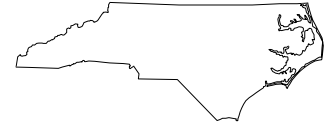


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# Statistical Brief



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## Child Service Coordination Program Coverage for Infants with Spina Bifida

by Robert E. Meyer, Ph.D., M.P.H.

### Introduction

North Carolina's Child Service Coordination Program (CSCP) is an early intervention and service coordination program for infants and young children with developmental delay, disabilities, or with risk factors for poor developmental outcomes. Administered by the Division of Women's and Children's Health, CSCP was established in response to the service coordination requirements mandated by Part H of the Individuals with Disabilities Education Act of 1990 (IDEA) and OBRA '89 for Title V programs.<sup>1-2</sup> The program operates statewide and is available to all children under age three and their families, regardless of income, with one or more specified risk conditions. CSCP extends coverage up to age five for children with certain diagnoses.

CSCP provides community-based care coordination and service referrals for approximately 26,000 infants and children each year, about seven percent (1,700) of whom are referred to the program because of a genetic abnormality or major birth defect. Because of the extensive medical and allied health care often required for children with birth defects, the resources offered by the CSCP are of particular benefit to the families of these infants. To ensure that the families of affected infants are aware of the program and the services it provides, CSCP conducts an extensive child-find activity. A major goal of child-find is to maximize the coverage of the CSCP or, in other words, to identify as many eligible infants in the state as possible.

The purpose of this report is to examine CSCP coverage for infants with spina bifida, and to identify factors that influence the program's coverage among these infants. Children with spina bifida were selected for study because the array of specialized services they require make them a particularly important target population for the CSCP.

### Methods

For this analysis, all North Carolina resident infants who were born between 1990 and 1993 and diagnosed with spina bifida were identified from the North Carolina Birth Defects Monitoring Program (NCBDMP). The NCBDMP is a statewide, population-based surveillance system that uses multiple methods and data sources for case ascertainment. Infants who died during their first year of life were excluded from the analysis, leaving 178 infants in the study population. To determine whether the infants had been identified by CSCP, NCBDMP records were computer-matched to 1990-1997 Health Services Information System (HSIS) data files. Children were considered to have been identified by the CSCP if a matching CSCP record was located in the HSIS database.

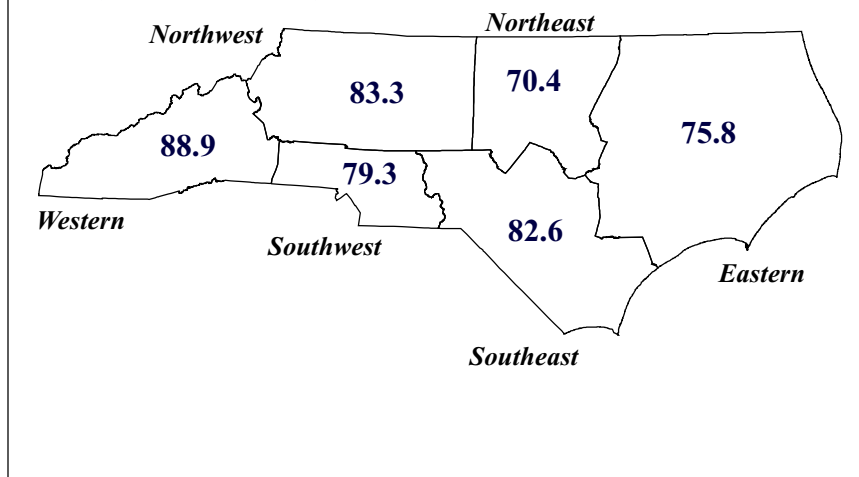
### Results

Of the 178 infants with spina bifida, 142 were identified by the CSCP, resulting in an overall program coverage rate of 79.8 percent. Of the 142 families whose infants were referred to the program, only 14 declined to participate. There was no significant trend over time in the coverage rate among infants who were born between 1990 and 1993. There were some geographic differences in program coverage, with the highest rate found in the western perinatal region (88.9 percent), and the lowest rate found in the northeast perinatal region (70.4 percent) (Figure 1).



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**Figure 1.**  
**CSCP Coverage for Children with Spina Bifida**  
**by Perinatal Region, North Carolina, 1990-1997**



CSCP coverage varied by certain demographic characteristics (Table 1). The coverage rate for children from rural counties was statistically significantly higher than the rate for urban children (89.6 percent vs. 73.9 percent). Coverage was also higher among minority populations than among whites, and for children of mothers less than 20 years old compared to children of older mothers; however, these differences were not statistically significant.

Program coverage rates also varied according to the mother’s use of other health services (Table 1). Coverage among children whose mothers had received prenatal care in a county public health department was significantly higher than that for those whose mothers received care elsewhere (88.9 percent vs. 75.8 percent). Children of mothers who were enrolled in maternity care coordination or in Medicaid were also more likely to have been identified by the CSCP, as were infants who were born in a tertiary care hospital.

**Comment**

With 8 out of every 10 infants with spina bifida being identified statewide, this study demonstrates that the Child Service Coordination Program maintains very good coverage for this group of high risk children. The rate of coverage for children with spina bifida is comparable to the program’s

coverage rate for very low birth weight infants (74-79 percent), who represent another important target population for the CSCP.<sup>3</sup> The high coverage rates for these two populations may be due, in part, to the fact that their medical conditions are readily apparent from the time of birth, making these infants more likely to be identified early by the CSCP. In contrast, children whose disabilities generally do not become apparent until later in life may be less likely to be identified by the CSCP.<sup>4</sup>

The findings of this study suggest that efforts focused on improving coverage in the state’s metropolitan counties and among private health care

providers could substantially increase the overall CSCP coverage rate of infants with spina bifida in North Carolina. For example, if the coverage rate among infants whose mothers received prenatal care outside a public health department were increased to the same level as those whose mothers did receive care in a health department, the statewide coverage rate for all infants with spina bifida would increase by nine percentage points (to 88.9 percent). The differences in coverage among the state’s perinatal regions suggests the need for a more detailed assessment of the identification and referral procedures used at the hospital and county level. Such an assessment may help to identify and resolve institutional barriers or other impediments to the referral process. Continued monitoring of CSCP coverage rates can be helpful in evaluating the effectiveness of efforts aimed at improving child-find.

As this study shows, North Carolina’s Birth Defects Monitoring Program is an important resource for monitoring and evaluating CSCP coverage for children with congenital defects. Improving the timeliness of data collected by the monitoring program and strengthening its linkages with other agencies can further enhance child-find and the timely delivery of services to children with special health care needs in North Carolina.

**Table 1. Child Service Coordination Program Coverage Rates for Infants with Spina Bifida by Selected Characteristics, North Carolina, 1990-1997.**

<b>Characteristic</b>	<b>Total Number Statewide</b>	<b>Covered By CSCP Number (%)</b>	<b>P-Value<sup>1</sup></b>
<b><i>Mother's Residence</i></b>			
Rural	67	60 (89.6)	0.012
Urban	111	82 (73.9)	
<b><i>Race</i></b>			
White	132	102 (77.3)	0.159
Other Races	46	40 (87.0)	
<b><i>Mother's Age</i></b>			
< 20	33	30 (90.9)	0.204
20-29	103	79 (76.7)	
> 29	42	33 (78.6)	
<b><i>Mother's Education</i></b>			
Less than High School	49	40 (81.6)	0.204
High School	76	64 (84.2)	
Beyond High School	53	38 (71.7)	
<b><i>Source of Prenatal Care</i></b>			
Health Dept.	54	48 (88.9)	0.046
Other	124	94 (75.8)	
<b><i>Enrollment in MCC</i></b>			
Yes	40	34 (85.0)	0.350
No	138	108 (78.3)	
<b><i>Enrollment in Medicaid</i></b>			
Yes	84	72 (85.7)	0.062
No	94	70 (74.5)	
<b><i>Level of Care at Birth</i></b>			
Tertiary Hospital	101	84 (83.2)	0.197
Other	77	58 (75.3)	

<sup>1</sup> P-value based on Pearson Chi-square.

**References**

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2. Shackelford J. State/Jurisdiction eligibility definitions for Part H. NEC TAS Notes: National Early Childhood Technical Assistance System, Chapel Hill, NC, February, 1995.
3. Farel AM, Herrick H. Statewide coverage of very low birth-weight infants and infants of young teenage mothers in North Carolina's Child Service Coordination Program. J. Pub. Health Management Pract. 3(5):58-63, 1997.
4. Meyer R, Howell E, Farel A, Roth M. Coverage of children with birth defects by North Carolina's Child Service Coordination Program: a population-based study. Paper presented at the 1997 Maternal, Infant, and Child Health Epidemiology Workshop: Partnerships Among Programs Serving Mothers, Infants, and Children. December 9-10, 1997, Atlanta GA.

Robert Meyer, Eleanor Howell (State Center for Health Statistics), Anita Farel (UNC Department of Maternal and Child Health), and Marcia Roth (Division of Women's and Children's Health) contributed to this report.

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