Children and Youth with Special Health Care Needs

Michigan Data Brief

2007
Introduction

This report provides a descriptive summary of information related to children and youth with special health care needs (CYSHCN).

This information is provided to assist Children’s Special Health Care Services (CSHCS) program staff at state and local health departments, health care professionals involved in the care of CYSHCN, policymakers, and families of CYSHCN to:

- Inform stakeholders about the status of CYSHCN in Michigan,
- Assess basic needs of CYSHCN,
- Discuss policies for CYSHCN, and
- Plan and develop programs for CYSHCN.

National definition of CYSHCN

The federal government defines children with special health care needs as “children who have or are at increased risk for chronic, physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.” Program definitions of CYSHCN vary based upon the population served, but these definitions are consistent with the national definition.

Michigan definition of CYSHCN

A person under age 21 “whose activity is or may become so restricted by disease or deformity as to reduce the individual’s normal capacity for education and self-support.”

CSHCS eligibility

The CSHCS program provides support for children with over 2600 eligible diagnoses as well as persons over the age of 21 with cystic fibrosis and certain blood disorders.

Table of contents

- CSHCS program enrollment…p3
- CSHCS disease prevalence…p4
- Vital statistics and birth defects…p5
- National Survey of CSHCN…p6
- National Survey of Children’s Health…p7

REPORT HIGHLIGHTS

- For 10 percent of CSHCS enrolled persons, CSHCS provides their only source of health coverage. An additional 46 percent of CSHCS enrollees rely solely on Medicaid and CSHCS.

- The most prevalent conditions among CSHCS enrollees are congenital anomalies (28%). Respiratory disorders were the most prevalent condition among young children enrolled (14% among ages 0 to 4 years) while juvenile diabetes was the most prevalent condition among adolescents enrolled (15% among ages 15 to 19 years).

- Preterm births and birth defects are substantial contributors to the CSHCS population. Several eligible CSHCS conditions rank among the leading causes of infant mortality.

- Prescription medications (89%), dental care (83%), and routine medical care (72%) were the three most frequently cited health service needs for Michigan CYSHCN according to the 2001 National Survey of CSHCN.
Children’s Special Health Care Services
2006 Program Enrollment Characteristics

CSHCS program population
Information about the CSHCS program in this report comes from children who were enrolled for at least one month during calendar year 2006.

Demographic profile of children enrolled in CSHCS, 2006

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 to 4</td>
<td>8,689</td>
<td>23.8</td>
</tr>
<tr>
<td>5 to 9</td>
<td>9,016</td>
<td>24.7</td>
</tr>
<tr>
<td>10 to 14</td>
<td>8,517</td>
<td>23.4</td>
</tr>
<tr>
<td>15 to 19</td>
<td>7,640</td>
<td>21.0</td>
</tr>
<tr>
<td>20 and over</td>
<td>2,579</td>
<td>7.1</td>
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Sex

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
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<tbody>
<tr>
<td>Female</td>
<td>16,372</td>
<td>44.9</td>
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<tr>
<td>Male</td>
<td>20,068</td>
<td>55.1</td>
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Race and ethnicity

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>25,135</td>
<td>69.0</td>
</tr>
<tr>
<td>Black</td>
<td>8,280</td>
<td>22.7</td>
</tr>
<tr>
<td>Native American</td>
<td>169</td>
<td>0.5</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1,418</td>
<td>3.9</td>
</tr>
<tr>
<td>Other</td>
<td>1,438</td>
<td>3.9</td>
</tr>
<tr>
<td>Total</td>
<td>36,441</td>
<td>100.0</td>
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</tbody>
</table>

Health insurance sources for CSHCS enrollees - 2006

Prevalence of CSHCS Enrollment - Overall, 12.3 per 1,000 children ages 0 to 17 years, or 1.2 percent of Michigan children, were enrolled in CSHCS at least one month during the 2006 calendar year. Monthly program enrollment increased 1.3 percent between January and December.

Monthly enrollment in CSHCS - 2006

Children and Youth with Special Health Care Needs, Michigan Data Brief, 2007
Page 3
The most prevalent conditions for which persons enrolled in CSHCS were congenital anomalies. The most prevalent conditions (excluding congenital anomalies) among young CSHCS enrollees were respiratory disorders and among adolescent CSHCS enrollees was juvenile diabetes. Profiles of common CSHCS-enrolled conditions differed between White and Black CSHCS enrollees.
Vital Statistics and Birth Defects
Preterm birth and low birth-weight infants are at risk for several chronic health conditions eligible for CSHCS. Between 2001 and 2003, 28 percent of children age 0 to 9 years enrolled in CSHCS had been born preterm. Several eligible CSHCS conditions rank among the leading causes of infant mortality. Congenital anomalies rank as the most prevalent diagnosed conditions for which children are enrolled in CSHCS.
Results from the National Survey of Children with Special Health Care Needs, 2001 7,8

Prevalence of CYSHCN
Child-level
Michigan (%) Nation (%)
Children 0 to 17 years of age 13.9 12.8

Household-level
Percentage of households with children that have one or more CYSHCN, 0 to 17 years old 22.1 20.0

Age
Michigan Nation
Children 0 to 5 years of age 7.7 7.8
Children 6 to 11 years of age 16.0 14.6
Children 12 to 17 years of age 17.4 15.8

Gender
Female 10.9 10.5
Male 16.8 15.0

Poverty level
Michigan Nation
0% to 99% FPL 12.4 13.6
100% to 199% FPL 16.4 13.6
200% to 399% FPL 14.9 12.8
400% FPL or greater 13.2 13.6

Race/ethnicity
Michigan Nation
Hispanic 12.7 8.5
White (non-Hispanic) 13.9 14.2
Black (non-Hispanic) 13.6 13.0
Multi-racial (non-Hispanic) 20.0 15.1
Asian (non-Hispanic) * 4.4
Native American/Alaskan * 16.6
Native (non-Hispanic) *
Native Hawaiian/Pacific Islander (non-Hispanic) * 9.6

*Data are not available

Proportion of CYSHCN who reported a need for health care services by service category

National Survey of CSHCN, 2001 8
The goals of this random digit-dialed telephone survey were to identify the prevalence of CYSHCN, identify both health needs and unmet needs of this population, and measure the social and economic impact on their families. The survey represents a sample of all CYSHCN in Michigan, regardless of enrollment into CSHCS.

Percent of CYSHCN...
Child health
Michigan Nation (%)
1) whose health conditions consistently and often greatly affect their daily activities 22.5 23.2
2) with 11 or more days of school absences due to illness 13.5 15.8

Health insurance coverage
Michigan Nation
3) without insurance at some point during the past year 8.5 11.6
4) currently uninsured 4.0 5.2
5) currently insured with coverage that is not adequate 28.0 33.8

Access to care
Michigan Nation
6) with one or more unmet needs for specific health care services 14.6 17.7
7) whose families needed but did not get all respite care, genetic counseling and/or mental health services 17.8 23.1
8) needing specialty care who had problems getting a referral 17.3 21.9
9) without a usual source of care (or who rely on the emergency room) 11.5 9.3
10) without a personal doctor or nurse 10.3 11.0

Family-centered care
Michigan Nation
11) without family-centered care 29.7 33.2

Impact on the family
Michigan Nation
12) whose families pay $1,000 or more in medical expenses per year 8.4 11.2
13) whose families experienced financial problems due to child’s health needs 16.1 20.9
14) whose families spend 11 or more hours per week providing and/or coordinating health care for child 10.3 13.5
15) whose health needs caused family members to cut back or stop working 23.7 29.8
Results from the National Survey of Children’s Health, 2003 7,9

Child-level prevalence

<table>
<thead>
<tr>
<th>Percentage of CYSHCN, 0 to 17 years old</th>
<th>Michigan (%)</th>
<th>Nation (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>21.0</td>
<td>17.6</td>
</tr>
</tbody>
</table>

Percent of children...

Child health

| 1) whose overall health is excellent or very good | 85.0         | 84.1       |
| 2) with health problems rated as moderate or severe by parents | 9.2         | 7.9        |

Asthma

| 3) affected by asthma during past year | 11.3         | 16.3       |
| 4) with asthma whose families are greatly or moderately affected in some way by child’s health condition | 9.2         | 8.0        |

Injury

| 5) ages 0 to 5 years with injuries requiring medical attention during past year | 11.4         | 9.4        |

Developmental and Behavioral

| 6) ages 0 to 5 years whose parents have one or more concerns about child’s learning, development, or behavior | 35.8         | 36.6       |
| 7) ages 3 to 17 years with moderate or severe difficulties in the area of emotions, concentration, behavior, or getting along with others | 10.1         | 9.2        |
| 8) ages 3 to 17 with mental or emotional problems whose families are greatly or moderately affected in some way by child’s mental or emotional health | 26.8         | 27.8       |

Body Mass Index of Michigan Children, 2003

- Underweight: 9%
- Normal: 55%
- At-risk: 14%
- Overweight: 9%

National Survey of Children’s Health, 2003 9

The goals of this random digit-dialed survey were to provide estimates for a variety of physical, emotional, and behavioral health indicators, measures of child experience in the health care system, and the interactions of children within the family.

Health insurance

| 9) without insurance at some point during the past year | Michigan (%) | Nation (%) |
| 10) currently uninsured | 10.9         | 14.9       |

Access to care

| 11) with preventive medical care in the past year | Michigan (%) | Nation (%) |
| 12) with both a preventive medical care visit and a preventive dental visit in the past year | 78.1         | 77.8       |
| 13) with current emotional, developmental, or behavioral problems who received some type of mental health care during the past year | 63.8         | 58.7       |
| 14) who have a personal doctor or nurse from whom they receive family-centered, accessible, comprehensive, culturally sensitive, and coordinated care | 48.4         | 46.1       |

Child’s school and activities

| 15) ages 6 to 17 who missed 11 or more days of school in the past year | 56.5         | 60.7       |
| 16) ages 6 to 17 years who participate in one or more organized activities outside of school | 84.9         | 81.0       |
| 17) ages 6 to 17 years who repeated at least one grade in school | 11.3         | 11.3       |
| 18) ages 6 to 11 years who stayed home alone during the past week | 12.6         | 15.9       |

Family and Neighborhood

| 19) who live in households where someone smokes | Michigan (%) | Nation (%) |
| 20) with mothers whose overall physical and mental health is excellent or very good | 38.4         | 29.5       |
| 21) ages 0 to 5 years whose parents had to make different child care arrangements in the past month or a job change for child care reasons in the past year, or both | 63.2         | 58.9       |
| 22) living in neighborhoods parents describe as supportive | 34.3         | 33.2       |
| | 84.4         | 81.4       |
REFERENCES
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2Michigan Public Health Code 333.5801
3Michigan Department of Community Health, Children’s Special Health Care Services.
4Michigan Department of Community Health, Division for Vital Records and Health Statistics.
5Michigan Department of Community Health, Michigan Birth Defects Registry.
7Maternal and Child Health Bureau, Child and Adolescent Health Measurement Initiative, Child Data Resource
Center.
8Blumberg SJ, Olson L, Frankel MR, et al. Design and Operation of the National Survey of Children with Special
9Blumberg SJ, Olson L, Frankel MR, et al. Design and Operation of the National Survey of Children’s Health,

TECHNICAL NOTES
• Enrollment information in CSHCS is updated daily and can include retrospective enrollment for
services already received. The results included in this publication reflect CSHCS as of February 5,
2007.
• CSHCS diagnoses only reflect the primary and secondary diagnoses associated with enrollment.
Many children experience conditions associated with more than two eligible diagnoses. Thus,
prevalence estimates may be underestimated for some conditions.
• State program estimates and national estimates may differ as a result of different case definitions for
meeting CYSHCN criteria.

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For additional information about this publication
contact:
Michigan Department of Community Health
Maternal & Child Health Epidemiology Section
201 Townsend St.
Lansing, MI 48913
Phone: (517)-335-9649
Email: paustianm@michigan.gov

For additional information about programs for
children with special health care needs contact:
Michigan Department of Community Health
Children’s Special Health Care Services
320 S. Walnut St.
Lansing, MI 48913
Phone: (517)-241-7186