



Family to Family Michigan Update

SUMMER 2015

F2F Michigan provides: “Resources, information and education for children and youth with special health care needs; the families who love them and the professionals who help them.”

Join our email list! Click on the tab on our website and fill out the form to be notified of upcoming news, resources and educational opportunities.

Top News You Can Use and more....

- In the **King v Burwell** ruling issued in June, the Supreme Court held that premium tax credits are available to offset the cost of health insurance regardless of whether or not a person signed up through a federal or state exchange. This decision upholds provisions in the Affordable Care Act (ACA) and will help to make health insurance affordable and accessible to more families.
- Sunday, July 26th marked the 25th Anniversary of the **Americans with Disabilities Act (ADA)**. President Obama gave a speech at the White House commemorating the milestone. For more information about the ADA, visit Disability.gov’s [Americans with Disabilities Act \(ADA\) Web page](#).
- At the state level, Lt. Governor Brian Calley signed legislation into law which updates state statutes by eliminating language with regard to programs for children with special health care needs. Public Acts 89-94 of 2015 remove all references to “crippled children” from Michigan law. The new language is “children and youth with special health care needs”.
- The Michigan Legislature is in the process of considering legislation to implement the **ABLE ACT**. Congress passed the legislation in December 2014, and now it is up to each state to adopt legislation to implement the new law at the state level. It is expected that Michigan residents will be able to take advantage of this new program by January 2016.

If you like to keep up on what is going on at the federal and state levels, Family Voices is an excellent resource. [Family Voices](#), one of Michigan Family to Family’s national partners, publishes a Washington update to which you can subscribe, and also has a great website full of resources, information and advocacy tips for families. In Michigan, the [Michigan Council for Maternal & Child Health](#) publishes *Friday Notes* each week to provide updates on state and national news and events related to maternal and child health news. Email info@mcmch.org to get on their mailing list.



Don't Forget to “Like” us on Facebook!

Like our page to get information on resources and events,
and to connect with other families!





Life isn't about waiting for the storm to pass, it's about learning to dance in the rain.

The Importance of Peer Support

Parenting a child with special health care needs can be difficult, and sometimes talking with other families with similar life experiences can be a great source of understanding and emotional support.

In this newsletter, we highlight two programs which offer parent-to-parent support for families, the **Parent to Parent Support Network** at the Family Center for Children's Special Health Care Services and the **Guide by Your Side** program with the Early Hearing Detection and Intervention program.

Many agencies and programs offer some sort of support services for parents and siblings of children with special health care needs. However, peer support doesn't have to be offered through a formal program.

Sometimes a chance meeting in a doctor's waiting room, or at a play group can be enough to make you feel like you are not alone.

Many parents say that in addition to emotional support and friendship, knowing other parents of children with special health care needs is a great source of information and resources. Parents who have experience navigating the system have great advice on how to access services. The Parent Coordinators at Michigan Family to Family are both parents too. It is our job to help connect you with resources.

If you would like more information about peer support programs, or how to connect with other families, please contact us. We are here to help!

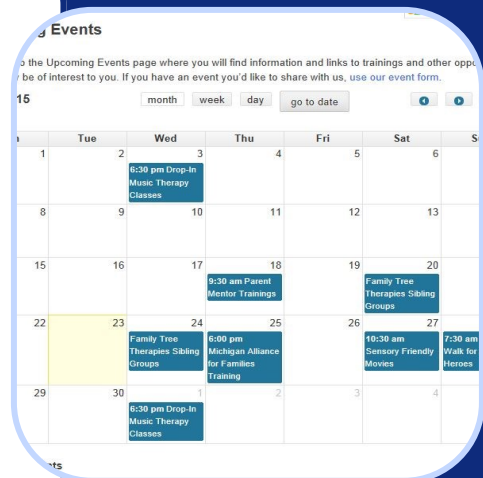
MI F2F Adds Event Calendar to Website

Michigan F2F has added an [event calendar](#) to our website! We are excited to offer this new feature to our families and providers.

We want the calendar to be as comprehensive as possible, so encourage you to send us your events so that we can include them.

Please send your events to jpilditc@mphi.org or call one of the Parent Coordinators at (517) 324-7396 or (517) 3224-8391.

In addition to the calendar, we have added the *Google Translate* feature so that the information we post is accessible to as many people as possible.



Family Center Offers Parent to Parent Support

In our last newsletter we featured the Parent Consultants who work with the **Family Center for Children and Youth with Special Health Care Needs**. The Family Center is the statewide parent-directed center within the Children's Special Health Care Services (CSHCS) at the Michigan Department of Health and Human Services (MDHHS). One of the programs that the Family Center offers is the **Parent-to-Parent Support Network**.

Sharing family experiences with others in similar circumstances is an important source of support for many parents. Other parents can share information about resources and services, as well having the unique perspective of understanding what it's like to parent a child with special health care needs. The Family Center facilitates matches between an experienced parent and a parent who is seeking information, resources, guidance, and support.

The Family Center offers Parent Mentor Trainings, where parents of children with a medical, physical, developmental, behavioral or emotional condition can become Parent Mentors and are trained in communication skills, listening techniques and community resources. After completing the training, Parent Mentors become part of a statewide network of volunteers.

When parents who are interested in being matched with a Parent Mentor call the Family Center, they will be asked about their child's age; diagnosis and specific challenges; reasons for seeking support; qualities they hope for in a Parent Mentor; and any unique preferences or issues related to the match. Family Center staff will check the roster of trained and available Parent Mentors to identify someone who seems to be a good match. If the Parent Mentor agrees to the match, then contact information for the referred parent is shared with the Parent Mentor. After the match is made, the Family Center provides follow-up support to ensure that the match is a success.

If you are interested in becoming a Parent Mentor or being matched with a Parent Mentor, contact the **Family Phone Line at 1-800-359-3722**.

*I am a stranger to you now, but let me walk with you for a while.
Because I have been where you are and where you are about to go.
I have no answers. I offer my hand, my heart, my listening ear,
my time and my experience.*

So that one day you can turn to another and say:

*I am a stranger to you now, but let me walk with you for a while.
Because I have been where you are and where you are about to go.
I have no answers. I offer my hand, my heart and my listening ear,
my time and my experience...
So that one day.....*



The Michigan Newborn Screening Program is celebrating 50 years of saving babies' lives! Since 1965, Michigan's screening panel has expanded from one to 55 conditions – all of which require early treatment to prevent illness, disability or death. Newborn screening looks for conditions that may affect blood cells, brain development, how the body breaks down nutrients from food, hormones, lungs and breathing, heart development, hearing and how the body fights infection. Some examples of these disorders are phenylketonuria (PKU), congenital hypothyroidism, sickle cell disease, cystic fibrosis and hearing loss.

About 6.9 million Michigan newborns have been screened since the start of this program leading to life altering diagnoses and treatment for over 7,200 babies. Through three simple screening tests (blood spot, hearing and heart screening) administered during the first hours of life, newborns can be identified with serious but treatable conditions, helping to prevent complications and improving the health and well-being for these children.

Please visit www.michigan.gov/newbornscreening to learn more about newborn screening and help celebrate the 50th anniversary of this important public health program in Michigan.

Early Hearing Detection & Intervention Program

Hearing screenings detect hearing loss at birth and are done before a baby leaves the hospital. This screen is mandated in Michigan because hearing loss is invisible and babies with hearing loss look and behave just like other babies. The test is quick, simple, safe, and just takes a few minutes.

Babies are born ready to learn about the world around them. Hearing is important for speech and language development, so it is important to start early intervention right away if any hearing loss is found.

Michigan Hands & Voices is an organization dedicated to supporting families of children who are Deaf or Hard of Hearing, regardless of the communication mode chosen by the family. Their philosophy is "What works for your child is what makes the choice right."

Michigan Hands & Voices also offers the **Guide by Your Side program**. Through this program, families can visit with a Parent Guide, who is another parent of a child with is Deaf or Hard of Hearing and is trained to provide non-biased information and resources. For more information, visit their [website](#) or call (517) 335-8955.



Tips for Transition

What's the difference between a High School Diploma and a Certificate of Completion?

If your son or daughter receives special education services you may have heard the term "Certificate of Completion". It is important to know the difference between this and a high school diploma. A diploma is an academic credential that is awarded to students who have met the Michigan Merit Curriculum graduation requirements established by the State of Michigan. A Certificate of Completion is given at the discretion of a local school district to students who have completed an alternate course of study, such as under an IEP. A Certificate of Completion allows a student to participate in graduation activities, but is not recognized by the State and does not exclude a student from continuing to receive special education services until the age of 26. For more information on this, and other special education topics, visit the [Michigan Alliance for Families website](#).



Catalyst Center Seeks Family Input



The Catalyst Center is a national center funded by the U.S. Department of Health & Human Services dedicated to improving health care coverage and financing for children and youth with special healthcare needs and disabilities. They are looking for stories from families that help illustrate the special challenges faced by families of color, immigrants and families from diverse cultural backgrounds, families who speak languages other than English, have limited income, or whose children have physical, mental, behavioral, or emotional needs that greatly impact their ability to do things the same way as other children their age.

They intend to include these family stories in written materials that can be printed and posted on their website and sent to policymakers, health care providers, family leaders, advocates, legislators and other interested parties. They may also use the information to publish research on outreach strategies to reduce inequities among CYSHCN. Neither your child's nor your family's identifying information will be used with your permission. **Share your story!** For more information on how to do this contact F2F Parent Coordinator Kristen Hawkins at khawkins@mphi.org.

What works for your child is what makes the choice right

Hands and Voices

I am Karina and I have MCADD too!

Hi! I am Karina and I have MCADD too! Having MCADD means that I have a special diet like I can't eat coconut cause it's a medium chain and my body can't break it down. And I eat for energy so I can play or do anything I want.

You know it's like putting gas in your car so you can go places. I also eat a carb and a protein before I go to sleep so that it gives my body energy while I am sleeping because my body can't go past so many hours without eating. And when I get sick I have to eat more often around the clock cause my body needs the energy to help me when I am sick. Oh yeah, I also take medicine carnitine that helps takes the toxins out of my body. And when I get really sick I go to the hospital to get D10 and Zofran when I throw up it helps me feel better. It really works!

I know I am always gonna be okay, I make sure I carry snacks and that I have my emergency protocol with me just in case. And I think it's important that doctors know and listen to us kids when we tell them we need D10 when we don't feel ourselves. So that we can speak about it so they know how we feel and to help us be better when we are sick. Cause we know when we don't feel good.



I want to help kids that have MCADD. I want them to know that they can do anything they want just like me! Just believe you can and not to worry because, I have MCADD too! I want to be a MCADD doctor to help kids when they get sick cause I have it too and so they won't be scared. It's okay to have MCADD.

Karina is 7 years old. She lives in Marysville, MI with her family. She will be going into 2nd grade this fall. MCADD stands for medium chain acyl-CoA dehydrogenase deficiency. It affects an individual's ability to break down fat into energy for the body.



Visit our website at www.f2fmichigan.org.



Michigan Family to Family Health Information Center (MI F2F)

assures that families of children and youth with special health care needs (CYSHCN) are able to participate in decision-making at all levels and be satisfied with the services they receive.

How Can MI F2F Help?

MI F2F can help families with CYSHCN because they are staffed by family members who have experience. They know firsthand how to navigate the maze of health care services and programs for CYSHCN. MI F2F staff understand the challenges families face. They help families make informed decisions to get the best possible care for their child.

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Disclaimer: The Michigan Family to Family newsletter includes information and links to internet and other resources. These resources are for your consideration only and are not endorsed by Michigan Family to Family Health Information Center, Michigan Public Health Institute or our funders. The information provided should not be used for diagnosing or treating a health problem or disease, and is not a substitute for professional care.

How to contribute to upcoming newsletters:

F2F Michigan is interested in sharing on topics of interest to families of children and youth with special health care needs across Michigan. If you have an upcoming event, learning opportunity, educational resource or other items you would like to share, please contact us at: F2Fmichigan@mphi.org.