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# Chronic Conditions, Functional Limitations, and Special Health Care Needs of School-aged Children Born With Extremely Low-Birth-Weight in the 1990s

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**A**DVANCES IN PERINATAL CARE in the 1990s, which included surfactant therapy and increased use of antenatal steroids, resulted in dramatic increases in the survival of extremely low-birth-weight (ELBW, <1000 g) infants.<sup>1</sup> This has been accompanied by an increase in the rates of neonatal complications and early childhood neurodevelopmental problems.<sup>1-4</sup> However, there is little information on how these children function at school age when neurological, cognitive, and health status has to a large extent stabilized. With the exception of an abstract from Sweden,<sup>5</sup> current information on the school-age outcomes of ELBW children is restricted to neurobehavioral and developmental disability.<sup>6,7</sup>

Information on the overall functioning and special health care needs of recent surviving ELBW children is needed to plan for the medical and educational services that they will require at

**For editorial comment see p 371.**

**Context** Information on the school-age functioning and special health care needs of extremely low-birth-weight (ELBW, <1000 g) children is necessary to plan for medical and educational services.

**Objective** To examine neurosensory, developmental, and medical conditions together with the associated functional limitations and special health care needs of ELBW children compared with normal-birth-weight (NBW) term-born children (controls).

**Design, Setting, and Participants** A follow-up study at age 8 years of a cohort of 219 ELBW children born 1992 to 1995 (92% of survivors) and 176 NBW controls of similar sociodemographic status conducted in Cleveland, Ohio.

**Main Outcome Measures** Parent Questionnaire for Identifying Children with Chronic Conditions of 12 months or more and categorization of specific medical diagnoses and developmental disabilities based on examination of the children.

**Results** In logistic regression analyses adjusting for sociodemographic status and sex, ELBW children had significantly more chronic conditions than NBW controls, including functional limitations (64% vs 20%, respectively; odds ratio [OR], 8.1; 95% confidence interval [CI], 5.0-13.1;  $P < .001$ ), compensatory dependency needs (48% vs 23%, respectively; OR, 3.0; 95% CI, 1.9-4.7;  $P < .001$ ), and services above those routinely required by children (65% vs 27%, respectively; OR, 5.4; 95% CI, 3.4-8.5;  $P < .001$ ). These differences remained significant when the 36 ELBW children with neurosensory impairments were excluded. Specific diagnoses and disabilities for ELBW vs NBW children included cerebral palsy (14% vs 0%, respectively;  $P < .001$ ), asthma (21% vs 9%; OR, 3.0; 95% CI, 1.6-5.6;  $P = .001$ ), vision of less than 20/200 (10% vs 3%; OR, 3.1; 95% CI, 1.2-7.8;  $P = .02$ ), low IQ of less than 85 (38% vs 14%; OR, 4.5; 95% CI, 2.7-7.7;  $P < .001$ ), limited academic skills (37% vs 15%; OR, 4.2; 95% CI, 2.5-7.3;  $P < .001$ ), poor motor skills (47% vs 10%; OR, 7.8; 95% CI, 4.5-13.6;  $P < .001$ ), and poor adaptive functioning (69% vs 34%; OR, 6.5; 95% CI, 4.0-10.6;  $P < .001$ ).

**Conclusion** The ELBW survivors in school at age 8 years who were born in the 1990s have considerable long-term health and educational needs.

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school age. We therefore sought to undertake a comprehensive examination of health outcomes at age 8 years in a cohort of ELBW infants born 1992 through 1995. Outcomes included

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functional limitations and special health care needs together with the more traditional measures of neurological and developmental status.

## METHODS

### ELBW Cohort

The study group included survivors of the cohort of 344 ELBW children admitted to the neonatal intensive care unit at Rainbow Babies and Children's Hospital, Cleveland, Ohio, during 1992 through 1995. Their outcomes at 20 months corrected age have been previously reported.<sup>2</sup> Thirteen children (10 with major malformations, 2 with AIDS, and 1 with tuberous sclerosis) were excluded, as their poor health or development may be due to their primary disease rather than preterm birth or ELBW. Of the remaining 331 children, 238 (72%) survived to age 8 years, of whom 219 (92%) were followed up. Of the 19 children not examined at 8 years, 8 parents refused to participate, 4 lived out of state, and 7 were lost to follow-up. The study children did not differ significantly from these 19 children in sociodemographic factors, birth data, or neonatal complications.

### Comparison Group

A normal-birth-weight (NBW) child born at term gestation (>36 weeks) by parent report was recruited at age 8 years from the same school as the ELBW child by randomly selecting a NBW child from a list of children in the school who were within 3 months of age and of the same race and sex as the ELBW child. The Individual with Disabilities Education Act mandates inclusion of all children in regular schools. Of the 219 ELBW children observed at age 8 years, matches were recruited for 176 children (80%). Reasons for not finding matches include refusal of the school principal to participate (18 children), inability to match (6 children, including 1 child who was home-schooled), and repeated failure to appear for scheduled appointments (19 children). One child with neurofibromatosis with cerebral involvement was excluded.

The 43 ELBW children who could not be matched compared with those with matches had higher rates of cerebral palsy (12 [28%] vs 19 [11%],  $P=.007$ ). The children's mothers were more often white (28 [65%] vs 57 [32%],  $P<.001$ ) and fewer had less than a high school education (1 [2%] vs 25 [14%],  $P=.03$ ).

### 8-Year Study Protocol

**Parent Questionnaires.** Questionnaires were administered to the parent or primary caregiver, usually the mother, and included sociodemographic information, the Vineland Adaptive Behavior Scales of social functioning,<sup>8</sup> and the Questionnaire for Identifying Children with Chronic Conditions (QUICCC).<sup>9</sup> Race/ethnicity was considered as a social construct and was self-identified from the list of racial/ethnic categories used for federal reporting.

The QUICCC incorporates the consequences of chronic health conditions lasting 12 months or more. It has 39 question sequences divided into 3 domains: functional limitations, which has 16 items concerning physical, cognitive, emotional, or social development; dependence on compensatory aids, which has 12 items, including medications, special diet, assistive devices, and personal assistance; and need for services above those routinely required by children, which has 11 items, including medical, psychological, or educational services, and special treatments and accommodations at home or school. The interviewer asks the parent if his/her child experiences any of the 39 specific health-related consequences of chronic conditions. If the parent answers "yes," he/she is then asked 2 follow-up questions regarding the presence and duration of the condition.

To qualify as having a chronic condition, the child must have at least 1 of the 39 consequences of a chronic condition, and each must be attributable to a medical, behavioral, or other condition lasting 12 months or more.<sup>10</sup> The QUICCC has good test-retest reliability and validity.<sup>9</sup> Following administration of the QUICCC, the research as-

sistant asked the parent to further describe the reported conditions and therapies provided.

**Child Assessment.** The child underwent a complete physical and neurological examination, performed by 1 of 2 pediatricians. Hearing was measured with pure-tone audiometry screening. Deafness was defined as the need for hearing aids. Mild hearing loss was defined as unilateral or bilateral hearing loss of more than 25 dB in at least 2 frequencies. Visual acuity was tested with Snellen's letters. Psychometric testing was performed by 1 of 3 trained research assistants who were blinded to whether the child was ELBW or NBW. The Kaufman Assessment Battery for Children was used as a measure of cognitive function<sup>11</sup> and includes 4 subtests: hand movements, triangles, word order, and matrix analogies. These form a mental processing composite score that has proved sensitive to the consequences of prematurity.<sup>7,12</sup>

Academic achievement was measured with the skills cluster of the Woodcock-Johnson Tests of Achievement III that included the letter/word identification, dictation, and applied problems subtests.<sup>13</sup> Motor skills were measured with the Short Form of the Bruininks-Oseretsky Test of Motor Proficiency.<sup>14</sup> All tests were scored according to the child's postnatal age. Impairments were defined in terms of standard scores on the psychometric measures that were either 1 or 2 SDs below the normative mean, corresponding to mild and severe impairments, respectively. One blind child was not tested and a score of 40 (3 SDs below the mean) was assigned to 9 additional children who were untestable (7 who had cerebral palsy and 2 with severe retardation/autistic-type behavior).

The study protocol was approved by the institutional review board of University Hospitals of Cleveland, Ohio, and written informed consent was obtained from parents.

### Statistical Analysis

Univariate comparisons between the ELBW and NBW groups were made us-

**Table 1.** Maternal Demographic Risk Factors and Perinatal Data

	Extremely Low-Birth-Weight Children (n = 219)	Normal-Birth-Weight Children (n = 176)
Maternal demographic data*		
Age, mean (SD), y†	38 (9)	35 (8)
Married, No. (%)	114 (52)	87 (49)
Education, No. (%)		
<High school	26 (12)	22 (13)
High school	63 (29)	44 (25)
>High school	130 (59)	110 (63)
Race, No. (%)		
White‡	85 (39)	58 (33)
Black	134 (61)	118 (67)
Percentage of families below the poverty level, mean (SD)§	18 (16)	20 (17)
Family income per US \$1000, mean (SD)§	39.9 (20)	36.8 (21)
Perinatal data		
Birth weight, mean (SD), g	810 (124)	3300 (513)
Gestational age, mean (SD), wk	26.4 (2)	≥37
Female sex, No. (%)	130 (59)	111 (63)
Multiple birth, No. (%)	39 (18)	0

\*Unless otherwise stated, refers to the primary caregiver, which was the biological or adoptive mother for 195 children (89%) in the extremely low-birth-weight group and 157 children (89%) in the normal-birth-weight group.  
†Biological and adoptive mothers only.  
‡Includes the mothers of 2 Asian extremely low-birth-weight children and 2 Asian normal-birth-weight children.  
§Mean percentage of families below the poverty level and mean of median family income per US \$1000, according to the 2000 Census tract neighborhood in which the families lived.

ing *t* tests for continuous variables.  $\chi^2$  Test or logistic regression was used to examine group differences in dichotomous outcomes. Because of known effects of sociodemographic status and sex on outcomes, we controlled for these factors in all analyses. As a measure of socioeconomic status, we formed a composite of the sample *z* scores of maternal education and median family income, according to the 2000 Census tract of the family's neighborhood. Preliminary analyses indicated that these 2 factors, although correlated, were independently associated with outcomes and that other factors, including marital status and neighborhood poverty levels, did not add to their validity. In separate analyses, we compared the outcomes of the ELBW and NBW children who were free of neurosensory impairments. We also examined the outcomes of singleton births after excluding multiple births. SPSS version 12.1 (SPSS Inc, Chicago, Ill) was used for all analyses and  $P < .05$  was considered statistically significant.

## RESULTS

### Demographic and Birth Data

The ELBW and NBW children did not differ significantly with regard to their mother's age, marital status, education, race, median family income, or mean percentage of families living below the poverty level of the neighborhood in which the family resided (TABLE 1). Twenty ELBW children (9%) had been adopted vs 4 controls (2%) ( $P = .005$ ). The ELBW children had a mean (SD) birth weight of 810 (124) g and mean (SD) gestational age of 26.4 (2) weeks. Seventy-three (33%) of their mothers received antenatal steroid therapy. Postnatal steroid therapy was administered to 129 children (59%) to treat or prevent chronic lung disease and 93 (43%) were oxygen dependent at 36-weeks corrected age. Fifty-one children (23%) had a severely abnormal cerebral ultrasound with either grade III or IV periventricular hemorrhage, periventricular leucomalacia, and/or ventricular dilatation at discharge. Eighteen children (8%)

had severe (stage >3) retinopathy of prematurity.

The ELBW children were studied at a significantly younger postnatal age than the NBW children (mean [SD], 8.7 [0.6] vs 9.2 [0.8] years;  $P < .001$ ), because NBW children were only recruited after the ELBW child's school had been verified so that matching could occur. The psychometric tests were, however, standardized for age and functioning, and special health care needs would not be expected to change in relation to this small age difference.

### Rates of Specific Diagnoses and Disabilities

Thirty-six ELBW children (16%) had neurosensory impairments, including cerebral palsy, deafness, and blindness, compared with none of the NBW children (TABLE 2). There were significant differences in mild hearing loss and uncorrected vision of less than 20/200, even when comparisons were restricted to neurosensory intact ELBW children. Asthma requiring therapy was reported in 21% ELBW vs 9% NBW children. Twenty-one ELBW children (10%) had both asthma and cerebral palsy. Rates of other medical conditions, including allergic disorders (13% in both), did not differ between groups.

The mean (SD) mental processing composite score was 87.7 (18) for the total group of ELBW children and 91.4 (15) for the neurosensory intact subgroup compared with 99.8 (15) for the NBW children ( $P < .001$  for both comparisons). The ELBW children differed significantly from the NBW group in rates of suboptimal intelligence, academic achievement, motor skills, and adaptive functioning. These differences remained significant after excluding ELBW children who had major neurosensory deficits. Sixty-three ELBW (29%) and 14 NBW (8%) children were receiving supplemental security income for identified disabilities ( $P < .001$ ).

### Consequences of Chronic Conditions

**Functional Limitations.** The ELBW children had significantly higher rates

of functional limitations compared with the NBW group (TABLE 3). These limitations included delay in growth or development, mental or emotional delay, need to reduce or inability to participate in physical activities, difficulty seeing, hearing, speaking, or communicating, and inability to play or socialize with others. With the exception of limitations in physical activities, these differences remained significant when ELBW children with neurosensory impairments were excluded. Severe functional limitations, such as difficulty with feeding, dressing, washing, and using the toilet, were mainly restricted to children with neurosensory impairments. Overall, 64% of the ELBW children, 57% of the neurosensory intact subgroup, and 20% of the NBW children had 1 or more functional limitations. For those chil-

dren with functional limitations, the mean number per child was 3.8 (SD, 3.5; range, 1-16) for the total ELBW group; 2.6 (SD, 2.0; range, 1-12) for the neurosensory intact subgroup; and 1.8 (SD, 1.1; range, 1-5) for the NBW group ( $P = .001$  for total ELBW vs NBW and  $P = .02$  for intact ELBW vs NBW).

A variety of symptoms or diagnoses contributed to the functional disabilities. For example, 41 parents reported that their ELBW child needed to reduce time and effort in activities. Fourteen reported asthma as the reason, 8 reported cerebral palsy, 10 reported that the child tired easily, 2 reported poor coordination, 3 reported attention-deficit/hyperactivity disorder, and 4 reported other conditions, including epilepsy, cold sensitivity, deformed fingers, and overweight.

**Compensatory Dependence Needs.** Significantly more ELBW than NBW children took a regular prescribed medication (TABLE 4). The need for help or special equipment for walking, feeding, dressing, washing, and toileting was restricted mainly to ELBW children who were neurosensory impaired. Overall, 48% of ELBW children, 40% of the neurosensory intact ELBW subgroup, and 23% of NBW children had 1 or more compensatory dependent needs. For those children with compensatory needs, the mean number in these groups was 2.1 (SD, 2.0; range, 1- 9); 1.4 (SD, 1.0; range, 1-7); and 1.2 (SD, 0.5; range, 1-3) ( $P < .001$  for total ELBW vs NBW and  $P = .33$  for intact ELBW vs NBW).

Medication usage, the most common compensatory need, was reported for 21% of ELBW children with

**Table 2.** Rates of Medical Developmental Disorders\*

	No./Total (%) of Children			Total Population of ELBW vs NBW		Neurosensory Intact ELBW vs NBW	
	ELBW		NBW (n = 176)	Odds Ratio (95% CI)	P Value†	Odds Ratio (95% CI)	P Value†
	Total Population (n = 219)	Neurosensory Intact (n = 183)					
Cerebral palsy	31/219 (14)‡	0	0				
Visual disability							
Bilateral blindness	1/219 (0.5)‡	0	0				
Vision <20/200§	20/219 (10)	15/183 (8)	6/176 (3)	3.1 (1.2-7.8)	.02	2.6 (1.0-6.9)	.053
Hearing disability							
Deafness, requiring hearing aids	4/219 (2)‡	0	0				
Mild hearing loss	25/219 (13)	20/183 (11)	9/176 (5)	2.7 (1.2-6.0)	.02	2.5 (1.1-5.7)	.03
Asthma¶	47/219 (21)	40/183 (22)	15/176 (9)	3.0 (1.6-5.6)	.001	3.1 (1.6-5.9)	.001
Low IQ by MPC score#							
<70	32/218 (15)	13/183 (7)	3/176 (2)	10.0 (3.0-33.2)	<.001	4.7 (1.3-17.1)	.02
<85	84/219 (38)	57/183 (31)	25/176 (14)	4.5 (2.7-7.7)	<.001	3.4 (1.9-6.0)	<.001
Limited academic skills#							
<70	39/215 (18)	22/183 (12)	7/176 (4)	6.1 (2.6-14.2)	<.001	3.9 (1.6-9.8)	.003
<85	79/215 (37)	58/183 (32)	27/176 (15)	4.2 (2.5-7.3)	<.001	3.3 (1.9-5.9)	<.001
Poor motor skills**							
<30	58/214 (27)	27/179 (15)	10/173 (6)	6.2 (3.1-12.6)	<.001	3.0 (1.4-6.4)	.005
<40	101/214 (47)	68/183 (37)	18/176 (10)	7.8 (4.5-13.6)	<.001	5.4 (3.0-9.5)	<.001
Poor adaptive functioning††							
<70	96/219 (44)	74/183 (40)	22/176 (13)	9.7 (5.2-17.9)	<.001	8.3 (4.4-15.7)	<.001
<85	150/219 (69)	122/183 (67)	59/176 (34)	6.5 (4.0-10.6)	<.001	5.8 (3.5-9.7)	<.001

Abbreviations: CI, confidence interval; ELBW, extremely low birth weight; MPC, mental processing composite; NBW, normal birth weight.

\*See "Methods" section for description of IQ, academic skills, motor skills, and adaptive functioning tests. The first cutoff for these tests (<70 or <30) represents 2-SD cutoff severe impairment and the second cutoff (<85 or <40) represents 1-SD cutoff and mild impairment. Odds ratios were derived from logistic regression and adjusted for socioeconomic status (average z score of maternal education and median income of Census tract of residence), race, and sex.

†Comparing proportions to the NBW group with Fisher exact test, or testing that the odds ratio is unity, whichever is applicable.

‡By Fisher exact test for total population vs NBW: cerebral palsy,  $P < .001$ ; bilateral blindness,  $P > .99$ ; and deafness, requiring hearing aids,  $P = .13$ .

§Rates of visual impairment in at least 1 eye, without glasses. Based on 203 ELBW children due to poor cooperation or lack of understanding.

||Excluding those with hearing aids. Based on 198 ELBW and 176 NBW children who had a hearing test. Denotes unilateral or bilateral hearing loss of more than 25 dB in at least 2 frequencies.

¶Data are for children who were taking asthma medication during the past 12 months.

#In 10 cases in which a child was not testable, a standard score of 40 (SD,  $\leq 3$ ) was assigned.

\*\*In 25 cases in which a child was not testable because of cerebral palsy, a score of 23 (SD,  $\leq 3$ ) was assigned.

††As reported by parents.

asthma vs 6% of NBW children with asthma; 7% vs 3% of those with attention-deficit/hyperactivity disorder; 7% vs 9% of those with allergic conditions; 3% vs 1% of those with constipation; and 2% vs 1% of those with epilepsy. Fifteen ELBW children with cerebral palsy received either botulinum toxin or baclofen medication, 14

**Table 3.** Functional Limitations Associated With a Chronic Condition of 12 Months or More

	No./Total (%) of Children			Total Population of ELBW vs NBW		Neurosensory Intact ELBW vs NBW	
	ELBW		NBW (n = 176)	Odds Ratio (95% CI)*	P Value	Odds Ratio (95% CI)*	P Value
	Total Population (n = 219)	Neurosensory Intact (n = 183)					
Physical delay	38 (17)	21 (12)	2 (1)	18.8 (4.5-79.5)	<.001	11.7 (2.7-51.1)	.001
Mental or emotional delay	57 (26)	41 (22)	9 (5)	7.0 (3.3-14.8)	<.001	5.8 (2.7-12.4)	<.001
Restricted in kind of activity	27 (12)	7 (4)	1 (1)	25.1 (3.4-187.6)	.002	7.2 (0.9-59.2)	.07
Reduced time/effort in activity	41 (19)	25 (14)	6 (3)	6.6 (2.7-16.0)	<.001	4.6 (1.8-11.5)	.001
Unable to participate in sports or other physical activities	20 (9)	3 (2)	1 (1)	17.6 (2.3-132.9)	.005	2.9 (0.3-27.8)	.37
Difficulty eating	13 (6)†	5 (3)	0				
Blind or difficulty seeing (uncorrected by glasses)	17 (8)	11 (6)	1 (1)	14.9 (2.0-114.1)	.009	12.0 (1.5-95.4)	.02
Deaf or difficulty hearing	19 (9)	10 (6)	2 (1)	8.2 (1.9-35.8)	.005	5.0 (1.1-23.2)	.04
Trouble understanding simple instructions	47 (22)	39 (21)	11 (6)	4.8 (2.4-9.9)	<.001	8 (2.3-9.9)	<.001
Unable to walk without help	17 (8)‡	0	0				
Trouble speaking/communicating	48 (22)	34 (19)	13 (7)	3.8 (1.9-7.3)	<.001	3.2 (1.6-6.4)	.001
Unable to play or socialize with others	16 (7)	8 (4)	1 (1)	13.9 (1.8-106.0)	.01	8.1 (1.0-66.1)	.05
Difficulty feeding him/herself	13 (6)†	1 (0.5)	0				
Difficulty dressing	28 (13)‡	7 (4)§	0				
Difficulty washing/bathing	20 (9)‡	4 (2)	0				
Difficulty using the toilet	22 (10)‡	4 (2)	0				
Any functional limitation	140 (64)	105 (57)	36 (20)	8.1 (5.0-13.1)	<.001	6.2 (3.7-10.1)	<.001

Abbreviations: CI, confidence interval; ELBW, extremely low birth weight; NBW, normal birth weight.  
 \*Derived from logistic regression adjusting for socioeconomic status (z score maternal education and median family income), race, and sex.  
 †P<.01 by Fisher exact test for total population vs NBW.  
 ‡P<.001 by Fisher exact test for total population vs NBW.  
 §P<.05 by Fisher exact test for neurosensory intact vs NBW.

**Table 4.** Compensatory Dependence Needs for a Chronic Condition of 12 Months or More

	No./Total (%) of Children			Total Population of ELBW vs NBW		Neurosensory Intact ELBW vs NBW	
	ELBW		NBW (n = 176)	Odds Ratio (95% CI)*	P Value	Odds Ratio (95% CI)*	P Value
	Total Population (n = 219)	Neurosensory Intact (n = 183)					
Takes regular prescribed medication	82 (37)	65 (36)	34 (19)	2.5 (1.6-4.0)	<.001	2.3 (1.4-3.7)	.001
Life-threatening allergic reactions	8 (4)	6 (3)	7 (4)	0.9 (0.3-2.5)	.79	0.8 (0.3-2.4)	.67
Follows physician-ordered special diet	13 (6)	8 (4)	9 (5)	1.1 (0.5-2.7)	.77	0.8 (0.3-2.2)	.71
Needs special equipment to see (other than glasses)	2 (1)†	1 (0.5)	0				
Needs special equipment to hear or communicate‡	9 (4)§	1 (0.5)	0				
Needs special equipment to walk	16 (7)	0	0				
Needs help or equipment to feed him/herself	7 (3)§	2 (1)	0				
Needs help or equipment to dress	25 (11)	6 (3)¶	0				
Needs help or equipment to wash	21 (10)	4 (2)	0				
Needs help or equipment for toileting	20 (9)	4 (2)	0				
Needs special equipment to eat	11 (5)§	2 (1)	0				
Any compensatory dependency need	105 (48)	73 (40)	41 (23)	3.0 (1.9-4.7)	<.001	2.2 (1.4-3.5)	.001

Abbreviations: CI, confidence interval; ELBW, extremely low birth weight; NBW, normal birth weight.  
 \*Derived from logistic regression adjusting for socioeconomic status, race, and sex.  
 †P = .50 by Fisher exact test for total population vs NBW.  
 ‡One autistic child used picture books in the neurosensory intact group.  
 §P<.01 by Fisher exact test for total population vs NBW.  
 ¶P<.001 by Fisher exact test for total population vs NBW.  
 ||P<.05 by Fisher exact test for neurosensory intact vs NBW.

required a wheelchair, 2 a walker, and 3 were tube fed.

**Services Needed Above Routine.** Children who were ELBW had a significantly greater need for services above routine than children who were NBW (TABLE 5). These services included visiting a physician regularly for a chronic condition, nursing care/medical procedures, occupational or physical therapy, special school arrangements, or an individualized education program. With the exception of nursing care/medical procedures, these differences remained significant when neurosensory abnormal children were excluded. Overall, 65% of the ELBW group, 58% of the neurosensory intact ELBW subgroup, and 27% of the NBW group received 1 or more services above routine. For those children requiring services, the mean number per child was 3.2 (SD, 1.8; range, 1-7) for the ELBW group; 2.7 (SD, 1.6; range, 1-7) for the neurosensory intact ELBW subgroup; and 2.0 (SD, 1.2; range, 1-6) for the NBW group ( $P < .001$  for total ELBW vs NBW and  $P = .007$  for intact ELBW vs NBW).

Of the ELBW children who visited a physician regularly for a chronic condition, 20% saw their pediatrician, 11% an ophthalmologist, 7% an orthopedist, 6% a neurologist, 3% a pulmonologist,

3% an audiologist, and 21% other specialists. Many children saw multiple specialists. Sixteen percent received physical therapy, 21% occupational therapy, and 22% speech therapy. Nursing care included aerosol treatments for asthma (7 children) and tube feeding or other help related to cerebral palsy (8 children). The majority of hospitalizations were for pulmonary problems or surgery for cerebral palsy.

**Rates of Conditions in Multiple Domains.** Overall, 76% of the ELBW children, 72% of the neurosensory intact subgroup, and 42% of the NBW children were identified with a chronic condition in 1 of 3 domains of the QUICCC. Thirty-eight percent of ELBW children, 28% of the neurosensory intact subgroup, and 6% of NBW children were identified in all 3 domains, and 27%, 15%, and 30%, respectively, in 2 domains.

When we compared the outcomes of singleton ELBW children with the NBW controls, after excluding multiple births, the results were similar to those of the total ELBW cohort with the exception that the difference in vision of less than 20/200 was no longer significant (20 [7%] ELBW children vs 6 [3%] NBW children,  $P = .19$ ). However, the overall rates of functional limitations, compensatory dependence, and services

above routine did not change. The results also did not change when the analyses were restricted to the 176 ELBW children who had controls.

**COMMENT**

This is the first report to our knowledge of the school-age outcomes of ELBW children born in the 1990s in the United States. Our results reveal that ELBW children have extremely high rates of chronic conditions compared with NBW children. These conditions include asthma, cerebral palsy, and visual disability, as well as poorer cognitive ability, academic achievement, motor skills, and social adaptive functioning. These differences are evident even in ELBW children who do not have major neurosensory impairments and manifest in a higher overall frequency of functional limitations and need for compensatory aids and services above those routinely required by children in general.

The studies of school-age outcomes of ELBW children born in the 1990s pertain to neurobehavioral and developmental disability but do not examine other aspects of health.<sup>6,7</sup> The study by Marlow et al<sup>7</sup> studied 6-year-old children born at less than 26 weeks' gestation in England, while the study by Anderson et al<sup>6</sup> studied 8-year-old chil-

**Table 5.** Services Needed Above Routine for a Chronic Condition of 12 Months or More

	No./Total (%) of Children			Total Population of ELBW vs NBW		Neurosensory Intact ELBW vs NBW	
	ELBW		NBW (n = 176)	Odds Ratio (95% CI)*	P Value	Odds Ratio (95% CI)*	P Value
	Total Population (n = 219)	Neurosensory Intact (n = 183)					
Visits physician or specialist on a regular basis	49 (22)	27 (15)	15 (9)	3.1 (1.6-5.7)	<.001	1.9 (1.0-3.7)	.07
Visits counselor, psychiatrist, psychologist, or social worker	21 (10)	19 (10)	14 (8)	1.2 (0.6-2.4)	.63	1.3 (0.6-2.8)	.43
Receives physical/occupational or other therapy	68 (31)	34 (19)	5 (3)	15.8 (6.2-40.7)	<.001	8.0 (3.0-21.2)	<.001
Receives nursing care/has medical procedures performed	15 (7)	7 (4)	3 (2)	4.2 (1.2-14.8)	.03	2.3 (0.6-9.0)	.24
Was hospitalized for conditions still present†	51 (23)	31 (17)	11 (6)	5.0 (2.5-10.1)	<.001	3.3 (1.6-6.9)	.001
Receives separate or special class instruction‡	59 (27)	37 (20)	11 (6)	5.9 (2.9-11.7)	<.001	4.0 (1.9-8.2)	<.001
Has special arrangements at school§	105 (48)	75 (41)	21 (12)	7.4 (4.3-12.8)	<.001	5.5 (3.2-9.6)	<.001
Has individualized education plan	85 (39)	53 (29)	16 (9)	6.9 (3.8-12.6)	<.001	4.4 (2.4-8.3)	<.001
Unable to get a needed medical service	7 (3)	6 (3)	1 (1)	6.9 (0.8-57.6)	.07	6.6 (0.8-56.1)	.08
Any services needed above routine	142 (65)	106 (58)	48 (27)	5.4 (3.4-8.5)	<.001	4.1 (2.6-4.5)	<.001

Abbreviations: CI, confidence interval; ELBW, extremely low birth weight; NBW, normal birth weight.

\*Derived from logistic regression adjusting for socioeconomic status, race, and sex.

†Hospitalization after the neonatal period.

‡Including home or hospital based.

§Modified schedule, classroom made accessible, special lunch, transportation, tutoring.

dren born weighing less than 1000 g or less than 28 weeks' gestation in Australia. Similar to our findings, both studies reported highly significant differences between their study populations and NBW controls. Compared with our results, fewer Australian infants, whose birth weight group was similar to our group, survived (53% vs 72%, respectively); and fewer children had neurosensory impairments (12% vs 16%, respectively) or subnormal IQ (5% vs 15%, respectively).<sup>15</sup> The study by Lorenz et al<sup>16</sup> similarly found that the higher survival rate of infants born at less than 26 weeks' gestation and who were treated in New Jersey in the United States was associated with higher rates of disabling cerebral palsy compared with similar infants treated in the Netherlands. We postulate that the differences in outcomes between our ELBW cohort and the Australian cohort are related to their lower survival rate and sociodemographic differences.

We presented our results from both a categorical and noncategorical perspective to provide a comprehensive overview of the clinical, educational, and health care implications of the chronic sequelae experienced by ELBW children. Our results indicate that, in addition to the more commonly described neurodevelopmental problems, asthma plays a major role in determining the functional limitations and special health care needs of ELBW children. The use of a noncategorical approach (independent of diagnoses) is especially important for examining the outcomes of survivors of neonatal intensive care as it provides an assessment of the impact of the multiple chronic sequelae of preterm birth on functioning and special health care needs.<sup>10,17</sup> Children identified in the QUICCC fit the definition of children with special health care needs (have, or are at risk for having, a physical, developmental, behavioral, or emotional condition, and require health or related services of a type or amount beyond that required by children generally). This definition is used for the identification and planning of federal aid and services for children.<sup>18</sup> The QUICCC

also encompasses most of the elements of the World Health Organization's International Classification of Functioning and Disability, which includes limitations in body/structure, personal activity, participation in society, and environmental facilitation.<sup>19-21</sup>

The functional limitations and special health care needs in our current ELBW cohort are comparable with those results for 11-year-old children born in the mid-1980s who weighed less than 750 g at birth and had odds ratios (ORs) of 4.7 (95% confidence interval [CI], 2.0-11.0) for mental and emotional delay and 9.5 (95% CI, 2.1-43.6) for special arrangements in school.<sup>22</sup> Our results are also comparable with those of 11-year-old Swedish children who were born less than 26 weeks' gestation and had ORs of 5.1 (95% CI, 1.8-14.7) for mental or emotional delay and 6.2 (95% CI, 1.3-30.6) for attending special schools.<sup>5</sup> However, the 42% rate of chronic conditions in our NBW group is higher than the 15% to 30% rate reported in other studies using the QUICCC,<sup>9,23,24</sup> its shortened version,<sup>25</sup> or the Children with Special Health Care Needs screener.<sup>23,26,27</sup> In these studies, higher rates of chronic conditions were reported among poor families, Medicaid recipients, and school-age children, findings which could partly explain the relatively high rates of chronic conditions in our NBW group.<sup>23,24,28</sup> The relationship that developed between the parent and research assistant during the 2- to 3-hour visit for our study might also have encouraged parents to report more conditions than during the 7-minute telephone administration of the QUICCC or 1-minute Children with Special Health Care Needs screener interview.<sup>9,23,24,28</sup> Another explanation for the high rate of chronic conditions is that we considered the full range of consequences of chronic conditions included in the QUICCC, which may represent conditions in the borderline or "gray zone," such as special diet, allergy medication, or a past life-threatening reaction.<sup>9,28,29</sup> Newacheck et al<sup>30</sup> in 1986 postulated that most of the increase in reported rates of disability of children in the United States could be attributed to a shift in parental

perception of the health of their children. Rates of disability have continued to increase in the United States,<sup>31</sup> as have general pediatric and subspecialty visits<sup>32</sup> and prescription drug use for children.<sup>33</sup> All these factors could have contributed to the high rates of chronic conditions in our NBW group.

The ELBW children in our study represent the outcomes of an urban tertiary perinatal center and are thus not representative of the United States as a whole. The mean poverty level of our families was 18% vs 12% nationally,<sup>34</sup> and 62% were black. However, because a disproportionate number of ELBW births in the United States are poor and black, our results provide important information for public agencies and health care insurance plans and organizations.<sup>35</sup>

Our study, which combined the assessment of functional health status and special health care needs with traditional measures of neurological and developmental status, provides important research-based and policy-related information needed for the planning and provision of services for the increased number of ELBW children who survive. Because survival has not changed since the mid-1990s, our results also have relevance for current survivors.<sup>1</sup> The majority of conditions that we described result from periventricular brain injury, chronic lung disease, and retinopathy of prematurity.<sup>36-38</sup> Continued research is thus critical to prevent these complications of prematurity.

In the United States in 2002, there were 22 845 live births with a birth weight of 500 to 999 g, of whom approximately 70% survived.<sup>35</sup> Our findings underscore the extraordinary costs of care that will be needed to manage the medical, educational, and other service needs of the large proportion of these ELBW children who develop chronic conditions.<sup>39</sup> Proactive planning for the long-term health and educational care needs of all ELBW survivors is essential to optimally treat and possibly improve outcomes through preventative and early intervention services.<sup>40,41</sup> The American Academy of Pediatrics has emphasized the impor-



tance of providing a medical home for children with special health care needs, coordinating their care, involving family, and assisting in navigation of the complex federal, state, and local systems that provide services required by these children.<sup>42-44</sup> All of these services are highly relevant for the continuing long-term care of ELBW children who survive as a result of neonatal intensive care.

**Author Contributions:** Dr Hack had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. *Study concept and design:* Hack, Taylor, Drotar, Wilson-Costello, Klein.

*Acquisition of data:* Hack, Cartar, Wilson-Costello, Klein. *Analysis and interpretation of data:* Hack, Taylor, Drotar, Schluchter, Cartar, Andreias, Wilson-Costello.

*Drafting of the manuscript:* Hack.

*Critical revision of the manuscript for important intellectual content:* Taylor, Drotar, Schluchter, Cartar, Andreias, Wilson-Costello, Klein.

*Statistical analysis:* Hack, Drotar, Schluchter, Andreias. *Obtained funding:* Hack.

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