FALL 2020

Michigan Family Connections Newsletter

WELCOME TO THE FALL EDITION

Greetings and Happy Fall to our readers! We are so excited to share this edition with you, and hope you find it helpful. You probably noticed it has been awhile since we have published, but we want you to know our newsletter is back and we are still here!

We were working on our Annual Stories Edition earlier in the year when, as you all know, it seemed like the world just flipped upside down! All of a sudden priorities changed and the timing no longer felt right for us to share the Annual Stories edition, as much as we know families loved reading it. It will be back when the time is right.

Before we all knew it schools were closed and we had to figure out a lot of new situations as the COVID-19 pandemic hit. Michigan Family to Family and the Family Center for Children with Special Health Care Needs staff all transitioned to work from home during this time, and we continue to do so.

Like many of you, this brought new challenges and adventures as we had to learn to juggle home life and virtual meetings simultaneously. As we approach the 8 month mark, some things have gotten easier, and some things are still hard. The isolation and stress may still be lurking, but we have all been working hard to pivot and find solutions for the new challenges our families are facing.

From hosting virtual trainings and Parent Connect calls for families to network and learn with each other (see page 3 and 7), to compiling resources regarding COVID-19 and its impact (see page 2), the Family Center for Children and Youth with Special Health Care Needs and Michigan Family to Family are still here to help. We remain committed to finding new ways to reach out and help you navigate new paths.

As always, we hope this newsletter brings you the trusted information and

resources you can use and we welcome your feedback for future editions. Stay warm, stay safe, and above all, stay well!

Kristen Reese & Candi Bush MI F2F Project Director

& Family Center Director





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!

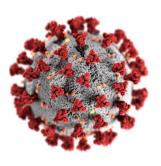
A quarterly publication brought to you by the Family Center for Children and Youth with Special Health Care Needs and Michigan Family to Family Health Information Center

COVID-19 RESOURCES ON MI F2F WEBSITE

As the health and safety of our families has moved into the forefront of our lives, Michigan Family to Family staff have compiled information for our fellow Michiganders regarding COVID-19.

As parents and caregivers of individuals with various vulnerable health conditions, MI F2F staff recognizes the unique skills many of us already possess to navigate tough times. While all of our in-person activities are currently suspended, we will continue to work with our

partners and families to provide trusted resources, information and support. Please visit the MI F2F website regularly for COVID-19 information you can use.



https://f2fmichigan.org/coronavirus-diseasecovid-19/

FAMILY TOOLKIT AVAILABLE TO ASSIST WITH TRANSITION



National data show that most youth with and without special health care needs are not receiving needed health care transition support from their health care providers.

Youth and families report many barriers to transition, which include feeling unprepared to move to a new doctor and manage their own care, anxiety about leaving their current doctor,

difficulty finding a new adult doctor, and understanding the adult health care system.

Got Transition and its National Family Health Care Transition Advisory Group have developed a new toolkit for families to use to guide their youth's transition from pediatric to adult health care.

The Family Toolkit includes easy-to-use resources for youth and families to help youth assume more independence in taking care of their own health and using health services. Materials include a transition timeline, questions to ask your doctor, what turning 18 means for one's health, and more.

https://www.gottransition.org/resource/?hct-family-toolkit

FREE DECISION-MAKING RESOURCES FROM THE ARC

People with intellectual and developmental disabilities (IDD) must make many daily and major life decisions, just like people without disabilities.

This can include decisions about buying things they need, managing a budget, and talking with doctors about their health care.

There are many ways people with IDD make decisions, both on their own and with support. But a person's ability to make decisions can change throughout their life.

It is important to have a plan for how decisions are made and to update this plan regularly. This way, everyone can make the decisions they want. The Arc's Center for Future Planning has created free resources to help.

Visit their website to:

- Learn about decision-making options for people with IDD
- Understand the myths and limits of guardianship
- Learn how to make, review, and adjust a decision-making plan throughout a person's life to maximize their ability to make their own decisions.

https://futureplanning.thearc.org/

NOVEMBER IS DIABETES AWARENESS MONTH

Diabetes is the seventh leading cause of death in the U.S. and Michigan, and to highlight the importance of preventing and managing diabetes, Gov. Gretchen Whitmer has proclaimed November 2020 as Diabetes Awareness Month in Michigan

The purpose of Diabetes Awareness Month is to help educate people on diabetes, what to watch for, and its impact on your health. While there are two types and they are vastly different in their cause, it is important to be aware of the warning signs and get treatment promptly.

Type 1 diabetes is an autoimmune disease where the pancreas stops producing insulin—a hormone that allows the body to get energy from food. Its onset has nothing to do with diet or lifestyle. This is most often diagnosed in adolescence, but can occur in adults as well.

With type 2 diabetes your body doesn't use insulin properly—which is known as insulin



resistance. As a result, your pancreas makes extra insulin to compensate, but over time it is unable to keep up.

Sometimes it takes a person a while to recognize the symptoms they are experiencing is diabetes. It's important to pay attention to your body, rather than simply brushing it off. According to the Center for Disease Control website, if you have any of the following diabetes symptoms, see a doctor about getting your blood sugar tested:

- Urinate (pee) a lot, often at night
- Are very thirsty
- Lose weight without trying
- Are very hungry
- Have blurry vision
- Have numb or tingling hands or feet
- Feel very tired
- Have very dry skin
- Have sores that heal slowly
- Have more infections than usual

With the right tools and support, diabetes can be managed to minimize the impact on you or your child's health.

For more information on diabetes, visit the Center for Disease Control's Diabetes Basics website:

https://www.cdc.gov/diabetes/basics/index.html

FAMILY CENTER OFFERING PARENT CONNECT CALLS

The Family Center for Children and Youth with Special Health Care Needs recognizes how difficult these past few months have been on families and especially families who have children with special health care needs.

We have been working hard over these past few months to create new virtual opportunities for families to support you all through these challenging times. To meet this need, the Family Center will provide ongoing virtual parent support and education through Parent Connect Calls webinars. These calls will include a short presentation and time for parents to share their own tips or ideas.

Parent Connect Calls will be held twice monthly for an hour long. The calls will alternate between day and evening times as well as different topics of interest.

The next Parent Connect Call, **Virtual Learning Strategies for Sensory Processing Challenges**, will be on Wednesday, December 2, 2020 at 11:00 am-12:00pm EST.

Click the link below to register on Eventbrite or contact the Family Center at 800-359-3722 for more information.

https://www.eventbrite.com/e/parent-connect-call-tickets-127177712963

THE FAMILY LEADERSHIP NETWORK HAS OPENINGS

Are you able to share your personal experience in a way that informs and empowers others? Do you have the desire to grow as a family leader? If you do, and you have an interest in providing input on important programs and services for families of children and young adults with special health care needs, we need you!

The Family Center for Children and Youth with Special Health Care Needs and Michigan Family to Family are looking for individuals to serve on our **Family Leadership Network** (FLN).

We are looking for individuals who have personal experience as a parent, guardian or caregiver of a child or young adult (up to age 26) with a disability or other special needs; or be a young adult (18 or older) with a disability or



other special needs. We currently have four openings in Northern Michigan and one opening in the Mid Michigan area. A map of the regions and open positions is available at the Michigan Family to Family website <a href="https://example.com/here.co

Some of the responsibilities of this position include:

- Participating in quarterly meetings including a yearly in-person meeting/training
- Identifying local community partners and resources available to families who have children and young adults with special health care needs (CYSHCN)
- Listen to feedback from families in your region so that you can represent a regional voice in the FLN on programs, priorities, and initiatives
- Encourage families in your region to use resources and activities sponsored by the Family Center and Michigan Family to Family

(For more information including the Position Description and Operating Guidelines, please see the Family Leadership Network Information Packet available here.)

UPCOMING WEBINARS FROM MI ALLIANCE FOR FAMILIES

Michigan Alliance for Families is a statewide resource to connect families of children with disabilities to resources to help improve their children's education.

They help facilitate parent involvement as a means of improving educational services and outcomes for students with disabilities. To do this, they offer learning opportunities for families. Due to the pandemic, all the events are being held online.

The following is a list of some of the upcoming webinars they are offering in December 2020.

 12/4/20 Partnering with your ISD/School District Around Assistive Technology with Carolyn O'Hearn from Alt+Shift, 12-1pm.

- 12/8/20 Log On and Log In to Virtual Meetings with Special Education Mediation Services, 11am-12pm.
- 12/9/20 Collecting Academic and Behavior Data at Home with Special Education Mediation Services, 11am-12pm.
- 12/15/20 Parent Advisory Committees: Roles and Responsibilities with Sandee Koski, 6-7pm.

For more information and to register, visit:

https://www.michiganallianceforfamilies.org/ upcoming-events/

MICHIGAN PROTECTION & ADVOCACY IS NOW DISABILITY RIGHTS MICHIGAN

Michigan Protection & Advocacy Service, Inc., the protection and advocacy agency for the state of Michigan designated to protect the rights of individuals with disabilities, announced it will begin operating under a new name.

As of August 24, 2020, the organization will be known as Disability Rights Michigan (DRM). This rebranding strategy better reflects the agency's mission and services. Throughout this reinvention, DRM has remained committed to its community and the rights of individuals with disabilities. The reputation and equity built under MPAS is a valuable asset, and DRM will continue to build upon that history of advocacy.

"While our commitment to the community we serve will not change, this rebrand will help us



better communicate the value we bring to our clients now and in the future," said Michelle Roberts, DRM Executive Director. "We wanted to accurately reflect our work in the new name and the significant changes to our logo and website allows us to better represent our services."

Along with this name change, a newly designed company logo has been revealed and a new website has launched at www.drmich.org.

NATIONAL FAMILY VOICES SURVEY ABOUT TELEHEALTH

Family Voices, a national family-led organization of families and friends of children and youth with special health care needs, has created a *Family TeleHealth Readiness Survey*. This survey will tell them about families access to, confidence in, and concerns about TeleHealth. The increased use of

telehealth is in direct response to the COVID-19 pandemic and it is an important way to ensure that children and youth with special health care needs continue to be able to access needed care.

To access the survey, please visit: https://www.surveymonkey.com/r/FamilyReadiness

FREE PHYSICAL LITERACY AND NUTRITION EDUCATION PROGRAM

Dr. Leah Ketcheson and the Center for Health and Community Impact at Wayne State University was awarded a grant from the Michigan Health Endowment Fund to launch PLANE (Physical Literacy and Nutrition Education), a two-year nutrition and physical activity program aimed at promoting positive health and well-being for children with Autism Spectrum Disorder (ASD) and their families.

This free program is open to families who have a child between 2-15 years of age who has Autism Spectrum Disorder (ASD). The goal of this program is to promote positive trajectories of health and wellbeing for children with ASD and their families residing in and around Detroit.

This program will be online for the first year and inperson programming for the second year. The goals are to increase physical activity participation, improve nutrition behaviors, and build engagement in social support and services.

The year one curriculum includes:

- a weekly online lesson,
- activity worksheets,
- bi-weekly grocery pick-up,
- snack recipes to try,
- weekly check-in via Zoom with your family's coach, and
- sports equipment to engage your family in activities

In-person engagement and programming will follow in the second year. If you are interested in enrolling your family or for more information, please email

lightup@wayne.edu

CDC TIPS FOR A SAFER THANKSGIVING HOLIDAY

For many families, Thanksgiving is about coming together to enjoy a meal with relatives and friends. But as the number of COVID-19 infections rise, dinner parties and other social get-togethers are risky this holiday season. The safest option is to celebrate with members of your own household.

Your family can still make lasting memories and new traditions while minimizing the risk of being exposed to or spreading COVID-19 to loved ones.

To help avoid getting and spreading COVID-19 this Thanksgiving, the Center for Disease Control (CDC) recommend the following:

- Limit in-person gatherings to people who live in your household
- Think of creative ways to share the experience remotely
- Plan a drop-off potluck and delight family or neighbors with a doorstep drop off
- Grocery shop online and help elderly or higher risk loved ones to do the same. If you need to shop in person, try to go at a time when stores are not as busy

If you do decide to have an in-person gathering with people outside your household, the CDC says these steps can help to make it safer:

- Keep the gathering small and reduce the amount of time you would ordinarily visit.
- Wear a mask and keep your distance. People from the same household can sit together but arrange for those who don't live together to stay 6 feet apart--especially while eating. Remind everyone to wear a mask when they are not eating or drinking.



- Open windows and stay outside when possible.
 If you're indoors, open windows for better
 ventilation if possible. If weather permits, gather
 outdoors. Remember to maintain physical
 distance and wear cloth face coverings even
 outside.
- Choose one person to do the serving to avoid everyone touching serving utensils. Remind everyone to wash their hands often and keep hand sanitizer available.
- For two weeks before coming to dinner, ask guests to be sure to follow steps that lower the risk of COVID transmission. This includes wearing a mask, physical distancing, limiting outings and social gatherings as much as possible, and washing hands often.

For more information about how to keep yourself and your family healthy this holiday season, visit the CDC website at:

https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/holidays/thanksgiving.html

"Never underestimate the power of dreams and the influence of the human spirit. We are all the same in this notion: The potential for greatness lives within each of us."

- Wilma Rudolph



UPCOMING VIRTUAL PARENT MENTOR TRAINING

Remember when your child was newly diagnosed? Would it have helped to have someone to talk to who has "been there"? Are you interesting in supporting other parents?

The Family Center for Children and Youth with Special Health Care Needs invites you to a Virtual Parent Mentor Training for Region 10* residents.

In this interactive Parent Mentor Training you'll learn from a fellow parent about:

- Parent-to-Parent Support
- Communication Skills
- Listening Techniques

If you are a parent, caregiver, or guardian of a child/youth with special health care needs and would like to make a difference in the lives of others, please join us for an opportunity to

become a trained Parent Mentor. This training is open to all families who have a child with a medical, physical, developmental, behavioral, or emotional condition.

Training dates are Dec 8-10, 2020. Hours are Tues & Wed 9:00 am—11:00 am and Thurs 9:00 am—12:00 pm

All participants will receive a \$50 gift card, a Family Center Notebook, and a Medical Care Binder (you must attend all days to receive the gift card)

For those who would like to take the training, but don't live in the listed counties, please contact us. Registration will open to all counties 3 weeks before the training. Register soon as spots are limited.

https://www.eventbrite.com/e/parent-mentor-training-tickets-125612629757

* Region 10 includes Oakland, Macomb and Wayne Counties

Michigan Family to Family Health Information Center (MI F2F) is 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.





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.

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.