

**Meeting Notes**  
**CSHCS Strategic Planning: Screening Work Group**  
**Monday, June 29, 2009**

**Participants: George Baker, Cheryl Celestin, Glen Copeland, Michelle Garcia, Kevin Garnett, Teresa Holtrop, Vicki Jenks, Carole Keefe, Dennis Lyne, Mary Marin, Marilyn O'Neill, Nancy Peeler, Jeff Spitzley, Peggy Taylor (phone), Lois Turbett, William Young.**

Vicki Jenks chaired the meeting and welcomed the members and guests.

Dr. George Baker reminded the group that early and continuous screening for special health needs is one of the six core outcomes set out in the Healthy People 2010 National Health Objectives to break down barriers to community inclusion for people with disabilities. The national goal is to increase the proportion of states and territories that have service systems for children with or at risk for chronic and disabling conditions. He noted that one of the first steps toward developing a system of care is to identify or screen kids likely to have a special health care need.

Parts of the system of care are to have a clear diagnosis and to use a registry to track children so as to help assure access and that they get the best care possible. Registries can include clinical guidelines that monitor the child's disease process and at certain points provide reminders about needed care. This allows for effective secondary prevention. In Michigan, this is in its beginning for some conditions including sickle cell disease, hearing impairments, developmental issues, and autism spectrum disorder. There are two major approaches to screening that we will talk about in the meeting: the public health approach as in newborn screening and screening that is done in the medical home as for developmental screening.

Kevin Garnett gave a presentation to illustrate how MCIR (the Michigan Care Improvement Registry) can provide a registry to track children and their care over time. Using an application developed for Sickle Cell Disease, he illustrated the various linkages possible and how different users could gain access to input data and to learn what care has been provided. The platform developed can serve as the foundation for tracking other diseases and conditions. He also discussed the safeguards that are a part of the system to protect privacy and confidential information. The Sickle Cell Center at Children's Hospital of Michigan in Detroit and its regional clinics <http://www.childrensdmc.org/?id=457&sid=1> are the designated centers to oversee all the cases of sickle cell trait and disease in the state. The Center in Detroit relates to other approved clinics across Michigan. To develop the data base, a panel of clinicians decided the data that should be included to assure evidence-based care. Though this is developed, the clinics have not yet begun to input individual client data.

Dr. Baker said that there are four medical management centers currently in place that are part of Newborn Screening in Michigan: 1) hematology (includes sickle cell), 2) metabolic disorders, 3) pulmonary (includes cystic fibrosis), and 4) endocrinology. The contracting medical management center does information management and the additional identified sites provide subspecialty care.

## **SICKLE CELL DISEASE ASSOCIATION OF AMERICA, MICHIGAN CHAPTER (SCDAA)**

The Sickle Cell Disease Association of America provides comprehensive services to all newborns with hemoglobinopathies detected by NBS in Michigan. The SCDAA is located in Detroit and is directed by Wanda Shurney, M.D. The primary responsibilities of the SCDAA are to assure that: (1) all newborns referred with positive sickle cell screening results are appropriately diagnosed, (2) penicillin prophylaxis is initiated, (3) sickle cell counseling and social work services are available, and (4) each newborn has a medical home. In addition to the central office in Detroit the program maintains offices for social workers (patient advocates) in Grand Rapids, Benton Harbor, Pontiac, Flint, Kalamazoo, Lansing, Muskegon, and Saginaw.

## **CHILDREN'S HOSPITAL OF MICHIGAN METABOLIC CLINIC**

The Children's Hospital of Michigan Metabolic Clinic is responsible for diagnosis and medical management of all newborns with the 42 metabolic disorders detected by NBS. The clinic also provides biochemical and molecular genetic diagnostic laboratory services. The clinic is directed by Gerald Feldman, M.D., Ph.D. while Robert Grier, Ph.D. is the director of the biochemical genetics laboratory.

## **NEWBORN SCREENING (NBS) AND COORDINATING PROGRAM FOR CYSTIC FIBROSIS, UNIVERSITY OF MICHIGAN HEALTH SYSTEM**

The NBS and Coordinating Program for Cystic Fibrosis (CF) is housed within the Department of Pediatrics of the University of Michigan Health System and coordinates with CF centers in Lansing, Grand Rapids, Detroit, and Kalamazoo to provide comprehensive services to all newborns with CF detected by NBS. The CF coordinating center is led by pediatric pulmonologist, Dr. Samya Nasr. The CF screening program is advised by a committee including the five CF foundation approved CF clinics' directors.

## **ENDOCRINE FOLLOW-UP PROGRAM, UNIVERSITY OF MICHIGAN MEDICAL CENTER**

The Endocrine Follow-up Program in the Department of Pediatrics, University of Michigan, maintains a centralized communication, referral and treatment assessment office that provides follow-up to ensure appropriate diagnostic evaluation and treatment of all infants with positive CH or CAH screening results. The overall program is directed by Ram Menon, M.D. Ming Chen M.D., Ph.D. is the director of the Center of Excellence for the Diagnosis and Management of CAH. The Pediatric Endocrinology Advisory Council (PEAC) provides advice to the Michigan NBS Program on screening, diagnosis and medical management of newborns with suspected endocrine disorders.

The next presentation was by Michelle Garcia on Newborn Hearing Screening and Follow-up. Her presentation is attached as a separate document. Some comments about various slides. Slide 9, she said that the auditory brainstem response (ABR) is the most used screening method. Slide 11, note the high percentage of reported hearing screenings relative to births. About 97% of hospital births are screened. It is estimated that 1% of children are not screened. There are about 600 home births in the state annually. One of the problems is that if a child is brought to the hospital for screening, there is often a charge and if the family can not pay or does not have insurance, these are barriers to screening. Slide 13, the identification of permanent hearing loss cases has risen since the reporting of screening was mandated in 2006. The rise in cases from 2005 to 2007 is thought to be because of better reporting. Slides 15 and 16, EHDI would like to improve loss to follow up. They have follow-up on about 63% of children screened. Vicki Jenks said that she had asked CSHCS nurse coordinators to do newborn screening follow-ups in the past, and they might be helpful to follow-up cases with EHDI. It was noted that they can be paid for case management to do the follow-up.

Dr. Teresa Holtrop discussed the ABCD (Assuring Better Child Development) project in Michigan and developmental screening in general. Her presentation is attached as a separate document. Note the references in slide 3. Dr. Holtrop said that the data really resonate with pediatricians when they learn that usual care results in missing 70% of children with developmental problems. Slide 23 refers to enhanced reimbursements. Providers can bill for up to three different screens a day using the 96110 code. Examples might be the ASQ, MCHAT and a screen for maternal depression. While Medicaid reimburses for the screenings, some private insurances do not. If a practice bills Medicaid, they also have to bill other insurances. This can mean that families may be billed for the screenings. In some instances, the practices bill but forego or write off the payments, so billing and reimbursement are still issues. A hopeful advance is to have developmental screening included as a HEDIS measure. This would likely encourage commercial insurers to do more and pay for screening. The screening efforts are making pediatricians more aware of local early intervention opportunities, but it is also clear that the referral process is complicated and the data sharing among public health, medical practices and educational entities is complicated.

Dr. George Baker made comments on building a system of care for autism spectrum disorder (ASD). There are evidence-based interventions, but no system of care. It is recommended that the MCHAT be used to screen for ASD at 18 and 24 months. Children who do not pass the screen receive a follow-up test from Early On or other designee. Then if still indicated, the child should be referred to a developmental evaluation team (social work, speech, psychology, medical consultant) for follow-up. There are tensions among stakeholders which include parents, educators and physicians. Currently there are two pilots under way in Holland and Ypsilanti. This web site can provide additional information about the pilot.

<http://www.cenmi.org/asd/Home.aspx>

After the presentations, Vicki Jinks reminded the work group of the strategic planning objectives assigned to the screening work group.

- **Provide statewide education of all providers to spread the knowledge of screening and the importance of screening follow-up.**
- **Support MICR as a single electronic record for the multiple data systems.**
- **Develop performance standards for screening and follow-up.**

It was noted that each screening needs to be tied to a system of care. MCIR has promise for evolving to a registry to support and track care. MCIR could serve a registry function for certain CSHCS diagnoses.

There are already systems of care in place for myelodysplasia, cleft palate, gastroschisis, and major cardiac defects.

It was suggested that it would be helpful to have an exhaustive list of screening that is occurring, and learn how the screening integrates with clinical guidelines and diagnostic and care coordination resources. Screening is happening in many settings outside primary care practices.

The question was asked about the scope of the work group. Dr. Baker noted that the screening scope is all children because that is the only way to assure early identification.

The Great Start mandate is “to ensure that every young child in Michigan has a Great Start and arrives at the kindergarten door healthy and ready to succeed in school, with parents who are committed to educational achievement.” It was advised that there are screening activities going

on in many different venues and without awareness and coordination there could be duplications and overlap. The Maternal and Infant Health Program is screening as is Head Start.

Dr. Baker said that the intent is to make recommendations for the CSHCS program so as to meet the core components of a system of care, but we need to consider also CYSHCN and assure that children are screened. In effect we need to look at the bigger picture and links to CSHCS.

If the group's mandate is screening, can we get a comprehensive picture of what is going on? A number of initiatives were mentioned.

Nationally, Bright Futures is a comprehensive and family-centered approach to screening and intervention. It is a national health promotion and disease prevention initiative that addresses children's health needs in the context of family and community. In addition to use in pediatric practice, many states implement Bright Futures principles, guidelines and tools to strengthen the connections between state and local programs, pediatric primary care, families, and local communities. Whether you are a health care or public health professional, a parent, or a child advocate, Bright Futures offers many different resources for your use in improving and maintaining the health of all children and adolescents.

<http://brightfutures.aap.org/index.html>

This is a link to the Bright Futures periodicity schedule for screening and risk assessment.

<http://brightfutures.aap.org/pdfs/AAP%20Bright%20Futures%20Periodicity%20Sched%20101107.pdf>

In looking at the three assigned objectives, the work group is making progress toward each. It may be helpful to catalog activities occurring in each focus area as we anticipate a future meeting, probably in September or early fall.

Notes submitted by Carole W. Keefe/Vicki Jenks