

## ISSUE BRIEF

**Outcome #5: Community-Based service systems will be organized so families can use them easily.**

*Michigan Department  
of Community Health*



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### **CHILDREN'S SPECIAL HEALTH CARE SERVICES STRATEGIC PLANNING 2008**

This background brief presents an overview of the **community-based services** 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 community based services 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 community based services 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 #5: **Community-Based service systems will be organized so families can use them easily.**

# Community-Based Services

## 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 easy to use community based services 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 #5.

### 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 Sickle Cell Disease, or a urinalysis ordered by the local pediatrician for a child with kidney disease whose specialist is 400 miles away).

CSHCS has a partnership with local health departments (LHDs) to provide a community-based "home" for the program. Each LHD in the state has a CSHCS office with staff support, which may include a public health nurse and a community representative. The amount of time and staff committed each week for services to CSHCS enrollees varies greatly and depends upon state and local funding structures. CSHCS relies on the LHDs to be the local "face and voice" of the program and is our best and most tangible way of being "community-based."

Historically, there has been no statewide access point to all services for children with special needs and their families. The range of services is often overwhelming, even for families with great resources. There are numerous state programs, home health agencies, specialty physicians, and clinics. Each of these programs and services has their own rules and procedures. In the broader view of services needed by children and their families, they may need to see many state agencies with related providers. The maps of services in every region of the state reveal that each of these agencies' service areas may be counties, multiple regions, cities or the entire state.

There was little top level coordination between state programs, home health agencies, specialty clinics, regional hospitals, and school systems. Compounding this situation, HIPAA and other privacy laws, or the interpretation of these laws, led to difficulty in communication among and between providers and authorizers of services. This leads to confusion for families who must deal with this situation by completing duplicative paperwork and multiple phone calls. Sharing complete health care information with consumers and between agencies is essential to the families' ability to participate in care and promote a positive outcome.

Michigan offers many services to families of CYSHCN. The CSHCS program relies on the LHDs to be aware of existing services to assist families in obtaining what they need. The needs of children and families are complex, as are the programs and funding streams available to serve them. To address the need for coordination at the community level, local public and private collaborative efforts came together in Michigan during early 2000 to work towards a shared vision and to mobilize resources for services and supports to families. This group of agencies and representatives in Michigan became known as the Multipurpose Collaborative Bodies of Michigan (MPCB).

The majority of MPCBs utilize community needs assessments to direct their work. MPCBs conduct their own needs assessment and use assessments done by member organizations. MPCBs use these assessments to guide decision-making on funding support for programs/services and allow for clear communication with elected officials (e.g., county commissioners, state legislators).

Many CYSHCN and their families must interface with a staggering number of systems and service providers. CSHCS enrollees must deal with distant, or not-so-distant sub-specialty providers, primary care providers, hospitals, pharmacies, durable medical equipment vendors, physical, occupational and/or speech therapists, and home health agencies, just to name a few. It is the goal that these systems and services, as well as CSHCS itself, be accessible as close to home as is feasible and be organized in an easy-to-use fashion for families. Much work needs to be done to achieve this goal.

#### Michigan Geography

- 96,810 square miles
- 11th largest of the 50 states
- largest state east of the Mississippi River

Additionally, Michigan is faced with the challenge of being an expansive state. This large area makes community-based services particularly challenging. This is further exacerbated by the location of most of the sub-specialty care being in the southern most part

of the state. The three children's hospitals and the sub-specialists who serve them are a minimum of ten hours away from the northern-most area.

Michigan is in various stages of progress in the development of telemedicine, one way to address the proximity issue. Michigan Medicaid policy allows for reimbursement of telemedicine services. Michigan's Upper Peninsula (UP) has a very advanced, well-developed, comprehensive telehealth system, including telemedicine. This has benefited many UP families (see Personal Narrative section) in their ability to interact with tertiary and quaternary care centers and sub-specialists based hundreds of miles away, but from the convenience and comfort of their local hospital and clinic. More connections need to be made between the UP and the down-state facilities and providers, and even more development work needs to occur in the Lower Peninsula, particularly between northern Lower Michigan and the southern most part of the state.

At one time Michigan had a well-developed perinatal regionalization system that helped organize the system into manageable portions as compared to the state as a whole. Much discussion is occurring across multiple systems regarding the benefits of re-creating a regionalize system of care across the state.

## Michigan and National Data

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 those with Michigan CSHCS coverage or eligibility for their children were interviewed. According to the National Survey:

- 75.7% of Michigan families report that community-based systems are organized so they can use them easily; this is above the national average of 74.3%.

- 17.3% reported having problems getting a referral for specialty care; this is below the national average of 21.9%.
- 14.6% had at least one unmet need for specific health care services; this is also below the national average of 17.7%.

The 2006 Child with Chronic Condition Custom Survey reported significant decreases from the previous year for meeting transportation and special therapy needs.

- 36.4 % received help with problems in getting special therapy in 2006 compared to 46.5 % in 2005.
- 58.7 % received help with transportation in 2006 compared to 77% in 2005.
- 72.7 % received transportation that met their needs compared to 85.7 % in 2005.
- All other provider attributes reflect an acceptable level of satisfaction for 2006.

### Personal Narrative

The following describes the experience of a local health department nurse and encapsulates the community-based approach that CSHCS strives to achieve.

Mary Meadows matter-of-factly describes her evening meeting with parents at their farm. "It was easier for me to drive to them," said the registered nurse who coordinates the CSHCS program in the Southwest Michigan area. "They would have had to hire a driver to get to me."

The family is Amish. That means, Meadows knows, they value self-sufficiency. Strict sects shun modern ways, such as cars. Meadows honored the dad's wish to be part of a meeting about CSHCS services. She drove to the farm. In order to meet after their farming work was done, Meadows flexed her hours.

A similar family followed their faith's practice of involving a bishop in a health decision. They included Meadows in the meeting. "A little guy needed to have a 'trach' and vent," she remembers. "We had to get special dispensation for electricity."

Summing up her experiences, Meadows said, "I think a lot of the trust I have built is because they know I respect their culture."

A foster-care family brought the following compelling story to the attention of MDCH policy makers in Medicaid and CSHCS.

A young child, who had been left in a car with his siblings while his mother gambled in a casino, was severely burned over his entire body when the interior of the locked car caught on fire as one of the children played with the cigarette lighter. The new foster family was making so many trips to Ann Arbor for appointments with sub-specialists at the children's hospital that they were going through a van a year. Each time another problem arose, it required strapping the children in their car seats and driving 10 hours to the children's hospital. This became not only a financial strain, but an emotional strain on the family as they had to leave their home community and travel long distances on a regular basis with small children unhappy to be confined in the car. Marquette General Hospital then found a way to connect the family with their specialty providers in Ann Arbor through telemedicine as part of a federal grant. The foster mom becomes emotional as she describes what this has meant to her family and particularly to the children. Not only is it a cost saver and convenience, but is so important for them to feel comfortable in their home community among people who know them well and are used to seeing this severely burned young child. This family's story played a significant role in Michigan being one of the first states to promulgate policy to pay for telemedicine services.

## Current Status in Michigan

CSHCS relies heavily upon **local health departments** (LHD) to assist families in locating additional health resources in their community that will meet their needs. Local CSHCS nurses and representatives work with families of CYSHCN to develop plans, access the services, and provide assistance they need. Financial resources are allocated to LHDs to provide care coordination and case management services to families who desire these services. Care plans are developed which guide how services will be obtained and delivered to CYSHCN. Some local CSHCS nurses work with *Early On*, the early intervention program administered by the Department of Education, and complete developmental assessments that are then coordinated with the CSHCS plan of care.

Local CSHCS nurses and representatives make referrals to and coordinate services with local interagency partners including: intermediate school districts (ISD), community mental health service providers (CMHSP), human service agencies (DHS) and primary care and specialty care providers. They assist families in the completion of enrollment applications and forms for other programs and services families need.

### Local Health Departments provide CSHCS Local Support

- Care coordination
- Case management
- Care plans
- Developmental assessments
- Links and referrals to community services
- Assistance to clients to navigate system and forms
- Transition information and guidance
- "Voice" of community and clients for CSHCS

(NOTE: not all services are provided by all LHDs and to all clients)

It is essential that the community base of CSHCS, the local health departments, are well trained and supported. To facilitate this, CSHCS has created new opportunities for education and input on

policy decisions. What was originally an ad hoc committee of various LHD staff has now been established into a full committee called the **CSHCS Local Advisory Council (CLAC)**. The CLAC meets every other month to inform the CSHCS division of needed improvements, comments on proposed policies, recommends policy revisions and problem-solves with the division staff to help improve the CSHCS system of care. CSHCS also holds two LHD meetings each year to bring the local staff together and provide program updates and education barring any budget restrictions.

In 2006, Michigan's CSHCS published and distributed a **Guidance Manual** for LHD staff. The Guidance manual includes CHSCS policy, forms, and procedures program to assist LHD staff help families easily navigate the CSHCS system. LHD staff from the CLAC also put together a supplement to accompany the **Guidance Manual** that includes an area for each LHD to add their procedures specific to the counties they serve. A **Transition Resource Manual** was also created for LHD staff. The Transition Resource Manual includes information and resources regarding the transition to adulthood and adult health care for young adults and family members of transition age.

The **Family Center for Children and Youth with Special Health Care Needs** (Family Center) provides community-based linkages and referrals through the **Family Phone Line**, a toll-free number, for parents and families to obtain information about services for their CYSHCN. The family phone line takes an average of 2,260 family calls monthly. Along with the family phone line, the Family Center also provides valuable services to assist family members to understand the CSHCS program. In 2004 the

Family Center published the “**Family Guide to Michigan’s Children’s Special Health Care Services Program.**” The Family Guide offers 44 pages outlining the CSHCS program and how to CSHCS access services.

The Family Center also has made great strides within the past year to bring attention and awareness to emergency preparedness and planning for families of children and youth with special health care needs. Approximately 30,000 **Family Preparedness Guides** are routinely mailed to all CSHCS enrollees to help plan for what to do before, during, and after an emergency, create an emergency plan, and prepare an emergency supply kit. Local health departments assist families in developing, maintaining and updating these plans through case management and care coordination.

The CSHCS **medical home** is an important community-based provider increasingly available to CYSCHN. Michigan is working to develop: (1) a mechanism for establishing medical homes; (2) a process to certifying that a practice meets criteria to be a medical home; and (3) a reimbursement strategy to compensate providers and practices for this extra time and effort. Without a medical home, it is difficult for families of CYSCHN to coordinate all of the complex medical care systems. Additionally, they can often lose track of important primary care services as they become consumed with specialty care providers, treatments, therapies, and other needs.

Because CSHCS continues to learn about families who were not aware of the program until several months after seeking specialty care, CSHCS is increasing **community awareness** through education. Many providers who serve CYSCHN and their families still view the program as insurance and not a system of care. **Targeted education** is provided for social workers and discharge planners at children’s hospitals across the state. **Better linkages** between the pediatric regional centers and the local health departments are also needed.

## Challenges/Barriers

1. There remains no single point of entry to services among state departments despite efforts to develop such access points. This is compounded by the wide variety of methods used to organize, deliver, and fund all services across communities across the state. For example, local DHS offices utilize a “state-employed” workforce with orientation directed to assisting in financial assistance programs. Community mental health organizations may be organized and funded from a county board but then implemented from a local office without direct control of the funding it receives. The lack of single entry point is further compounded by the plethora of services offered at various points without coordination of efforts among agencies. Included within this problem is the misinformation given by one agency of or about another agency. There is not single source of information about the programs offered, or criteria used for inclusion/utilization leading to fragmentation of efforts.
2. MDCH, CSHCS has inadequate funds to sufficiently fund local health departments to do what is needed for CYSCHN in their communities. Without sufficient funding,

inconsistencies of what can be expected of local CSHCS agencies become widespread.

3. Michigan's 57 Intermediate school districts (ISDs) are not clearly defined by county lines. All schools find themselves squeezed continually by federal, state, and local funding cuts and uncertainty. There are overlaps and potential for conflicts between federal requirements and funding of the No Child Left Behind (NCLB) law, which regulates all education and the Individuals with Disabilities Education Act (IDEA) that regulates and funds Special Education services. School districts are also expected to coordinate their health care services and therapies with the ever-changing public agencies seen by many of their children and students, including primary care providers, managed care organizations and clinics. Unfortunately, the only common thread in this jungle is the family, who is expected to know how to navigate these systems for their child who has complex and urgent needs from the various organizations.
4. CSHCS continues to hear of the challenge of discerning what is a school-based service versus what is a health service, a rehabilitation service, or a habilitation service. It appears there remains an issue of mental health services versus medical treatment with accompanying questions as to the use of developmental services versus medical services. A single source of accurate information about services across the spectrum of medical, mental, and developmental issues remains elusive
5. Long distance travel and lack of access to transportation is a major barrier for family members and young adults with special health care needs, with 50% of authorized providers located in a different county than the client. This provides a logistical problem to maintain ongoing coordinated care. Systems of care tend to be fragmented, uncoordinated, overlapping, duplicative, and regional rather than statewide. The CSHCS program and Medicaid provides some financial assistance with transportation but funding is extremely limited and always vulnerable to budget cuts.
6. Documentation also becomes a barrier for families as application letters, eligibility and renewal notices use medical diagnosis terminology that is difficult to discern by families. Also the lack of time and redundancy in information collected appears to be a burden to both the family and the CSHCS system.
7. The reduction of staffing levels in all community based organizations has increased the burden upon families to be knowledgeable of the resources within their community. This is compounded by the frequent staff turnover experienced within community organizations, which in turn leads to less collaboration during periods of orientation for the new staff.
8. Separate funding of programs leads to a silo approach by communities which then tends to exacerbate the previous issue. Differing opinions on the importance of outreach to the effected population are also effected by the funding sources.
9. There are not mental health coverages/services for CSHCS .

## Strengths/Opportunities for Improvement

1. Statewide expansion of telemedicine using the expertise developed in the UP. There may exist an opportunity to incorporate private agencies in the effort.
2. There are multiple points of entry to the system (medical from hospital, family mailed application, or completed at hospital)
3. Dedicated staff at local health departments, where a human (live body) answers the phone as opposed to infinite voice mail systems.
4. Utilization of human resources in combination with technology services.

## Prioritized Recommendations (outcomes from Strategic Planning)

- \*1. Increase system efficiency by 1). Resolve the transportation problem (singular definition/provider); 2). Streamline documentation among and between agencies; 3). Provide webpage directions for who to go to in the agency (“Guide for Dummies”, for services); 4). Develop a Who’s/who list of important contacts within the county; 5). Develop a Statewide Plan with incentives/reward for collaboration, 6). Change the hours of operation of community agencies to allow for “non-work hour” availability to parents.
- \*2. Health Communications Technology:
  - (1) Implement Telemedicine statewide; (Example: incentives to communities to make it worthwhile to host a site for multiple users)
  - (2) Increase the use of Infomatics ( example: Portable Health Record, which is family-controlled, HIPPA Compliant, allow for distribution of thumb drives)
3. Funding: Develop/Implement alternative resources for funding community services, identify cost-efficiency within the system, and enhance revenue generation by community agencies to support services being rendered.
4. Educate the Masses re: CSHCS/ Develop Public Relations Materials: Directed to Family, Provider, and Community agencies as to available services in the community; attempting to eliminate the turf campaigns. Increase family-to-family mentoring and support; develop web page instructions as to how one enters, to utilize services.
5. Additional recommendations included:
  - a. Increase communication technologies, telemedicine (the ability to utilize)(there may be grants from federal sources to improve access, utilize existing expertise to develop)
  - b. Resolve the transportation problems by coordination of efforts and opportunities; among and between agencies
  - c. Pursue coordination of top level administrations.
  - d. Incentivize Innovation/Investigations with public/private partnerships
  - e. Standardize/Formulate common forms for similar services
  - f. Improve the approval/review process

g. Coordinate with private foundations for funding.

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