This background brief presents an overview of the status of health screening 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 health screening 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 health screening 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 #4: All children will be screened early and continuously for special health care needs.
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 early and continuous screening for all children 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 CSCHS 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 CSCHS 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 #4.

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MI CSHCS Issue Brief, Outcome #4, 2008
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).

Rationale and Definition of Screening

Early detection of disabilities and developmental problems is critical to ensure early access to services and treatment, cost-savings for the health and educational systems, and improving the quality of life for children and families. The six MCHB outcomes are all based on timely and complete identification of children and youth with special health care needs. In that sense, screening is the foundation for other elements in a system of care that will achieve these outcomes.

Screening is defined as the administration of a brief standardized test to help identify children at risk of a disorder. The goals of screening are two-fold:
1. To identify children and youth who have special health care needs as early as possible in order to provide appropriate intervention services to address their needs; and
2. To continually monitor children and youth identified with special health care needs in order to identify or prevent secondary conditions that interfere with development and well-being.

There are two main categories of screening tests: (1) public health screening (population-based) and (2) medical home-based screening (individual-focused).

Public health screening is implemented in a setting where the entire population can be reached. Historically, public health screening programs began with screening newborns for phenylketonuria (PKU). In the United States, birthing hospitals provide such a setting for dried blood-spot screening that identifies PKU and other disorders in infants. A second example is the school setting, where public health vision and hearing screening may occur. Typically, public health screening programs include a follow-up database or registry to which screening results are reported. Children with positive screens are then monitored to assure they receive a diagnostic evaluation by appropriately skilled providers, and timely intervention with needed medical or nutritional steps. At times, these interventions can be life-saving for children with rare life threatening conditions.
The second type of screening is **medical home-based screening**, where screening compliments the surveillance process. Surveillance within a medical home is a flexible, continuous process, in which knowledgeable professionals perform skilled observations of children throughout the provision of health care. This is often done in consultation with families, specialists, child care providers, and other health care professionals. Screening is integrated with surveillance to detect a particular condition or disease through the regular or periodic use of a (professionally-administered) screening tool for all children, and/or when a parent raises a concern. Screening that targets an area of concern is indicated whenever a problem is identified during surveillance. A structure for the currently recommended screening tests and their appropriate periodicity is provided in the American Academy of Pediatrics (AAP) Policy Statement.

**Michigan Health Screening Programs**
The following provides a brief description of Michigan public health and medical-home based screening programs that assure early detection of disabilities and developmental problems among Michigan’s infants, children, and youth.

**Dried Blood Spot Screening (Newborn Screening Program)**
Michigan began screening for PKU in 1965. Since then, additional tests have been added to the dried blood spot screening, which now identifies 49 disorders. Medical Management Centers provide follow-up medical care of disorders identified through the newborn screening panel. Centers for hemoglobinopathies and metabolic conditions are located at Children’s Hospital of Michigan, while the center for pediatric endocrine disorders and the cystic fibrosis coordinating center are located at the University of Michigan Health System. The Newborn Screening Follow-up Program maintains short-term and long-term databases to coordinate communication among families, hospitals, the State laboratory, Medical Management Centers and the child’s primary care provider.

**Newborn Hearing Screening**
The Early Hearing Detection and Intervention (EHDI) Program, established in 1997, is a statewide system to assure all Michigan infants will be screened for hearing loss. Children who have hearing loss require early intervention and high quality support to develop communication and language skills equivalent to their hearing peers. The EHDI program works with hospitals and clinics to identify infants with hearing loss and assure that appropriate diagnostic and intervention services are received. Although not mandated by state law, all Michigan birthing hospitals now voluntarily screen every newborn for hearing loss. About 150 babies with hearing loss are reported to EHDI each year. Because hearing loss can still occur later in infants who initially pass the screening test, continued surveillance...
in the context of the medical home is needed to identify progressive or acquired hearing loss at the earliest possible time.

**Birth Defects Registry**
Michigan’s Birth Defects Registry (BDR) was implemented in 1992. Hospitals and laboratories submit reports on infants and toddlers (birth to two years of age) with a wide range of congenital anomalies, chromosomal disorders and other conditions. BDR reports are linked with vital records data via the electronic birth certificate. Thus, the physical exam completed on each newborn serves as a screening tool to identify major congenital anomalies such as cleft lip and palate and spina bifida. Michigan’s Public Health Code requires MDCH to develop, extend and improve services for identifying children with special health care needs and for referring these children to the appropriate services. As such, the BDR has the potential and the legal mandate to serve a coordinating function similar to that of the NBS program and EHDI. For example, the Birth Defects Follow-up Program contacts new families of children with neural tube defects by letter to assure they receive the services they need. At the same time, the letter informs mothers about the role of folic acid in reducing the risk of neural tube defects in future pregnancies. Pilot projects are underway to determine whether the families of children with other reportable diagnoses would also benefit from follow-up services at the state level.

**Blood Lead Screening**
The Childhood Lead Poisoning Prevention Program (CLPPP) supports the coordination of lead poisoning prevention and surveillance services for Michigan children. CLPPP also funds pilot sites for primary prevention of lead poisoning by identifying lead hazards in housing and using special environmental cleaning techniques to minimize lead hazards. Infants, children under six years and pregnant women are priorities for screening and testing. A state-local agency approach is used for program delivery including education and outreach; blood screening and testing; tracking; reporting; primary prevention activities; policy development and program management; quality assurance and evaluation. Children with severe lead toxicity are eligible for CSHCS.

**Hearing and Vision Screening**
Local health departments provide hearing and vision screening in schools throughout the state. CSHCS rarely interacts with the vision program because low vision is not among the CSHCS qualifying diagnoses. CSHCS, however, has a significant tie to the hearing screening program. Children who have abnormal screening results are referred to their primary care provider or to a system of CSHCS-underwritten otology field clinics. The otologists’ reports are submitted to
determine CSHCS medical eligibility. Children who qualify are then covered by CSHCS for otological services and/or audiologic and hearing augmentation services for hearing loss.

**Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)**

EPSDT sets the requirements for child health screening provided to Medicaid-enrolled children during their well-child care visits. Michigan’s EPSDT program holds as its standard for screening the AAP Periodicity Table published by the AAP in Recommendations for Preventive Pediatric Health Care. The AAP Recommendations are the same standards as those published in *Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents*, Third Edition.

**Developmental Screening**

The AAP recommends that all children receive periodic developmental screening, even if they do not have any identifiable risk or developmental delays. In the absence of risk factors or parental or provider concerns, they recommend a general developmental screen be provided at the 9-, 18- and 30-month well-child visit. These recommendations, however, are used only as a starting point. The health care provider should continue to carefully observe the child’s developmental progress, and developmental screenings should be conducted anytime that concerns are raised by parents, child health professionals, or others involved in the care of the child. Michigan is one of twenty states selected for participation in the National Academy for State Health Policy (NASHP) Assuring Better Child Health and Development (ABCD) screening Academy II. The ABCD project promotes developmental screening using a standardized tool in practices across the state. In addition to general developmental screening, “the AAP has recommended administering autism-specific screening tool at the 18-month preventative care visit.” (Bright Futures, 2008)

**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:

- 68.8% of Michigan respondents were successfully screened early and continuously. This is slightly above the national average of 63.8%.
  - When reported by age groups, those responding they were successfully screened increased with the age of their children.
    - Age group 0-3 reported a 52.3% success rate; and
    - The 6-11 age group reported a much higher success rate at 74.9%.
- While 67.5% of people without a medical home were successfully screened, those with a medical home were more likely to be screened (73.3%).
  - There is a clear increase in success rate for early and continuous screening that occurs for those receiving care within a medical home.
However, there remains a population of children whose need for services was not addressed in a timely way.

**Personal Narrative**

These stories reflect the parent and provider view on the importance of health screening and the need for increased coordination among screening providers.

**Parent Perspective**

When I took my daughter to her doctor for her 1-year check up, I was asked a lot of questions about my home and work and whether she has been exposed to lead. The nurse told me she needed to have a blood test to check for lead. I go to WIC and I am pretty sure they did a blood test there, but I am not sure and I don't have the results. The nurse insisted we go to the lab for a blood test – just to be sure. I want my daughter to be safe, but I don't want to have her poked a second time if it isn't necessary. Why doesn't my doctor know the results of the test we had done at WIC?

**Provider Perspective**

Jack came to clinic for his four-year health maintenance visit. This is our second time seeing Jack; he was seen a few months ago for a minor respiratory infection. He went to the health department for check-ups and immunizations in the past. Jack seems to be growing well; his height and weight are both at the 50 percentile. When I asked his father about what he can do, everything checked out fine – review of the major developmental milestones that I cover in a routine visit were all on track. However, responses on the ASQ (Ages and Stages Questionnaire) revealed that he may have a delay in fine motor development. The results of the ASQ prompted me to ask more questions of Jack's father. I learned that Jack is one of four children; both parents work. Jack watches television about 35-40 hours/week. Jack has not had a chance to hold a pair of scissors, he has no puzzles and he doesn't get to scribble at home. He is not enrolled in preschool or daycare. I doubt Jack has any underlying neurological condition, but he is delayed in his development and needs intervention. I referred him to Project Find for further evaluation and services. I don't think I would have picked up on his needs without the ASQ.

**Parent Perspective**

We are Carl and Sandy, the parents of four children ages 13 to 21. Our youngest two children Jenna (15) and Jess (13) have a rare metabolic disorder called “Maple Syrup Urine Disorder” (MSUD). This is a genetic disorder. Their bodies cannot metabolize 3 amino acids contained in protein and these become toxic to the brain. MSUD must be diagnosed in the newborn period or the child becomes brain damaged or dies. We are fortunate to live in Michigan, where Newborn Screening for MSUD has saved children's lives and protected their brains. The screening for MSUD began in 1987. Jenna was born in 1991, and was the first baby diagnosed with MSUD from Newborn Screening.... Jenna and Jesse are now healthy, smart kids in 10th and 8th grades. ... So it is easy to understand that for our family, Newborn Screening is a gift from God! We know that every day of health is a gift, and we were given the wonderful gift of newborn screening—the perfect gift we did not even know we needed....
Current Status in Michigan

Initial efforts have provided a basis for building a more comprehensive infrastructure to support screening and long-term follow-up in medical homes. The MIAAP (Michigan Chapter, American Academy of Pediatrics) Committee on Children with Special Health Care Needs has an initiative to create residency training curriculum to assist the state in achieving two of the MCHB outcomes:
1. All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home; and
2. All children will be screened early and continuously for special health care needs.

CSHCS participates with the NBS program to monitor, track and periodically screen children identified with sickle cell disease. A statewide network of pediatric hematologists and their clinics are proposed to enter pertinent clinical information in the Michigan Care Improvement Registry (MCIR). CSHCS proposes to provide access to the MCIR sickle cell database information system for the residency clinics at primary care/medical home sites. This will allow CSHCS to explore the utility of the information system as a convenient guide to remind the primary care provider of special steps needed for this population at each well-child or chronic care visit. Upon successful implementation by the pediatrics residencies, the curriculum content will be offered to interested family medicine residency programs.

On January 15-16, 2008 a two-day workshop was held to identify how Michigan can improve health outcomes for young children through Early Periodic Screening, Diagnosis, and Treatment (EPSDT). The workshop brought together over 35 key stakeholders, including state-level leaders in child health policy and programs and leaders in direct service provision, e.g., the Michigan chairpersons of the Academy of Pediatrics and Family Practice. The final workshop objective was to develop priorities for publicly-financed child health services. The six priorities identified by the Michigan stakeholders are:
1. Expansion of the current MCIR to include other important health and screening information, in addition to immunization records, which will assist medical home providers.
2. Development of a state procedure whereby CYSHCN can be co-managed by Michigan Medicaid Health Plans (MHP) and the Title V program.
3. Development of a system by which stronger linkages can occur between public screening programs and the medical home.
4. Further development and spread of the medical home particularly for CYSHCN.
5. Proper financing of Early On so that equivalent services are available statewide.
6. Revision of the current MHP mental health benefit to include a more appropriate option for young children.

For each of these priorities work groups have been formed and are committed to moving that topic forward.
As noted above, Michigan is one of 20 states participating in the NASHP ABCD program to **promote developmental screening using a standardized instrument.** Several Michigan health care providers have implemented a standardized screening tool. Physician champions from these practices meet regularly to learn from each others’ experiences. There exists a direct link between the medical home initiative of the MDCH and the ABCD program. A medical home demonstration project at Michigan State University is also a pilot site for the ABCD project. This intersection provides an opportunity to gain experience on the real world implementation of screening in a medical home.

Michigan CSHCS medical consultants participate in the **Region 4 Genetics Collaborative** which has the goal to improve access to genetic resources to children and families across the region. One of the priorities of the Collaborative is to integrate the medical home into newborn metabolic screening.

Michigan CSHCS medical consultants participated in a 2007 regional conference “Getting the House in Order: Creating Medical Home Solutions for Individuals with Autism.” **Early identification of children with Autism Spectrum Disorder** by implementing a standardized screening tool was identified as one of the responsibilities of a medical home.

**Challenges/ Barriers**

1. Michigan has many new born screening programs in place across the state but the methods, reporting and follow up are inconsistent.
   a. The Newborn Screening (NBS) program has an effective system to find and follow infants who screen positive on one of the tests. However, there is not an adequate system in place to track those infants who are not screened, either because of oversight or parental refusal of the test. Primary care providers receive NBS results on most but not all infants they follow. Most primary care offices do not have a mechanism to notice if an infant was not screened.
   b. Newborn hearing screening is occurring in hospitals across the state. The results of screening tests are often not available to primary care practices. Doctors and nurses rely on parent report or spend time tracking down results. Past the newborn period, surveillance is used to identify hearing impairment that was not evident in the newborn period. Hearing screening using a standardized test is available in health care provider offices, but implementation is not uniform.
   c. Michigan does not have a central repository of the results of screening tests. Health care provider practices are responsible for tracking and monitoring results and for noting if a child has not been screened. Results from screening tests do not follow the patient and are not available to health care providers when the child/family changes providers. We do not have a database that health care providers can access to learn if their patients have been screened and, if so, the result. The absence of an accessible database leads to duplication of efforts and,
more significantly, omissions and the potential to miss identifying a
c Condition that can be treated if found early.

2. Vision screening occurs in most health care provider offices, but is not uniform. Local Health Departments no longer receive funding or training on performing the vision screening. Opportunities to identify problems in vision are lost if the child is uncooperative at the time of the visit. Communication between Headstart, Early On, schools and health care providers is haphazard.

3. Developmental screening:
   a. Some practices in Michigan are using a standardized developmental screening tool, but implementation is not uniform.
   b. There is concern that Michigan Early On providers will be unable to respond to all the referrals generated once screening is implemented broadly.
      i. Current referral rates are lower than 3% in most counties; prevalence of developmental delays requiring early intervention is between 5 – 7%.
      ii. In many, if not all, Michigan counties, the intermediate school districts do not have adequate personnel or funding to evaluate and serve all the children who will be referred if universal screening is implemented.
      iii. Compounding this situation, the two screening tools most often used (the ASQ and PEDS) both have specificity rates of about 80% -- meaning that some children who screen positive will not have developmental delays. Early On providers would need to evaluate all children who screen positive to determine who is eligible for services.

4. Similarly, implementation of a screen for autism at the 18-month visit will increase the load on an already overburdened mental health system struggling to meet the needs of young children and their families. Mental health services for young children are uneven across the state and generally inadequate.

5. Implementing developmental and/or social-emotional screening using a standardized tool such as the ASQ or PEDS takes time, effort and materials. Some third party payers (MI Medicaid) reimburse physician offices for the service as a separate and identifiable service (99610) at the time of the preventive care visit. Many payers (Blue Care Network, PHP) consider it a part of the preventive care visit and do not reimburse additionally for the service. Physician offices are less likely to offer a service that costs time and money but is not reimbursed.

6. There is no dental screening in Michigan.

7. There is no standardized screening for Children’s Special Health Care Services.

8. EPSDT is no longer supported through the LHD and the physician are not providing this screening uniformly across the state.

9. There is no funding for screening either to the LHD or the physicians.
10. Parents are in need of education on the screening that is available, the results of those screenings and where to go for follow up.

11. The question of how to handle the ethical problems of screening and referral needs to be addressed when developing further testing.

**Strengths/Opportunities for Improvement**

1. Michigan has a well established newborn screening program that includes blood and hearing testing.

2. Michigan has a web-based data system in place for immunizations. Called MICR. A data system may be able to be developed for screening test results building on MCIR. Results for newborn screening, hearing, lead, developmental, social, emotional and vision screening could all be entered and tracked on the database.

3. Michigan has a Birth defect registry which could be used for contacts with children that may need additional screening.

4. Work with private insurance companies to assure payment for screening with a standardized tool as a separate and identifiable service.

5. Michigan has the Governor’s Great Start Initiative/Michigan Early Childhood Investment Corporation (ECIC) Pediatric and Family Health Committee that will bring together leaders in pediatrics and family health to create a Michigan forum for shared leadership, coordinated planning and strategic action. This may be able to be used to help develop standards and coordination of programs.

6. Michigan has a Family to Family support group for hearing loose in place that may be able to be used for families receiving positive screenings.

**Prioritized Recommendations (outcomes of Strategic Planning)**

*1. Support MCIR as a single electronic record for the multiple data systems.

*2. State-wide education of all providers to spread knowledge of screening and importance of follow-up (through MI-CHIP mechanism).

*3. Develop performance standards for screening and follow-up.

4. Establish partnerships among all stakeholders, (EO, Genetics, Birth Defect Registry, CSHCS, LHD) that will promote strategies to move from screening to reporting to appropriate referrals, through a work group.
5. Promote use of existing educational materials for parent education and networking.

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