

Michigan Family Connections

for Families of Children and Youth with Special Health Care Needs

Fall 2016

*A newsletter
for families of
children and
youth with special
health care needs,
and professionals
who help them.
Connecting you
with information
and news you
can use!*

**A quarterly publication
brought to you by the
Family Center for Children
and Youth with Special
Health Care Needs and
Michigan Family to Family
Health Information Center.**

Seeking Story Submissions

Have you ever wished you had the opportunity to share your experience with others? One way to do this is through writing. Michigan Family Connections is seeking personal stories and/or poems from families of children and youth with special health care needs. Six stories or poems will be featured in the February 2017 "Sharing our Stories" newsletter.* The authors of the stories featured in the newsletter will receive a \$50 Visa gift card for their submission.**

We are looking for stories of emotion, courage and lessons learned. Stories that highlight the experience of living with all abilities, including your joys, your sorrows and your pride.

You may submit your original, unpublished personal story or poem to the MI F2F website. Below are a few suggested topics:

- Grief and acceptance
- Youth or young adult living with a disability
- Insurance issues
- Inclusion
- Transition
- Sibling or family relationships
- Family-centered care
- Newborn screening
- Mental health
- Peer-to-peer support

These are just suggestions, please feel free to choose your own topic or submit your own idea.

We ask that you please be respectful of others and be sure all opinions and beliefs are stated as your own. If you cite facts within your story, please provide a link to a credible source.

To submit your story, use the link below:

<https://f2fmichigan.org/family-stories/>

Then click on the "share your story" link.

We would love to hear from you. We are inspired by the families we serve. Your story can motivate, encourage and inspire others. Share your family's challenges and successes. Let us know what's worked for you, and what hasn't worked for you. Share your tips and what you would like other families to know.



*Depending on the number of stories received, not all submissions will be used for the special edition. All stories submitted will be shared on the MI F2F Website.

**By submitting your story you are agreeing to have it published in the newsletter without additional financial compensation. Your story may be edited as necessary for length and content.

Time to Check Your Health Insurance

Why is now a good time to look at your health care needs and options?

If you're uninsured or looking for more affordable health insurance, the "open enrollment" period is the time to visit healthcare.gov. During "open enrollment", private health insurance options can be reviewed and coverage can be purchased.

People with low and moderate incomes may be able to get financial help to pay for health insurance coverage. Assistance to pay for premiums and other cost-sharing may be available for individuals and families, depending on which plan is purchased. If you get health insurance through your employer, Medicaid or Medicare, you are not eligible for this assistance.

You can sign up for insurance outside of the open enrollment period, if you lost your job, married, divorced or had a baby.

Do you already have health insurance through the Marketplace?

It is also important to update your income and household information in the Marketplace to make sure you get the assistance that is available.

- This is a good time to check your health insurance coverage and see if it still meets your healthcare needs.
- You may enroll in a different plan each year or you will be automatically re-enrolled in your current plan or a similar one by December 15, 2016.
- If a new plan does not cover your providers or services, seek more information about transition rights.
- You should carefully read all health insurance notices and updates.

If you have a disability or a health condition, pay attention to details or possible changes:

- Are a broad range of health care providers included in the health plan's network of providers?
- Are there enough medical specialists in the network to meet your needs?
- Are needed medications included in the plan's list of covered drugs?
- Is there adequate access to non-clinical, disability-specific services and supports?
- Does the plan have service limits, such as caps or limits on the number of visits for therapy services?



- Are mental health services covered to the same extent that other physical health benefits are covered?

Why should you check your coverage?

- Even if you like your current health plan, new plans may be available and premiums or cost sharing may have changed since last year.
- Even if your income has not changed, you could be eligible for more financial assistance.
- If your income has increased, updating your information with the Marketplace will help avoid paying future penalties.

Where to get help?

Purchasing health insurance can be complicated. If you need assistance with understanding the options, healthcare.gov can help. This website has information about seeking assistance in your community, explanations of health insurance terms, enrollment information, assistance with out-of-pocket cost estimation and more.

There is also a 24-hour phone line for consumer assistance at 800-318-2596 to call for help. In addition, each state has health insurance "navigators" to assist individuals with enrollment. Many are even able to meet with you in person.

You can find them at:

<https://localhelp.healthcare.gov/#intro>

2017 Open Enrollment

November 1, 2016

Open enrollment begins

December 15, 2016

Enroll before this date to have coverage Jan 1, 2017

January 31, 2017

Open enrollment ends

From the MI F2F Website

Be a Community Partner

The Michigan Family to Family website provides a clearinghouse of information, educational materials and resources for families, youth, providers and other community organizations. We invite you to partner with us by joining our network of resources. We would like to share information on our website about your organization and the valuable work you do with families and youth.

To be listed on our website, use the following link:

<https://f2fmichigan.org/partners/>

Then, double-click on [click here to register](#).

On this form, you will be able to provide information about your agency or organization that you want to share with the public. You can include information you feel would be relevant to families, youth and others regarding how you work with or assist families with children and youth with special health care needs. A confirmation email will be sent to you once you are added to the website.

Programs Help with Low-Cost Internet

Did you know there are several providers that offer a low-cost option for home internet services for low income families? Currently these three providers in Michigan are offering discounts: AT&T's [Access from AT&T](#) program, Comcast's [Internet Essentials](#) and CenturyLink's [Internet Basics](#).

The goal of these programs is to offer access to the internet for those who may not have any other way to do this. The internet can be life changing and offers an opportunity for many things such as finding jobs, affordable housing, help with resources, etc.

Each program has specific qualifications to receive the reduced rate, but one of the qualifications of all three programs is that at least one child is receiving free or reduced price lunches.

Those participating in Comcast's Internet Essentials program receive benefits such as in-home training, a low-cost computer at enrollment and reduced internet fees.

According to AT&T's Access program site, "as a participant in the Access program from AT&T, you could save a lot of money on your Internet bill. In

Looking for a Good Book?

Did you know that Michigan Family to Family has a book list on the website? This list of books may be helpful for some families. Some of the books were added based on recommendations from participants at our trainings. The list is provided to help you find resources that may help you raising your child with a disability or other special health care needs.

There are many categories, including Autism Spectrum Disorder, Cystic Fibrosis, Special Education and Inclusion, just to name a few. You'll want to browse through the entire list since so many of the books would be helpful for many different families.

If you have a book that you love and want to share with others you can contact a parent coordinator or fill out a contact form on the Michigan Family to Family website to add a suggestion to the list. Sharing resources with other families is a great way to support and empower one another!

To find the book list visit: <https://f2fmichigan.org/news/>

addition, you won't have to pay for installation or activation, or pay modem or gateway charges."

CenturyLink has assistance programs for Lifeline, which is a discounted phone, and Internet Basics, which offers discounts on High-Speed Internet service.

If you do not have any of these companies serving your area, you may want to call your provider and ask if they have a special rate.



Bridging the Gaps with BridgingApps

Helping to bridge the gap between technology and people with disabilities

BridgingApps is a program of Easter Seals Greater Houston that provides access to educational and therapeutic tools for parents, teachers, and therapists to use mobile devices and apps to help children and adults with disabilities reach their highest potential.

BridgingApps is a community of parents, teachers, therapists, and doctors who share information on how they are using touch-based, mobile devices such as the iPad®, iPhone®, iPod Touch® and Android® devices and apps with people who have special needs. They have created a community to discuss technology in respectful, creative ways that focus on people who have disabilities.

By sharing research and success stories, the website captures the potential power of using technology to significantly impact the lives of people with disabilities. Using technology can provide accessibility for people who may have been previously disengaged from the world as a result of language, motor, or other delays.

BridgingApps helps users choose apps for children and adults that are appropriate, useful and life-enhancing. With the overwhelming number of apps



emerging on a daily basis, this seemingly simple task becomes challenging with children and adults who are developmentally or physically delayed. Many parents and well-intentioned professionals are at a loss as to how to get started.

For example, for most children with special needs, age categories provided by the developer may not be helpful in selecting apps because of the wide range of skill sets some children possess.

BridgingApps includes an assessment level, a list of the embedded skills, a narrative of trialing the app and where possible, short video clips.

You can access the website at: <http://bridgingapps.org/>

Building A Care Notebook

Family members are often the primary caregivers and supports in their child's life. Having a child with complex medical needs can often mean there is a lot of paperwork to organize. One way families can maintain a record of their child's care, services, providers and other notes is a care notebook.

The care notebook can be customized to fit your family's needs and can be a good way to keep track of your child's health history and other records. You can also personalize your child's care notebook to include information about your child for family or other caregivers. A detailed care plan helps ensure good communication and consistent care.

There are many resources online to help create a care notebook. One is from the National Center for Medical Home Implementation. Their website features a collection of forms you can personalize and use to build a care notebook for your child. Visit them at:

<https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx>



Using People First Language

People first language is used to speak appropriately and respectfully about an individual with a disability. People first language emphasizes the person first not the disability. For example, when referring to a person with a disability, refer to the person first by using phrases such as: “a person who ...”, “a person with ...” or, “person who has...”

Here are suggestions on how to communicate with and about people with disabilities.

People First Language	Language to Avoid
Person with a disability	The disabled, handicapped
Person without a disability	Normal person, healthy person
Person with intellectual, cognitive, developmental disability	Retarded, slow, simple, moronic, defected, afflicted, special
Person with an emotional or behavioral disability, person with a mental health or psychiatric disability	Insane, crazy, psycho, manic, nuts
Person who is hard of hearing	Hearing impaired, suffers from hearing loss
Person who is deaf	Deaf and dumb, mute
Person who is blind/visually impaired	The blind
Person who has a communication disorder, is unable to speak or uses a device to speak	Mute, dumb
Person who uses a wheelchair	Confined or restricted to a wheelchair, wheelchair bound
Person with a physical disability	Crippled, lame, deformed, invalid, spastic
Person with epilepsy or seizure disorder	Epileptic
Person with multiple sclerosis	Afflicted by MS
Person with cerebral palsy	CP victim
Accessible parking or bathrooms	Handicapped parking or bathroom
Person of short stature	Midget
Person with Down syndrome	Mongoloid
Person who is successful, productive	Has overcome his/her disability, is courageous

For more information about disability and health, visit www.cdc.gov/disabilities



“My mission in life is not merely to survive, but to thrive; and to do so with some passion, some compassion, some humor, and some style.”

-Maya Angelou

Military Families Research Study*

If you are an active duty, reserve or retired military family who have a child or children between the ages of 8 to 17 years with a chronic condition, you are invited to participate in a research study to describe the experience of managing chronic health conditions in children. The chronic conditions being studied for this research study are persistent asthma, cystic fibrosis, diabetes mellitus, cardiac disorders, chronic renal disease, epilepsy, juvenile rheumatoid arthritis, migraine/tension headaches, and sickle cell disease.

The information from this study will help to understand the ways families manage pediatric chronic conditions during daily life and a child's quality of life. The results will be used to help other families, like yours, who are managing a child's chronic condition.

<https://www.surveymonkey.com/r/MilFamilyManagement>

*MI Family Connections neither recommends nor endorses this study. This opportunity is shared for informational purposes only.



Michigan Family to Family Health Information Center (MI F2F) is part of a federally funded project.

They share information and resources on disability and health

issues with families of children and youth with special health care needs. MI F2F also works with health and other professionals.

MI F2F helps families make educated decisions and supports families to partner with professionals. They work to make services for children and youth with special health care needs better.

For more information and helpful resources, look for them on Facebook or go to their website at:



www.f2fmichigan.org



The Family Center for Children and Youth with Special Health Care Needs (Family Center) is the statewide parent-directed center within Children's Special Health Care Services (CSHCS) and the Michigan Department of Health and Human Services (MDHHS).

The primary role of the Family Center is to offer emotional support, information and connections to community-based resources to families of children and youth with special health care needs, including all children who have, or are at an increased risk for: physical, developmental, behavioral or emotional conditions.

Children do not have to be enrolled in CSHCS to receive services from the Family Center.

Family Phone Line 800-359-3722

Disclaimer: The Family Connections newsletter includes information and links to internet and other resources. These resources are for your consideration only and are not endorsed by the Family Center for Children and Youth with Special Health Care Needs, Michigan Family to Family Health Information Center, or our funders. The Michigan Family to Family Health Information Center is a project of the Michigan Public Health Institute. It is funded by Health Resources Services Administration Maternal and Child Health Bureau under Grant H84MC26214. The information or content and conclusions of the author should not be construed as the official policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government. Furthermore, the information provided should not be used for diagnosing or treating a health problem or disease, and is not a substitute for professional care. Please direct any questions through the Family Phone Line or MI F2F website listed above.

If you have something you would like to share in a future newsletter, please contact us for information on how to submit articles, events, etc. We welcome contributions from families, caregivers, youth, healthcare and other professionals, as well as agencies and organizations. Thank you.