

ISSUE BRIEF

Outcome # 3: All families of children with special health care needs will have adequate private and/or public insurance to pay for all the services they need.

*Michigan Department
of Community Health*



Jennifer M. Granholm, Governor
Janet Olszewski, Director

CHILDREN'S SPECIAL HEALTH CARE SERVICES STRATEGIC PLANNING 2008

This background brief presents an overview of the **insurance status** for children and youth with special health care needs in Michigan. It has been prepared as a step in assessing the readiness, capacity, and barriers to a fuller implementation of adequate insurance coverage for children and youth with special health care needs (CYSHCN) in Michigan. Members of the **Children's Special Health Services Advisory Committee (CAC) and other partners** have compiled this brief to document the current status of insurance activity in both the U.S. and Michigan. This brief was developed as background material in preparation for the April 16 and 17, 2008 Michigan CYSHCN Strategic Planning Meeting. The meeting will result in a five year strategic plan. The overarching goal is to address for Michigan the 10-year Action Plan to Achieve Community-based Service Systems for Children and Youth with Special Health Care Needs and Their Families (U.S. Department of Health and Human Services, 2001). The focus of the CSHCS Strategic Plan is on assessing Michigan's current status of reaching the 2010 outcomes for CYSHCN, exploring strategies with key stakeholders from across the state to achieve these outcomes and in developing a prioritized five year plan to get us there. This brief is specific to the federal Maternal and Child Health Bureau Outcome #3: **All families of children with special health care needs will have adequate private and or public insurance to pay for all services they need.**

Insurance Status

Background

The 2010 Action Plan for Children with Special Health Care Needs (CSHCN) is a ten-year plan developed and promoted by the Maternal and Child Health Bureau (MCHB) in the Health Resources and Services Administration of the U.S. Department of Health and Human Services, and is endorsed by the American Academy of Pediatrics (AAP), Family Voices, the March of Dimes and over 50 other national organizations.

The Action Plan includes the specific outcome of adequate insurance for all children with special health care needs by 2010. Work on this outcome is proceeding at both the state and national levels. At the present time, the definition for CYSHCN by MCHB and Michigan CSHCS do not fully coincide (see box). Michigan's CSHCS program provides medical and support services to eligible children. Due to budget constraints CSHCS cannot currently open up eligibility for medical care and treatment. The CSHCS program can, however, provide education and outreach to the broader CYSHCN population.

The document, *Healthy People 2010*, offers a set of health outcomes for the nation and reflects current health planning at the national level. The nation's health plan recognizes the key to improving care for CYSHCN lies in a systems approach to organizing and delivering services. Healthy People 2010 objective 16.23 is to "increase the proportion of states and territories that have service systems for children with special health care needs." Achieving this objective has been further defined by the federal MCHB as accomplishing six core outcomes (USDHHS, 2001):

1. Families of children with special health care needs will participate in decision making at all levels and will be satisfied with the services they receive.
2. All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.
3. **All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.**
4. All children will be screened early and continuously for special health care needs.
5. Community-based service systems will be organized so families can use them easily.
6. All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.

This Issue Brief focuses specifically on Outcome #3.

**Definition:
Children and Youth with
Special Health Care Needs**

National (MCHB)

Children and youth who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Michigan CSHCS

Michigan's CSHCS eligibility criteria for children and youth focuses almost exclusively on physical health conditions and services provided by pediatric sub-specialists.

The Michigan Story

Michigan has a long and proud history of making children with special needs a priority, dating back to the late 1800's when organized state-run services first were made available to "crippled children." In more recent history, the focus of the program has been medical care, treatment and support services for eligible children and some adults with one or more of approximately 2,500 physical-health-related diagnoses. The treatment and supports that the program provides must be specific to the qualifying condition(s). Except in unusual circumstances, CSHCS focuses on the services provided by pediatric or other sub-specialists and does NOT cover primary care services or providers unless they directly relate to the qualifying condition (e.g. pneumococcal vaccine covered for a child with Sick Cell Disease, or a urinalysis ordered by the local pediatrician for a child with kidney disease whose specialist is 400 miles away).

Michigan has historically had a lower proportion of residents without health insurance than the national average, due primarily to the high rate of employer-based coverage in Michigan. Michigan is a manufacturing state with the majority of the manufacturing stemming from the Big Three automakers and suppliers. The continued loss of manufacturing jobs, combined with a sluggish economy, has diminished employer-based coverage in Michigan. Michigan, like the nation, continues to struggle with increased demand for public insurance coverage.

Health care delivery in the United States is an enormously complex enterprise, and its more than \$1.7 trillion annual expenditures involve a host of competing interests. Lack of insurance compromises the health of the uninsured because they receive less preventive care, are diagnosed at more advanced disease stages, and once diagnosed, tend to receive less therapeutic care and have higher mortality rates than the insured. While arguably the nation offers among the most technologically advanced medical care in the world, the American system consistently under performs relative to its resources. Gaps in financing and service delivery pose major barriers to improving health, reducing disparities, achieving universal insurance coverage, enhancing quality, controlling costs, and meeting the needs of patients and families.

CSHCS has had an Insurance Premium Payment benefit in place for over 12 years whereby the state pays the private health insurance premium for the CSHCS eligible client. One reason CSHCS has this benefit is that it maintains private health care coverage for families that could not afford it. This enables the state to prevent a shift in cost of medical services from the private health insurance company to CSHCS state funding. The majority of the premiums paid by CSHCS are when COBRA coverage is offered to a family when the policyholder loses a job or when a young adult is no longer a dependent. CSHCS also pays for a client's premium for a private health insurance policy they purchased themselves or a reimbursement of insurance premium that is payroll deducted out of the paycheck of a CSHCS parent or client. Cost-effectiveness must be proven in order for CSHCS to pay premiums. It is a well-established benefit, and the number of

families CSHCS has assisted in paying insurance premiums has remained fairly constant over the years. In 2003-2004, CSHCS paid insurance premiums for 128 families with CYSHCN. CSHCS evaluated each of these cases, and it was determined that the CSHCS saved over \$1.3 million by paying the premiums for this time period.

Michigan and National Data

General Population and Insurance

From 2000 to 2005, the average increase in inflation has been 2.5% while health care premiums have escalated an average of 11.4% annually (Medical Expenditure Panel Survey, June 2005). The cost of employer-based health benefits increased at a rate of five times more than that of wages (Health Research & Educational Trust). Kaiser Foundation and the National Coalition on Health Care reported that in 2006, nearly 47 million Americans were uninsured. The same study indicated that in 2006, employer health insurance premiums increased by 7.7% - two times the rate of inflation. The annual premium for an employer health plan covering a family of four averaged nearly \$11,500. The annual premium for single coverage averaged over \$4,200.

Access to insurance is a major barrier. According to the 2000 Census, 1.1 million Michigan residents are uninsured. Of those without insurance, 57% lived below 200% of the poverty level. State data indicated that there are 175,000 uninsured children. Many low-income children who are eligible for health insurance under Michigan Medicaid or MICHild programs are not enrolled. The 2004 Kids Count data indicated that 27.5% of Michigan's children ages 0-18 were insured by Medicaid; while 56.3% of that population was in Detroit. Despite these gaps, Michigan ranks better in every age and poverty-level strata than the U.S. with regard to percent of adequately insured children.

Uninsured
<u>United States</u>
47 million
<u>Michigan</u>
1.1 million
<u>Michigan Children</u>
175,000

In a Special Report on the *Characteristics of the Uninsured and Select Health Insurance Coverage in Michigan* (Nov. 2003), Michigan children continue to have a lower chance of being without health insurance than nationally. Of Michigan's estimated 2.6 million children, 8.1% were without health insurance in 2001, down from 9.7% in 1999. This report also revealed that children in families below 200% of the poverty level were 13.3% more likely to be uninsured as compared to children in families at or above 200% of the poverty level.

Families with CYSHCN and Insurance

The National Survey of CYSHCN (2005/2006) is a national telephone survey. Participants are those who report having a child with a special need. Persons beyond

Michigan will spend more than \$1.1 billion in 2005 to provide uninsured residents with health services, often for preventable diseases or diseases that physicians could treat more efficiently with earlier diagnosis. This amount will grow to \$1.6 billion by 2010. (Families, USA)

those with Michigan CSHCS coverage or eligibility for their children were interviewed. Michigan data indicated that:

- 64.3% of CYSHCN had adequate insurance compared to 66.9% nationally.
- 35.7% of the insured have insurance that is not adequate, and 6.7% were without insurance at some point in the past year.
- Currently, 2.7% of families surveyed were uninsured.

When considered as a whole, these figures represent significant challenges in obtaining needed health care services. Lack of adequate insurance could be another reason Michigan's indicator is high for CYSHCN without a usual source of care (or who rely on emergency room).

Personal Narrative

The following scenario was written by a mom of a child with special needs enrolled in CSHCS; she is getting her son's share of her insurance premium paid by the CSHCS Insurance Premium Payment benefit.

My son has Canavan disease and is dying. While my focus should be on helping my son live a quality life I instead spend the majority of my time battling the insurance company. I had to first prove my son sick enough to warrant skilled nursing care in the home. The premiums have gone from \$1,100 to \$1,900 a month over the years my income has not kept up. Each year I shudder at the thought of how much the premium will go up. In addition to these premiums there are many medical and doctor costs that are not covered under the insurance, and I pay for out of pocket, not to mention day to day living expenses.

Since this situation began, I have wiped out my entire life savings including retirement in order to maintain appropriate health coverage for my family. Insurance has finally conceded that my son's medical involvement warrants 24 hour care, but state they will only pay twelve hours because of the policy. My argument has been our policy has what is called case management for those catastrophic situations, such as this, and can be altered. The insurance company refuses. Having a child born with a rare disease is no one's fault. But having a child die because he cannot access good health care is a crime that I know no punishment severe enough!"

Current Status in Michigan

In an attempt to **assist families to access more coverage**, Michigan sent a specific mailing, letter and application to families with CSHCS coverage when it appears they may be eligible for the MICHild/Healthy Kids programs to invite them to apply. CSHCS also provide the Insurance Premium Payment benefit to clients and their family who may qualify. The **Insurance Premium Payment** benefit will assist families in maintaining private health insurance through COBRA coverage payments and continuing health care payroll deducted premium payments. Materials are being developed for better outreach and to

notify families to contact CSHCS for assistance if they have access to other insurance that they are about to lose or that they could have but do not.

The Michigan **Family-to-Family Health Information and Education Center** (F2FHIEC) is a web-based center developed thru a federal grant thru the Centers for Medicaid and Medicare Services. The purpose of The Michigan (F2FHIEC) is to provide information, education, parent-to-parent support and decision making opportunities to all families of children with special needs. They do so by expanding and improving parent-to-parent information, support and education activities to underserved families. One of the components addresses public and private health insurance.

Challenges/Barriers

1. CSHCS could improve monitoring for access to private health insurance among its clients.
 - a. Many times, we do not know if a child has access to private health insurance and the family is not utilizing the benefit due to cost.
 - b. Often, we do not know when a child is losing private health insurance, due to loss of parental job or other circumstances.If we have a broader knowledge of these two scenarios, CSHCS may be able to assist the family with the Insurance Premium Payment benefit.
2. We do not know the number of working families who are employed by companies not offering health insurance, and who earn too much money to qualify for the MICHild Program.
3. Many families of children and youth enrolled in CSHCS are not aware of the Insurance Premium Payment benefit that could be of great assistance at some point in time.
 - a. The CSHCS program has created updated brochures on the topic and relies heavily on local health departments to identify and refer clients in need of assistance to this benefit.
 - b. While there have been efforts to educate families on this benefit, there is still more work to do.
4. There is a stigma regarding the Medicaid program.
5. CSHCS covers eligible conditions only and is not a comprehensive program.
6. There is not any mental health coverage for CSHCS
7. There is a lack of contact with Birth Defect Registry families

8. Providers don't always want to accept CSHCS due to low reimbursement rates and long prior authorization process.
9. The income threshold for MI Child qualification is 200% of poverty, and should be raised to 300% to increase the number of eligible for Program.
10. Funding for providers and local health departments is not adequate.
11. Excess funds that are not used during a fiscal year can not be carried over to the next year.

Strengths/Opportunities for Improvement

1. CSHCS has an insurance premium payment benefit in place.
2. Michigan has a lower rate of uninsured children and a high rate of employee based insurance than many other States
3. There is a proactive CSHCS Advisory Committee in existence made up of key stakeholders that help in making decisions
4. Michigan's CSHCS program covers a comprehensive list of diagnoses than many other States
5. Michigan has legislative support that has protected the financing of CSHCS from drastic budget cuts
7. There is an opportunity to expand outreach by having the CSHCS website be a direct link on various non profit groups' websites (Michigan Cleft Network, Hemophilia foundation, etc.)
8. We need to expand interagency infrastructure
9. Expand education to providers, employers, social workers, to raise awareness and expand case finding of children who would be eligible for CSHCS
10. There is a lack of information about all available programs. More collaborative efforts between local service programs are needed.

Prioritized Recommendations (outcomes from Strategic Planning)

- *1. Send letters to families reported to the Birth Defect Registry educating them on CSHCS.
- *2. Pursue the Medicaid buy-in option available for children with special health care needs through the federal Family Opportunity Act (families with incomes up to 300% of poverty could buy full Medicaid coverage).

- 3.* Improve communication, collaboration, and education (regarding healthcare) to all stakeholders between public/private agencies, professional organizations (AMA, MDA, MAPD, etc.)
4. Operate as regions; improve connections between regional hospitals and local health departments and other community agencies.
5. Insurance premium payment benefit: Expand/improve awareness and increase enrollment.

*High priority as determined by participants at the Strategic Planning session.