

# The Michigan Monitor

Following trends, promoting prevention  
and linking families to resources

Fall 2008  
Volume 2, Issue 1

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## Michigan’s Birth Defects Registry and Follow-up Program

The Michigan Birth Defects Program is a statewide, population-based, passive surveillance system, housed within the Michigan Department of Community Health. The Program encompasses the Michigan Birth Defects Registry (MBDR) and Follow-up Program. The primary aims of the Michigan Birth Defects Program are to monitor the rate of birth defects, conduct follow-up, ensure families are

connected with resources and support, and work towards prevention. The MBDR relies on reporting by hospitals and cytogenetic laboratories for case ascertainment.

Since 2005, the Birth Defects Program has provided service and recurrence prevention information to families who have a child with a neural tube defect. In 2008, the program initiated a pilot project with the Wayne RESA *Early*

*On*® Program to help connect children with risk factors with the Michigan system for early intervention.

This issue of the *Michigan Monitor* explores opportunities for the Birth Defects Program in partnership with the Children’s Special Health Care Services (CSHCS) Program to link families with medical care and support. Specifically, we explore factors that may influence entry into CSHCS for children identified through the MBDR Program.

## Children’s Special Health Care Services Program

Children’s Special Health Care Services (CSHCS) is a program in the Michigan Department of Community Health that assists Michigan’s children and families in receiving medical care and support. CSHCS serves primarily individuals up to 21 years old with special health care needs. While more than 2,600 medical conditions are eligible for coverage and over 500 of these conditions are also reportable to the MBDR, diagnosis alone does not ensure entry into CSHCS. Individuals who are referred for entry and meet criteria regarding

level of severity, chronicity, and the need for annual medical care and treatment by a physician subspecialist may choose to enroll in CSHCS.

During 2006, the average monthly enrollment in CSHCS was 31,184. Figure 1 shows the rate of enrollment by county for children ages 0 to 17 years in 2006; approximately 1.2% of all Michigan children were enrolled in CSHCS for at least one month.<sup>2</sup> The two most common racial/ethnic groups, white and black, represent more than 90% of children enrolled in CSHCS in 2006 (Figure 2).

**Goals of CSHCS<sup>1</sup>**

- Assist individuals with special health care needs in accessing appropriate specialty healthcare, health education, and support systems
- Assure delivery of services and supports in a family-centered, culturally competent, community-based and coordinated manner
- Promote and incorporate parent/professional collaborations
- Remove barriers that prevent individuals with health care needs from achieving their goals



Figure 1. 2006 Enrollment Rate (per 1,000 children) in CSHCS, Ages 0 to 17 Years

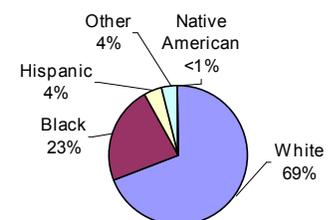


Figure 2. Race/Ethnicity of Children Enrolled in CSHCS in 2006

## Link Between CSHCS and MBDR

### Purpose:

The purpose of this study was to determine the number of children who may have been eligible to enroll in CSHCS due to birth defect diagnoses\* and evaluate factors associated with enrollment into CSHCS.

### Methods:

Data for this study were obtained by linking MBDR and CSHCS data from 1998-2003. The enrollment numbers were examined for all children in the MBDR with CSHCS-eligible diagnoses\* and for a subset of children with select birth defects recognizable at birth. The six selected conditions include: cleft lip/palate, limb deformities, spina bifida, major heart defects, microcephaly and hydrocephaly. Data from hospitals reporting fewer than 20 of the selected birth defects during the study period were excluded. The analyses were conducted using Statistical Analysis Software (SAS) version 9.1.

### Results:

Since many factors may influence enrollment in CSHCS, the findings from this study should be interpreted carefully. CSHCS enrollment is dependent on: eligible diagnosis for referral, referral to the program, examination of specific criteria to determine eligibility, and parental acceptance of the program. This study examined enrollment based on eligible diagnosis alone, so it does not provide information on the number of infants referred, the number determined to be eligible for entry into CSHCS, or the number of parents who refused enrollment.

#### All Eligible Birth Defect Diagnoses

While the MBDR maintained 45,224 records of Michigan resident children born from 1998 through 2003 having a CSHCS-

\*Enrollment into CSHCS is dependent on diagnosis and fulfillment of other

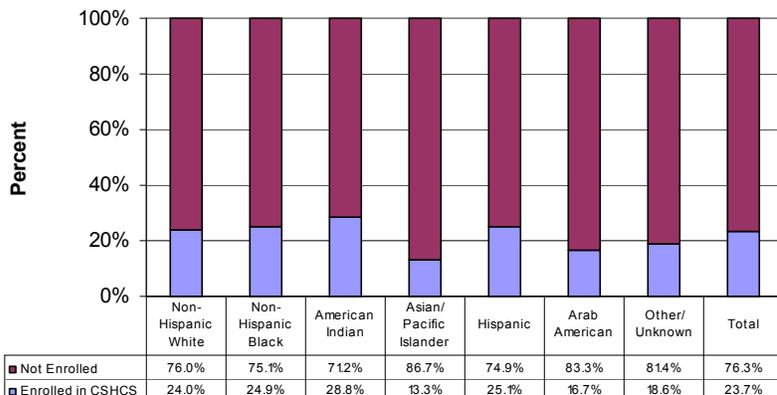


Figure 3. All MBDR Cases Eligible for CSHCS by Mother's Race/Ethnicity and Enrollment Status, 1998-2003

eligible birth defect diagnosis\*, 23.7% of these children were enrolled in CSHCS (Figure 3). The lowest and highest enrollment rates were seen among children of Asian/Pacific Islander and American Indian mothers, respectively.

#### Selected Birth Defect Diagnoses

Of the 4,240 children with one or more of the six selected defects, 60.8% were enrolled in CSHCS. Enroll-

Table 1. Maternal and Infant Factors Associated with Enrollment into CSHCS for Children with Select\* Birth Defects, Resident/Occurrent Birth Years 1998-2003

Predictor	Odds Ratio (OR)	Adjusted OR** (95% CI)
<b>Hospital Level of Care</b>		
Level 3	1.00	Reference group
Level 1 or 2	<b>1.22</b>	<b>1.19 (1.03, 1.37)</b>
<b>Maternal Age (years)</b>		
<20	<b>2.03</b>	<b>1.44 (1.07, 1.93)</b>
20-24	<b>1.89</b>	<b>1.54 (1.15, 1.81)</b>
25-29	<b>1.43</b>	<b>1.40 (1.14, 1.73)</b>
30-34	0.95	0.99 (0.80, 1.22)
35+	1.00	Reference group
<b>Education</b>		
<High School	<b>1.82</b>	1.17 (0.94, 1.46)
High School	<b>1.44</b>	1.13 (0.97, 1.32)
>High School	1.00	Reference group
<b>Number of Anomalies</b>		
Single Anomaly	1.00	Reference group
Multiple Anomalies	<b>2.90</b>	<b>2.95 (2.51, 3.46)</b>
<b>Resident</b>		
Urban	1.00	Reference group
Rural	<b>2.22</b>	<b>2.13 (1.75, 2.61)</b>
<b>Maternal Race</b>		
White	1.00	Reference group
Black	<b>1.21</b>	1.09 (0.91, 1.31)
Other	<b>0.66</b>	<b>0.63 (0.43, 0.92)</b>
<b>NICU Admission</b>		
NICU no	1.00	Reference group
NICU yes	<b>2.00</b>	<b>1.71 (1.48, 1.98)</b>
<b>Insurance Source</b>		
Private/Other	1.00	Reference group
Medicaid	<b>2.21</b>	<b>1.87 (1.56, 2.16)</b>

\*Cleft lip/palate, limb deformities, spina bifida, major heart defects, microcephaly and hydrocephaly

\*\*Adjusted for all other predictors in the table

ment percentage by reporting hospital ranged from 21.4% to 86.7%; 39 hospitals reported 20 or more cases having one or more of the selected birth defects.

Table 1 (page 2) provides the unadjusted and adjusted associations between maternal and infant factors (predictors) and enrollment into CSHCS for children with the six selected birth defects. The odds ratio indicates the likelihood of enrollment into CSHCS for one group compared to a reference group, which is typically the group least likely to enroll in CSHCS. Prior to adjustment for other predictors, the presence of multiple anomalies was the strongest predictor of CSHCS enrollment. While adjustment attenuated the association between maternal and infant factors and CSHCS enrollment, only education and black maternal race were rendered statistically insignificant. Hospital care level 1 or 2, rural residence, younger maternal age (<29 years old), multiple anomalies, NICU admission, and Medicaid insurance were all associated with an increased likelihood of CSHCS enrollment. "Other" maternal race was associated with a significantly decreased likelihood of CSHCS enrollment. Children born in urban areas were less likely to be enrolled in CSHCS, and this association was similar for 1) urban residence excluding Wayne County and Detroit, 2) Wayne County excluding Detroit, and 3) Detroit alone.

## Public Health Implications and Future Directions

We used Michigan Birth Defects Registry (MBDR) and Children's Special Health Care Services (CSHCS) linked data to identify families who potentially underutilize available resources.

Among potentially eligible children, more than three-quarters were not enrolled in CSHCS, and the enrollment levels appeared to differ by maternal racial/ethnic group. For children with easily identifiable birth defects only, nearly 40% were not enrolled in CSHCS and potentially missing valuable opportunities for needed assistance. Additionally, the enrollment levels were less in urban areas. This study has identified targets for interventions to increase awareness about CSHCS and available services. Specifically, ongoing education of racial/ethnic minority groups and residents of urban areas and healthcare providers is needed to increase enrollment. Also, further research is needed to assess factors that predict CSHCS enrollment among families who are both seeking and eligible for services.

## Information and Resources

More information and educational materials, including an online "Family Guide" about CSHCS are available from the **Children's Special Health Care Services** website ([www.michigan.gov/cshcs](http://www.michigan.gov/cshcs)). A free course titled, "What is Children's Special Health Care Services?" is available at <http://training.mihealth.org/course/detail.htm>.

Information on the Family Center for Children and Youth with Special Health Care Needs, including their newsletter and helpful links, can be found at [www.bridges4kids.org/f2f](http://www.bridges4kids.org/f2f).

For more information about CSHCS, call the Family Phone Line at 1-800-359-3722 or e-mail [cshcsfc@michigan.gov](mailto:cshcsfc@michigan.gov).

For **Michigan Birth Defects Statistics** per MBDR reporting, visit

[www.mdch.state.mi.us/pha/osr/index.asp?Id=7](http://www.mdch.state.mi.us/pha/osr/index.asp?Id=7).

### *For Health Care Providers*

**Do:** Encourage every family with a child with a CSHCS-eligible medical condition to apply for enrollment into CSHCS.

**Do:** Provide education to families with children diagnosed with birth defects about the available resources, such as CSHCS.

## References

1. Children's Special Health Care Services: [www.michigan.gov/cshcs](http://www.michigan.gov/cshcs).
2. Paustian M, El Reda D, Grigorescu V. Michigan Department of Community Health; Division of Genomics, Perinatal Health, and Chronic Disease Epidemiology. Children and Youth with Special Health Care Needs: 2007 Michigan Data Brief. 2007.

## Following trends, promoting prevention and linking families to resources

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*You can find the Michigan Monitor  
online at [www.michigan.gov/genomics](http://www.michigan.gov/genomics)*

*Michigan Department  
of Community Health*



Jennifer M. Granholm, Governor  
Janet Olszewski, Director

## Program Updates

The MBDR and Follow-up Program, along with the Colorado birth defects surveillance system, will pilot the utilization of a comprehensive planning and evaluation process. Developed by the CDC National Center on Birth Defects and Developmental Disabilities, the evaluation process will soon be implemented in each of the State Birth Defects Program Cooperative Agreements. Look for updates about this project in subsequent newsletters.

Recent attention has been given to the release of the new ICD-10-CM and ICD-10-PCS disease classification systems. The use of these systems will increase the accuracy of health statistics and provide more opportunities to learn about morbidity and mortality. The MBDR will be working to implement the new classification systems by transitioning our own data systems to be in line with those of the healthcare organizations that report to us. For more information regarding the new classification systems, please visit [www.ahima.org](http://www.ahima.org) or [www.aapc.com](http://www.aapc.com).

## Acknowledgments

We publicly express thanks to the members of the MBDR Steering Committee for their continued commitment and contributions to this study.



## Suggested Citation

Kleyn M, Pollett J, Ehrhardt J, Bach J, Korzeniewski S, Grigorescu V. Michigan Department of Community Health. **Michigan Monitor**. Volume 2, Issue 1. Fall 2008.