralized, Web-based reporting system managed by CPQCC. Statewide training and quarterly executive committee meetings ensure consistency, quality, and accuracy of data collection.

### Study Design and Participants

We conducted a primary data analysis of the first wave of data from the High-Risk Infant Follow-up Quality of Care Initiative. This was a cross-sectional observational cohort study of high-risk infants born after January 1, 2009, who were seen at NFU visit 1 and visit 2 and were entered into the data set by February 2, 2011.

### Developmental Testing or Screening

Programs have discretion on the choice of a standardized developmental test or developmental screener at each visit. The standardized test was selected over a screener if both were done on the same child. All participants who underwent standardized developmental testing received a developmental quotient (DQ) or standardized score based on standard administration and scoring procedures for that particular test. The majority (71%) used the Bayley Scales of Infant Development–3rd Edition, followed by the Capute Scales (20%),

Gesell Developmental Observation-Revised (9%), and Mullen Scales of Early Learning (1%).<sup>11–14</sup> DQ scores were dichotomized into infants with a DQ  $\leq 70$  and infants with a DQ  $> 70$  in at least 1 domain of development (eg, motor, language). We selected 70 as the cutoff because  $\geq 2$  SDs below the mean indicate severe delay on most standardized developmental tests.

All participants who underwent a developmental screener received either a “pass” or “fail” based on standard administration and scoring procedures for that particular screener. Common screeners included the Bayley-III Screening Test (52%) and the Bayley Infant Neurodevelopmental Screener (23%).<sup>15,16</sup>

### Developmental Concern

We grouped infants on the basis of results from their developmental assessment: children with DQ  $\leq 70$  or failed screen were categorized as “high concern” and children with DQ  $> 70$  or passed screen were categorized as “low concern” for long-term disability.

### Child Characteristics

We divided the study population into 4 birth weight groups:  $\geq 2500$  g, 1500 to 2499 g, 1000 to 1499 g, and  $< 1000$  g. Birth weight and gestational age were highly correlated ( $r = 0.89$ ;  $P < .001$ ). A gestational age of 40 weeks was used to determine adjusted age at developmental assessment for preterm infants born  $< 37$  weeks' gestational age.

### Neonatal Medical Problems

To characterize the severity of neonatal medical problems, we selected a set of problems as descriptors. Each problem was a dichotomous variable based on definitions determined by using CCS medical eligibility criteria for NFU.<sup>9</sup> “Persistently unstable” includes any infant who had “prolonged hypoxia,

acidemia, hypoglycemia and/or hypotension requiring pressor support.” “Other neurologic abnormality” included problems resulting in neurologic abnormalities, such as history of central nervous system infection and hypoxic ischemic encephalopathy. Children with vision impairment (eg, retinopathy of prematurity, strabismus) and home oxygen were included in the analysis of medical referrals.

### Maternal/Family Characteristics

All maternal/family characteristics were dichotomized: white or non-white maternal race, English as a primary or nonprimary language spoken at home, a maternal education of less than a high school degree or a high school degree or greater, and public health insurance (Medi-Cal) or private insurance.

### Outcome Measure

Referral to state-funded (Part C) EI at the NFU visit was the main outcome measure coded as either “yes” or “no.” We also determined if children were referred to other therapies, such as private physical or occupational therapy.

### Statistical Analysis

Data were analyzed with SPSS version 19.0 for Macintosh (SPSS Inc, Chicago, IL). We used frequency tables to describe child, neonatal medical, and maternal/family characteristics of the study population and determine the proportion of infants referred to EI. We conducted  $\chi^2$  analyses to determine associations between child, neonatal medical, and maternal/family factors and developmental concern. EI referral rates were compared among high-concern infants with referral rates to ophthalmology among infants with vision impairment and pulmonology among infants on oxygen support using a  $\chi^2$  goodness-of-fit test with a hypothesized 80% referral success rate. Multivariate

associations were performed between independent variables of interest and referral to services among infants not previously receiving EI. We created bivariate logistic models for 2 dependent variables: referral to EI (model A) and referral to other therapies (model B). Both models included child characteristics, neonatal medical, and maternal/family characteristics that were selected a priori. A  $P$  value of  $< .05$  was set as the level of statistical significance. The Stanford University Institutional Review Board exempted this study from review because the data set contained de-identified information.

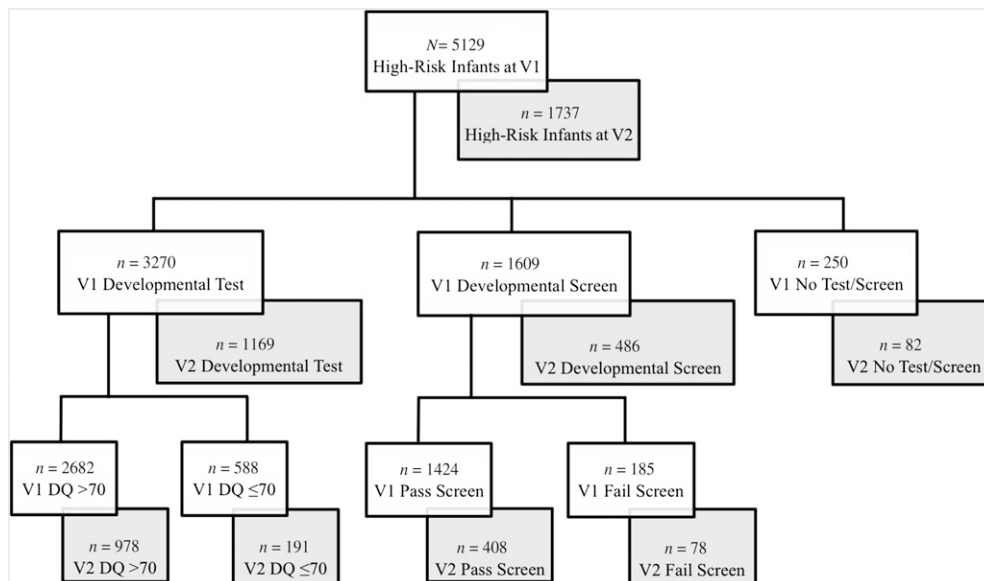
## RESULTS

### Study Population

Figure 1 shows the distribution of the study population according to developmental status at visits 1 and 2. Among the 5129 infants at visit 1, 64% had a standardized developmental test. Of those, 82% had a DQ  $> 70$  and 18% had a DQ  $\leq 70$  in at least 1 domain of development. Among the 1609 infants who had a developmental screen, 89% passed and 11% failed. The remaining 5% received neither a developmental test nor screen. These proportions were similar in visit 2.

### Characteristics of Infants With Developmental Assessments

Table 1 compares the child, neonatal medical, and maternal/family characteristics according to developmental status at visit 1 for those with low and high concerns. Greater proportions of infants with birth weights  $< 1000$  g and  $> 2500$  g had high concerns than those with birth weights 1000 to 1499 g and 1500 to 2500 g ( $\chi^2 = 91.9$ ;  $df = 3$ ;  $P < .001$ ). There were no statistically significant differences between the  $< 1000$ -g and  $> 2500$ -g infants and between the 1000- to 1499-g infants and 1500- to 2499-g infants. A greater proportion of infants with high concerns had medical



**FIGURE 1**  
Flowchart of the study population. V1, visit 1; V2, visit 2.

problems in the neonatal period when compared with infants with low concerns, including prolonged oxygen support ( $\chi^2 = 41.5$ ;  $df = 1$ ;  $P < .001$ ), persistently unstable condition ( $\chi^2 = 18.3$ ;  $df = 1$ ;  $P < .001$ ), intracranial hemorrhage ( $\chi^2 = 29$ ;  $df = 1$ ;  $P < .001$ ), neonatal seizures ( $\chi^2 = 75.8$ ;  $df = 1$ ;  $P < .001$ ), and other neurologic abnormalities ( $\chi^2 = 37.3$ ;  $df = 1$ ;  $P < .001$ ). There was an

excess number of infants with high concerns whose mother's primary language was not English ( $\chi^2 = 29.7$ ;  $df = 1$ ;  $P < .001$ ), whose mother had less than a high school degree education ( $\chi^2 = 15.5$ ;  $df = 1$ ;  $P < .001$ ), and who had government health insurance ( $\chi^2 = 16.1$ ;  $df = 1$ ;  $P < .001$ ). These differences in child, neonatal medical, and maternal/family characteristics according to

developmental status in visit 1 were consistent in visit 2.

### Referrals to EI

Table 2 shows the EI status of the study population at visits 1 and 2. Among infants with low concerns, 16% were already receiving EI at the time of the visit. At the conclusion of the visit, an additional 4% were referred to EI, 13%

**TABLE 1** Visit 1 Study Population Characteristics

Characteristic	Low Concern		High Concern		No DQ/Screen ( <i>n</i> = 250)	Total ( <i>N</i> = 5129)
	DQ >70 ( <i>n</i> = 2682)	Pass Screen ( <i>n</i> = 1424)	DQ ≤70 ( <i>n</i> = 588)	Fail Screen ( <i>n</i> = 185)		
<b>Child characteristics</b>						
Male gender	56 (1500)	54 (765)	58 (339)	52 (97)	56 (140)	55 (2841)
<b>Birth weight, g</b>						
<1000	20 (539)	22 (306)	27 (160)	25 (47)	25 (62)	22 (1114)
1000–1499	34 (904)	36 (513)	22 (131)	21 (38)	34 (84)	33 (1670)
1500–2499	26 (691)	24 (337)	18 (104)	27 (49)	20 (49)	24 (1230)
≥2500	20 (548)	19 (268)	33 (193)	28 (51)	22 (55)	22 (1115)
Adjusted age of test/screen, mo	6.3 ± 2.0	6.4 ± 2.3	6.3 ± 2.1	7.0 ± 2.6	5.1 ± 3.0	6.3 ± 2.2
Chronological age of test/screen, mo	8.3 ± 2.2	8.5 ± 2.4	8.2 ± 2.3	8.9 ± 2.7	7.2 ± 2.9	8.3 ± 2.4
<b>Neonatal medical characteristics</b>						
Oxygen >28 d and CLD	10 (269)	13 (178)	18 (105)	23 (43)	25 (63)	13 (658)
Persistently unstable	13 (352)	10 (140)	18 (108)	15 (28)	17 (43)	13 (671)
Seizures	4 (95)	4 (53)	11 (63)	11 (21)	7 (18)	5 (250)
Intracranial hemorrhage	7 (185)	7 (98)	12 (73)	13 (24)	14 (34)	8 (414)
Other neurologic abnormality	22 (585)	18 (251)	30 (177)	31 (57)	28 (71)	22 (1141)
<b>Maternal/family characteristics</b>						
Maternal non-white minority status	37 (697)	41 (414)	38 (169)	39 (48)	34 (63)	38 (1391)
Non-English-speaking mother	26 (641)	31 (381)	38 (202)	40 (63)	35 (78)	30 (1365)
<High school degree maternal education	20 (353)	23 (166)	29 (103)	35 (29)	36 (49)	23 (700)
Public health insurance	48 (1278)	55 (779)	58 (342)	57 (106)	66 (166)	52 (2671)

Data are presented as % (number) or mean ± SD.

**TABLE 2** EI Status at Visit 1 and Visit 2

Status	Low Concern		High Concern		V1 No DQ/Screen (n = 250)	V1 Total (N = 5129)
	V1 DQ >70 (n = 2682)	V1 Pass Screen (n = 1424)	V1 DQ ≤70 (n = 588)	V1 Fail Screen (n = 185)		
EI before V1	399 (15)	259 (18)	187 (32)	67 (36)	47 (19)	959 (19)
No EI before V1	2283 (85)	1165 (82)	401 (68)	118 (64)	203 (81)	4170 (81)
Referred to EI	65 (3)	55 (5)	31 (8)	12 (10)	10 (5)	173 (4)
Referred to EI + OTH	62 (3)	39 (3)	78 (19)	25 (21)	43 (21)	247 (5)
Referred to OTH	313 (14)	150 (13)	156 (39)	39 (33)	28 (14)	686 (16)
Not referred to EI/OTH	1843 (81)	921 (79)	136 (34)	42 (36)	122 (60)	3064 (73)
	V2 DQ >70 (n = 978)	V2 Pass Screen (n = 408)	V2 DQ ≤70 (n = 191)	V2 Fail Screen (n = 78)	V2 No DQ/Screen (n = 82)	V2 Total (n = 1737)
EI before V2	210 (22)	64 (16)	108 (57)	43 (55)	24 (29)	449 (26)
No EI before V2	768 (79)	344 (84)	83 (45)	35 (45)	58 (71)	1288 (74)
Referred to EI	9 (1)	14 (4)	1 (1)	5 (14)	1 (2)	30 (2)
Referred to EI + OTH	14 (2)	5 (2)	17 (21)	11 (31)	3 (5)	50 (4)
Referred to OTH	104 (14)	46 (13)	34 (41)	7 (20)	5 (9)	196 (15)
Not referred to EI/OTH	641 (84)	279 (81)	31 (37)	12 (34)	49 (85)	1012 (79)

Data are presented as number (%).OTH, other therapies; V1, visit 1; V2, visit 2.

to other therapies, 3% to both EI and other therapies, and 80% to neither. In contrast, among infants with high concerns, 33% were already receiving EI by visit 1. At the conclusion of the visit, an additional 8% were referred to EI, 38% to other therapies, 20% to both EI and other therapies, and 34% to neither. Visit 2 showed a similar pattern of distribution. The difference in referral rates between children who failed a screener and children with a DQ ≤70 was not statistically different.

### Referrals to Ophthalmology and Pulmonology

Among the 347 infants at visit 1 with vision impairment, 290 (84%) were referred to ophthalmology. Among the 175 infants on home oxygen at visit 1, a total of 140 (80%) were referred to pulmonology. These proportions did not differ significantly from the hypothesized value of an 80% referral rate. In contrast, the proportion of referrals to EI or other therapies among high-concern infants was significantly lower ( $\chi^2 = 66.3$ ;  $df = 1$ ;  $P < .001$ ). This trend was consistent at visit 2.

### Likelihood of Referral to Services

By visit 1, a total of 367 (9%) of the 4170 EI-naïve infants were referred to EI. The results of the bivariate regression analyses are shown in Table 3. After adjusting

for various child, neonatal medical, and maternal/family variables, high-concern status seemed to be the major predictor of referral to EI or other therapies. CLD during the neonatal period and Medi-Cal insurance were also consistent independent contributors to the likelihood of referral to EI or other therapies. In contrast, older age of assessment was associated with a decreased likelihood of referral to EI but an increased likelihood of referral to other therapies.

### DISCUSSION

Many high-risk infants with a DQ ≤70 or failed developmental screen at NFU

were not referred to EI. We expected higher rates of referrals at visit 2 with the rationale that providers would be less inclined to take a “wait-and-see” approach in referring developmentally delayed children >12 months of age. The proportion of nonreferrals to EI, however, was consistent with the proportion at visit 1. We were reassured that an additional 20% to 40% of infants in the high-concern group were referred to other therapies at both visits, but it is alarming that 34% to 37% received neither referrals to EI nor to other therapies.

The failure of eligible children to use EI has been well reported.<sup>17–20</sup> In one

**TABLE 3** Bivariate Regression for Factors Associated With Referral to Services Among Infants With No Previous EI at Visit 1

Factor	Model A, Referral to EI		Model B, Referral to Other Therapies	
	OR	95% CI	OR	95% CI
Female gender	0.952	0.743–1.221	1.045	0.872–1.252
Age of assessment	0.842 <sup>a</sup>	0.787 <sup>a</sup> –0.902 <sup>a</sup>	1.093 <sup>a</sup>	1.049 <sup>a</sup> –1.139 <sup>a</sup>
Birth weight, g				
<1000	1.281	0.874–1.875	1.67	1.23–2.267
1000–1499	0.685	0.479–0.981	1.268	0.967–1.663
1500–2499	0.506	0.34–0.753	0.786	0.54–1.059
≥2500	—	—	—	—
High concern	5.21 <sup>a</sup>	3.992 <sup>a</sup> –6.792 <sup>a</sup>	2.014 <sup>a</sup>	1.593 <sup>a</sup> –2.547 <sup>a</sup>
Oxygen >28 d, CLD	1.736 <sup>a</sup>	1.204 <sup>a</sup> –2.503 <sup>a</sup>	1.579 <sup>a</sup>	1.186 <sup>a</sup> –2.102 <sup>a</sup>
Seizures	1.656	0.985–2.784	1.279	0.805–2.033
Persistently unstable	0.758	0.515–1.115	0.996	0.753–1.319
Non-English speaking	0.901	0.687–1.181	1.265	1.037–1.542
Public health insurance	1.85 <sup>a</sup>	1.42 <sup>a</sup> –2.409 <sup>a</sup>	1.286 <sup>a</sup>	1.064 <sup>a</sup> –1.554 <sup>a</sup>

CI, confidence interval; OR, odds ratio.

<sup>a</sup> Values are statistically significant for both models.



population-based study of nationally represented children, only 10% of developmentally delayed children received EI at 24 months.<sup>19</sup> The current study is the first, to our knowledge, to look at EI referral rates among a population of high-risk infants after NICU discharge. Although the referral rates of our population cohort are higher than what has been reported in the general population, these infants were evaluated at clinics specializing in developmental assessment and care coordination of children with or at high risk for special health care needs. Our findings indicate that NFU programs are missing opportunities to refer potentially eligible developmentally delayed infants to EI. This failure raises an important quality improvement opportunity in the support and management of infants after NICU hospitalization.

More than 30% of infants in the high-concern group had birth weights >2500 g. Previous studies report high rates of service use and unmet needs after NICU hospitalization; however, these studies used small sample sizes or focused on children born <32 weeks' gestational age or with birth weights <1500 g.<sup>21–24</sup> Further analysis of the data will look closely at how the >2500-g birth weight group uses services differently than their lower birth weight counterparts.

Several infants in the low-concern group (16%) were already receiving EI before visit 1. These infants may have strong advocates for parents (>50% had college-educated mothers), been made eligible for EI based on medical risk factors (eg, birth weight <1500 g), or presented with significant delays before NFU but showed rapid improvement with EI. Future analysis will look at factors associated with the referral and receipt of EI, especially among children who do not meet eligibility criteria for EI. Several sociodemographic factors have been implicated as predictors for low EI use, such as non-English-speaking

mothers and poverty.<sup>17,25,26</sup> Wang et al<sup>20</sup> reported higher EI enrollment among children with birth weights <1000 g who were receiving public insurance. Results from our regression analyses also showed that EI referrals were positively associated with public insurance. This finding suggests that privately insured children are not referred to state or private programs at the same rate as publically insured children. To our knowledge, this is the first study to compare referral rates between Part C and non-Part C services. Infants with CLD demonstrated a high likelihood of EI referral. CLD is a strong predictor of neurodevelopment impairment.<sup>27</sup> Interestingly, high-concern status was predictive of EI referral even though a sizable proportion of developmentally delayed children were not referred. The regression models explained <20% of the variance, indicating that other factors, perhaps not captured by this data-reporting system, are important predictors of EI referrals.

Not knowing how many children referred to EI at NFU were actually enrolled in EI is a limitation of the current study. Longitudinal analysis, however, will allow us to estimate EI enrollment and factors associated with lack of referral. Another limitation is absent information about whether children were referred to EI outside NFU. In the general population, primary pediatric providers play a central role in referring developmentally delayed children to EI.<sup>28</sup> Families also have the option to make referrals themselves. Some families may be declining the recommendation for referral for reasons ranging from denial of their child's delays to mistrust of state agencies. A random survey of families in the high-concern group would provide insight as to why some children were not referred or whether someone other than the NFU provider made a referral. Data abstraction errors are expected in any statewide study involving a

heterogeneous mix of centers and programs even with training workshops and accessible technical support. Knowing the extent of these errors is not feasible without investigating beyond the existing data set (eg, chart reviews). Our confidence in the quality of our data grew, however, when EI referral rates were compared with other medical services. Referrals of infants on oxygen support to pulmonology and infants with vision impairment to ophthalmology were more consistent with expectations than referrals of developmentally delayed infants to EI. These differences suggest that quality improvement or systems issues are contributing to nonreferrals of developmentally delayed infants.

NFU providers may be continuing to take a wait-and-see approach after visit 2. Previous research suggests that pediatric providers are more likely to refer children to EI if their delays are severe, if they are >24 months of age, or have an established diagnosis.<sup>29–31</sup> In one national survey, the mean time between identification of a developmental delay and EI referral was >5 months.<sup>32</sup> The consequence of waiting is a shorter period for the child to benefit from state-funded EI. Part C services are available until 36 months of age when eligibility and services then shift to the school districts and operate with an Individual Education Plan rather than Individual Family Service Plan.

Major changes to California's EI programs occurred over the course of data collection. Most significant have been massive state budget cuts to fund developmental services for children. The eligibility criteria to qualify for EI in California have changed.<sup>33,34,35</sup> The developmental delay threshold is higher, and children who are high-risk for having a developmental disability on the basis of biomedical indicators are no longer eligible. These system changes may be influencing the practice patterns of NFU providers. Consequently, providers may

be referring children to private therapies or no services at all. Qualitative methods will add valuable insight into the reasons behind why referrals are not made for high-risk infants with developmental delays. Further investigation into programmatic factors (eg, team composition, regional location) is also needed.

This article targets a specific population of children (children previously hospitalized in the NICU at-risk for developmental disorders) where there is ample research on neurodevelopmental and health outcomes but little on service outcomes. Much is to be learned about how developmental services are used by young children and their families. Although this article focused on children attending NFU programs in California, we are confident that the findings will also

be informative to pediatric providers in other states who care for high-risk infants.

The American Academy of Pediatrics has promoted developmental screening and timely referrals to early intervention for children at risk for developmental disorders. This study alerts the academy and other policy makers that subspecialty programs should also be targeted for education and training about the importance of early intervention for children.

## CONCLUSIONS

Many severely delayed high-risk infants are not being referred to EI at NFU based on these initial findings. Identifying reasons associated with lack of referrals can inform targeted interventions

(eg, education, training), substantiate policy change (eg, automatic EI referrals for all high-risk infants), and help develop new standards of care. With budgets for children's services threatened across the nation, a high priority should be made to evaluate how follow-up care is provided to this patient population. Much has been invested in their survival, but they remain at high-risk for lifelong health and neurodevelopmental impairments.

## ACKNOWLEDGMENTS

We thank Ms Erika Gray for her leadership as project manager, Ms Yuan Lin for assistance with data set preparation, and all of the NFU coordinators in California for their efforts in the abstraction and reporting of data.

## REFERENCES

- Anderson LM, Shinn C, Fullilove MT, et al; Task Force on Community Preventive Services. The effectiveness of early childhood development programs. A systematic review. *Am J Prev Med*. 2003;24(suppl 3):32–46
- Bailey DB Jr, 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
- Centers for Disease Control and Prevention. Learn the signs. Act early. Available at: [www.cdc.gov/ncbddd/actearly/](http://www.cdc.gov/ncbddd/actearly/). Accessed June 9, 2011
- Duby JC; American Academy of Pediatrics Council on Children With Disabilities. Role of the medical home in family-centered early intervention services. *Pediatrics*. 2007;120(5):1153–1158
- Bhutta AT, Cleves MA, Casey PH, Cradock MM, Anand KJ. Cognitive and behavioral outcomes of school-aged children who were born preterm: a meta-analysis. *JAMA*. 2002;288(6):728–737
- Hack M, Taylor HG, Drotar D, et al. Chronic conditions, functional limitations, and special health care needs of school-aged children born with extremely low-birth-weight in the 1990s. *JAMA*. 2005;294(3):318–325
- Marlow N, Rose AS, Rands CE, Draper ES. Neuropsychological and educational problems at school age associated with neonatal encephalopathy. *Arch Dis Child Fetal Neonatal Ed*. 2005;90(5):F380–F387
- Shillingford AJ, Glanzman MM, Ittenbach RF, Clancy RR, Gaynor JW, Wernovsky G. Inattention, hyperactivity, and school performance in a population of school-age children with complex congenital heart disease. *Pediatrics*. 2008;121(4). Available at: [www.pediatrics.org/cgi/content/full/121/4/e759](http://www.pediatrics.org/cgi/content/full/121/4/e759)
- Department of Health Care Services. High risk infant follow up. Available at: [www.dhcs.ca.gov/services/ccs/Pages/HRIF.aspx](http://www.dhcs.ca.gov/services/ccs/Pages/HRIF.aspx). Accessed June 1, 2011
- Wirtschaffter DD, Powers RJ. Organizing Regional Perinatal Quality Improvement: Global Considerations and Local Implementation. *Neoreviews*. 2004;5(2):e50–e59
- The Gesell Developmental Observation-Revised: An Overview. Available at: [www.gesellinstitute.org/GDO-R\\_Overview\\_Document.html](http://www.gesellinstitute.org/GDO-R_Overview_Document.html). Accessed March 21, 2012
- Bayley N. *Bayley Scales of Infant and Toddler Development*. 3rd ed. San Antonio, TX: Harcourt Assessment, Inc.; 2005
- Accardo PJ, Capute AJ. *The Capute Scales*. Baltimore, MD: Brookes Publishing Co; 2005
- Mullen E. *Mullen Scales of Early Learning*. Circle Pines, MN: American Guidance Service; 1995
- Bayley N. *Bayley Scales of Infant and Toddler Development Screening Test*. 3rd ed. San Antonio, TX: Harcourt Assessment, Inc.; 2005
- Aylward GP. *Bayley Infant Neurodevelopmental Screener*. 3rd ed. San Antonio, TX: Harcourt Assessment, Inc; 1995
- Clements KM, Barfield WD, Kotelchuck M, Wilber N. Maternal socio-economic and race/ethnic characteristics associated with early intervention participation. *Matern Child Health J*. 2008;12(6):708–717
- Roberts G, Howard K, Spittle AJ, Brown NC, Anderson PJ, Doyle LW. Rates of early intervention services in very preterm children with developmental disabilities at age 2 years. *J Paediatr Child Health*. 2008;44(5):276–280
- Rosenberg SA, Zhang D, Robinson CC. Prevalence of developmental delays and participation in early intervention services for young children. *Pediatrics*. 2008;121(6): Available at [www.pediatrics.org/cgi/content/full/e1503](http://www.pediatrics.org/cgi/content/full/e1503)
- Wang CJ, Elliott MN, Rogowski J, Lim N, Ratner JA, Schuster MA. Factors influencing the enrollment of eligible extremely-low-birth-weight children in the part C early intervention program. *Acad Pediatr*. 2009;9(4):283–287
- Hintz SR, Kendrick DE, Vohr BR, Poole WK, Higgins RD; National Institute of Child Health and Human Development (NICHD) Neonatal

- Research Network. Community supports after surviving extremely low-birth-weight, extremely preterm birth: special outpatient services in early childhood. *Arch Pediatr Adolesc Med.* 2008;162(8):748–755
22. Leijon I, Finnström O, Sydsjö G, Wadsby M. Use of healthcare resources, family function, and socioeconomic support during the first four years after preterm birth. *Arch Dis Child Fetal Neonatal Ed.* 2003;88(5):F415–F420
  23. van Zeben-van der Aa DM, Verloove-Vanhorick SP, Brand R, Ruys JH. The use of health services in the first 2 years of life in a nationwide cohort of very preterm and/or very low birthweight infants in The Netherlands: rehospitalisation and out-patient care. *Paediatr Perinat Epidemiol.* 1991;5(1):11–26
  24. Porter KL, Rudolph C, Williams ML, Petonito G. Patterns of medical services utilization by infants discharged from a neonatal intensive care unit. *Med Care.* 1986;24(1):14–23
  25. Barfield WD, Clements KM, Lee KG, Kotelchuck M, Wilber N, 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
  26. Feinberg E, Silverstein M, Donahue S, Bliss R. The impact of race on participation in Part C early intervention services. *J Dev Behav Pediatr.* 2011;32(4):284–291
  27. Anderson PJ, Doyle LW. Neurodevelopmental outcome of bronchopulmonary dysplasia. *Semin Perinatol.* 2006;30(4):227–232
  28. Hauser-Cram PW. Early intervention services. In: Carey WB, Crocker AC, Elias ER, Feldman HM, Coleman WL eds. *Developmental-Behavioral Pediatrics.* 4th ed. Philadelphia, PA: Elsevier; 2009:922–933
  29. Bailey DB, Skinner D, Hatton D, Roberts J. Family experiences and factors associated with the diagnosis of fragile X syndrome. *J Dev Behav Pediatr.* 2000;21(5):315–321
  30. Silverstein M, Sand N, Glascoe FP, Gupta VB, Tonniqes TP, O'Connor KG. Pediatrician practices regarding referral to early intervention services: is an established diagnosis important? *Ambul Pediatr.* 2006;6(2):105–109
  31. Epps S, Kroeker R. Physician early intervention referral as a function of child age and level of developmental delay. *Ment Retard.* 1995;33(2):104–110
  32. Bailey DB Jr, Hebbeler K, Scarborough A, Spiker D, Mallik S. First experiences with early intervention: a national perspective. *Pediatrics.* 2004;113(4):887–896
  33. York A, Riccardi N. Deeper cuts to state budget expected. *Los Angeles Times.* November 17, 2011. Available at: <http://articles.latimes.com/2011/nov/17/local/la-me-state-budget-20111117>. Accessed March 22, 2012
  34. Buchanan W. California leaders say time for cuts may be ending. *San Francisco Chronicle.* December 18, 2011. Available at: [www.sfgate.com/cgi-bin/article.cgi?f=/c/a/2011/12/17/BADB1MD11H.DTL&ao=all](http://www.sfgate.com/cgi-bin/article.cgi?f=/c/a/2011/12/17/BADB1MD11H.DTL&ao=all). Accessed March 22, 2012
  35. State of California Department of Developmental Services. Budget information. Available at: [www.dds.ca.gov/Budget/Home.cfm](http://www.dds.ca.gov/Budget/Home.cfm). Accessed March 21, 2012

**INTERVAL TRAINING:** For years, physicians and researchers have tried to determine how much exercise a day or week is necessary to ensure good health in adults. According to an article in *The New York Times* (Blogs: February 15, 2012), *The American Heart Association* and other organizations recommend that adults engage in 30 minutes or more of continuous, moderate-intensity exercise five times a week. The problem with the recommendations is that most adults who do not exercise say they don't because they do not have enough time. Now some researchers are looking at exercise from a somewhat different perspective. Instead of thinking about how much time needs to be dedicated to exercise, they are concentrating on how little time needs to be dedicated to exercise to maintain health. The secret may lie in interval training. According to the article, elite athletes have always incorporated interval training, short periods of maximum exertion followed by short periods of rest, into their exercise schedules to build speed and endurance. Research has shown that short, exclusively high intensity workouts have the same benefit as longer, lower intensity, continuous exercise programs. The benefits of interval training extend to non-elite athletes. Sedentary but healthy middle aged adults alongside a group of adults with cardiovascular disease participated in a modified interval program. The modified program consisted of 10 cycles of one minute of exercise at 90 percent of a person's maximum heart rate followed by one minute of easy recovery. Despite committing only 20 minutes a day to exercise, within a few weeks both the healthy sedentary adults and those with cardiovascular disease demonstrated improvement in their health and fitness. The adults with cardiovascular disease had no complications and reported they liked the shorter workouts more than the usually recommended longer but low intensity workouts. In other studies, modified high intensity workouts have been shown to improve insulin sensitivity and blood sugar regulation. While longer duration exercise has clearly shown to be beneficial, for those with a limited amount of time, high intensity brief duration exercise may be the way to go.

Noted by WVR, MD



## Missed Opportunities in the Referral of High-Risk Infants to Early Intervention

Brian G. Tang, Heidi M. Feldman, Lynne C. Huffman, Kimie J. Kagawa and Jeffrey B. Gould

*Pediatrics* 2012;129;1027

DOI: 10.1542/peds.2011-2720 originally published online May 21, 2012;

<b>Updated Information &amp; Services</b>	including high resolution figures, can be found at: <a href="http://pediatrics.aappublications.org/content/129/6/1027">http://pediatrics.aappublications.org/content/129/6/1027</a>
<b>References</b>	This article cites 20 articles, 5 of which you can access for free at: <a href="http://pediatrics.aappublications.org/content/129/6/1027#BIBL">http://pediatrics.aappublications.org/content/129/6/1027#BIBL</a>
<b>Subspecialty Collections</b>	This article, along with others on similar topics, appears in the following collection(s): <b>Fetus/Newborn Infant</b> <a href="http://www.aappublications.org/cgi/collection/fetus:newborn_infant_sub">http://www.aappublications.org/cgi/collection/fetus:newborn_infant_sub</a> <b>Neonatology</b> <a href="http://www.aappublications.org/cgi/collection/neonatology_sub">http://www.aappublications.org/cgi/collection/neonatology_sub</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.aappublications.org/site/misc/Permissions.xhtml">http://www.aappublications.org/site/misc/Permissions.xhtml</a>
<b>Reprints</b>	Information about ordering reprints can be found online: <a href="http://www.aappublications.org/site/misc/reprints.xhtml">http://www.aappublications.org/site/misc/reprints.xhtml</a>

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



# PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

## **Missed Opportunities in the Referral of High-Risk Infants to Early Intervention**

Brian G. Tang, Heidi M. Feldman, Lynne C. Huffman, Kimie J. Kagawa and Jeffrey B. Gould

*Pediatrics* 2012;129;1027

DOI: 10.1542/peds.2011-2720 originally published online May 21, 2012;

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

<http://pediatrics.aappublications.org/content/129/6/1027>

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 © 2012 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 1073-0397.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

