

2024 - 2025 ONLINE LEARNING OFFERINGS

We are pleased to share with you the upcoming 2024-2025 online learning opportunities brought to you by the Family Center for Children and Youth with Special Health Care Needs and Michigan Family to Family Health Information Center. In addition, the *Growing as Leaders* series is also in collaboration with the Parent Leadership in State Government initiative.

Learning Connections Webinars – These are replacing the Parent and Professional Connect Calls. These one-hour webinars are open to anyone (parent, family member, professional, youth, educator, etc.) interested in a variety of topics of interest. These webinars provide resources, information, and skill development on relevant topics related to children with disabilities or special health care needs. They are led by seasoned parent staff and/or guest speakers with expertise in the topic.

Navigating Healthcare Workshops – These one-hour webinars are open to anyone (parent, family member, caregiver, youth, professional, educator, etc.) interested in learning more about navigating healthcare and other systems that provide services and supports for families of children and youth with disabilities or special health care needs in Michigan from expert guest speakers.

Growing as Leaders: Leadership Series - These one-hour webinars are for ANY parent of a child in Michigan interested in further development of their leadership skills (you do NOT have to have a child with a disability or special health care needs). This is a series; however, you may attend just those of interest to you. They provide a focused learning opportunity on a variety of leadership skills for both seasoned and emerging parent leaders. No previous leadership training required to attend. There are five webinars in the series, running every other month from Oct to June.

For a full description of the online trainings offered, and the link to register, visit the MI Family to Family Event page:

<u>Events - Michigan Family to Family (f2fmichigan.org)</u>

FALL 2024

A newsletter for families of children and youth with special health care needs, and the professionals who care for them.

Connecting you with information and news you can use.

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



CAMP SCHOLARSHIPS OFFER OPPORTUNITIES AND MORE

The Family Center for Children and Youth with Special Health Care Needs offers a camp scholarship program for any child or youth in the State of Michigan up to age 21 with special health care needs or a disability. They do not have to be enrolled in Children's Special Health Care Services.

Camp scholarships are made available with funding from the Children with Special Needs Fund and offer children with special health care needs the opportunity to engage in the community, gain a sense of belonging, have fun in a safe and supportive environment, and build relationships.

New applications will be accepted starting in January 2025 and will award up to \$500 per child. The camp must be licensed to operate in Michigan (certain exceptions apply).

Paty J.'s daughter received a camp scholarship earlier this year to attend the Eric "RicStar" Music Therapy Camp in East Lansing in June.



Paty shared, "Camp has been lifechanging for our daughter. It allows her to participate in a camp as nondisabled children do. It allows her to connect with friends and community.

She also added, "It gives her a sense of joy and pride, especially when she and her friends perform during the final music showcase. When she is happy and excited - her body and mind also do well."

Sign up for Gov.Delivery to receive notice when applications become available:

Michigan Dept of Health & Human Services - Sign up for our Family Connections Newsletter (govdelivery.com)

MICHIGAN FAMILY TO FAMILY WELCOMES MOLLY MARTZKE

Molly Martzke recently joined the MPHI staff as a Senior Program Coordinator, where she brings passion and real-life experience to her role with the Michigan Family to Family (MI F2F).

Molly has extensive experience working with diverse groups, from local to international, to provide family leadership training.

She is a parent who has dedicated her life's work to improving the experiences and outcomes of all families with children with special health care needs.

Molly is committed to actively engaging families as equal partners in their child's health care. She strives to ensure that

the family voice is represented throughout the family's journey and within their system of care.

She believes that change happens at the system level when there is



diverse representation and honest dialogue amongst all parties.

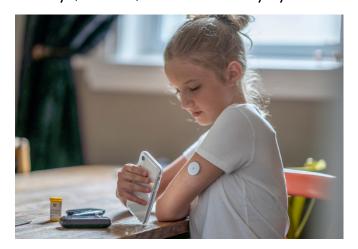
Please join us in welcoming her to the Michigan Family to Family team. You can reach her via email at:

mmartzke@mphi.org.

DIABETES AWARENESS MONTH COMING IN NOVEMBER

Diabetes Awareness Month takes place in November in honor of the Nov. 14 birthday of Dr. Frederick Banting, who helped discovered insulin in 1921. It is a time every year to spread awareness about a very common chronic condition that affects both children and adults.

In type 1 diabetes, the pancreas produces little or no insulin. Without daily insulin, children with type 1 diabetes can experience damage to the heart, eyes, kidneys, nerves, and circulatory system.



Type 1 diabetes cannot be cured or prevented by diet or exercise. According to the CDC (as of 2021) over 300,000* children have type 1 diabetes in America.

In type 2 diabetes, the body produces insulin but is resistant to its effects. As in type 1 diabetes, type 2 diabetes can damage the eyes, heart, nerves, kidneys and more. Healthy lifestyle changes may delay or prevent type 2 diabetes.

This year, diabetes detection is more important than ever. During the COVID-19 pandemic, there was a spike in the cases of children diagnosed with type 2 diabetes.

For more information on both types of diabetes, including symptoms, visit the following Healthline article:

<u>Type 1 vs. Type 2 Diabetes: Difference,</u>
<u>Symptoms, and More (healthline.com)</u>

*National Diabetes Statistics Report | Diabetes | CDC

FREE DIGITAL LITERACY LEARNING COURSES AVAILABLE

Are you or a loved one with an intellectual or developmental disability feeling left behind in our digital world? Help is available. The Arc Muskegon is bringing free, accessible digital skills training to Muskegon and Ottawa Counties as part of a nationwide initiative by the Arc of the United States and AT&T.

People with disabilities face significant barriers to understanding and adopting digital tools, often due to higher rates of poverty and limited access to adaptive technology.

The Arc Muskegon will deliver accessible, easy-to-understand digital literacy training through both in person and virtual workshops using plain language

materials and adaptive technology.

The workshops run from Oct 2024 through June 2025.



Workshops will cover digital safety, basic web searching, online job searching, how to use email and social media and more.

For more information on sessions or to register, contact Alex Latz by email at alatz@arclakeshore.org or by phone at 231-216-3682. For more on digital learning opportunities from AT&T, visit:

AT&T - DigitalLearn

EMBRACING COMFORT AND STYLE: THE IMPORTANCE OF ADAPTIVE CLOTHING FOR INDIVIDUALS WITH DISABILITIES

The fashion industry has a long way until it's truly inclusive to all people. Accessible fashion for people with disabilities is often overlooked.

But today, more and more brands are embracing adaptive clothing with assistive technology. This enables people to wear the latest trends while still accessing adjustable and functional designs.

Adaptive clothing meets the needs of people with disabilities. It combines comfort, function, and style. As more people learn about the needs of those with physical and mental challenges, the market for adaptive clothing has grown. This provides fashion options that help people express themselves and meet their needs.

Adaptive clothing often has Velcro fastenings instead of buttons, wider neck openings, and adjustable hems. These changes make it easier to put on and take off. They also help people be more independent and comfortable.

For example, clothes for wheelchair users have special cuts and openings to prevent bunching. Sensory-friendly materials are also popular among people with autism and other sensory issues. These materials are soft and do not irritate the skin. There are also shoes that open all the way and are wider, to accommodate foot orthotics.





Finding adaptive clothing can seem challenging, but there are resources available to help individuals and caregivers:

- Online Retailers: Some brands specialize in adaptive clothing, such as Tommy Hilfiger's Adaptive Line, Zappos Adaptive, Kohl's Adaptive Collection, and Target's Adaptive Collection.
- Social Media and Online Communities:
 Platforms like Facebook and Instagram
 host various groups dedicated to
 adaptive fashion. These communities
 often share recommendations,
 reviews, and personal experiences,
 making it easier to discover brands
 and styles that suit individual needs.

Adaptive clothing is not just a necessity; it's a statement of individuality and style for people with disabilities. By using the available resources, individuals can discover fashionable and functional clothing that meets their unique needs. This enhances both comfort and confidence.

As the demand for inclusive clothes continues to rise, the future looks a bit more promising for adaptive fashion.

MICHIGAN FORMS RARE DISEASE ADVISORY COUNCIL

The Michigan Rare Disease Advisory Council (MI-RDAC) held its first ever meeting October 8, 2024. The MI-RDAC was created to provide Michigan's rare disease community with a stronger voice in state government. Nationwide, twentynine states have established RDACs, with others in various stages of the process.

The MI-RDAC consists of up to eighteen individuals, representing balanced and diverse perspectives, including individuals with rare diseases. A rare disease is a condition that affects fewer than 200,000 people in the United States.

The MI-RDAC responsibilities include:

- provide information about rare diseases on a publicly available website
- collaborate with MDHHS to investigate and report to the state legislature on at least one rare disease per year

Meetings will be held quarterly, with virtual access available.

Cystic Fibrosis
advocate and MIRDAC member
Laura Bonnell has
been passionate
about the creation
of a Michigan RDAC
for many years. Her
two daughters are



diagnosed with Cystic Fibrosis. She is also the founder and president of <u>The Bonnell Foundation</u>, which provides support and advocacy for those impacted by Cystic Fibrosis.

Laura shared, "The first meeting of the RDAC was incredible. To have a group of people, made up of doctors, parents, non-profits, nurses, researchers and other backgrounds all working toward the same goal (to give lawmakers helpful information) was moving."

For more information on the MI-RDAC visit the MDHHS website at:

Michigan Rare Disease Advisory Council

NEW SPECIAL OLYMPICS FACILITY IN GRAND RAPIDS AREA

Special Olympics Michigan held a ribbon-cutting ceremony September 18th to celebrate the new outdoor sports complex and indoor activity space at the Special Olympics Michigan Unified Sports & Inclusion Center. The center, just south of Grand Rapids, is now the world's largest inclusive sports training facility.

Its design was created with input from athletes, families, and community members, focusing on accessibility.

The facility was designed to provide space for athletes of all abilities. It includes athlete activity rooms, locker rooms, fitness areas, and a podcast room. The outdoor facility includes a track, football field, pickleball courts, soccer fields, and more.



The goal of the center is to be inclusive to all and give Special Olympics programs throughout the state of Michigan a place to come together to train and compete.

They also house partnering organizations that support those with physical and intellectual disabilities as well as mental health challenges. They utilize the building for day-to-day activities and special events.

AFTER I AM GONE PROGRAM OFFERED BY WAYNE COUNTY

If you are like most parents, you worry about your child's future caregiving needs. This can be compounded by concerns about what will happen when you are no long here or able to provide care for your child.

The After I'm Gone Program (AIG) helps families plan and prepare for the future of their family member with a disability. It is free and open to anyone in the state.

Topics covered include Estate Planning, DHHS Programs, Social Security Programs, Housing Options, Supported Decision-Making, Able Accounts, and Transition Planning. Each session is a webinar and held via Microsoft Teams.

This program is currently being offered by The Arc Western Wayne County and The Arc Northwest Wayne County, funded by the Detroit Wayne Integrated Health Network.



Taking action allows you to be involved and paves the path to a happy and secure future for your family member with a disability.

While this can be difficult to think about, and even more difficult to plan for, a lack of planning could leave your child in crisis. The time to start planning is now!

For more information and to RSVP for sessions, please visit:

After I'm Gone | The Arc of Western Wayne County (thearcww.org)

DISCOVERING ACCESSIBLE RESOURCES IN NORTHERN MI

Northern Michigan is known for its beautiful Fall foliage and opportunities to enjoy the outdoors. Traverse City and the surrounding area is especially popular for families. But for families of individuals with disabilities, finding opportunities for recreation and fun can be challenging.

That is why Disability Network Northern Michigan supports the community of people with disabilities and their families. They recognize the importance of accessibility in motion and inclusion in recreational opportunities.



Because of this, they have created a list of accessible resources for Northern Michigan residents and guests.

Disability Network Northern Michigan's Accessible Recreation Pulse provides a portal for people of all abilities that are looking for accessible activities to engage in their communities.

It features accessible parks, outdoor recreational activities, art, and peer support activities. They also share a list of other organizations that provide adaptive equipment and services.

For more information on this and other supports offered, call them at 231-922-0903. You can access the Accessible Recreation Pulse at:

<u>Accessible Recreation Pulse | Disability</u> <u>Network Northern Michigan</u>

FEEDBACK REQUEST AND ART CONTEST FROM BCCHPS

The Bureau of Children's Coordinated Health Policy and Supports (BCCHPS) is looking to partner with youth, young adults, and parents and caregivers.

There are several ways that individuals can be involved in shaping services, supports, and policy for not just their family, but also families across Michigan.

The first opportunity is for youth and young adults to showcase their artistic talents by submitting their artwork to be featured on a new Specialty Behavioral Health Dashboard and in other publications. Requesting a parent/guardian consent form and submitting artwork can be emailed to MDHHS-BCCHPS-Reporting@michigan.gov.



The second is through a feedback survey, which asks for possible ways individuals might want to be part of an outreach project. A representative of the Bureau will follow up directly to discuss survey responses and experience with the behavioral health system.

Participants will be fully supported and can contribute at the level that feels most comfortable to them. The survey can be accessed here:

Youth, Caregiver, Provider Feedback on Michigan's Public Behavioral Health System (office.com)

WHO WE ARE

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



They share resources and information on disability and health issues with families of children and youth with special health care needs in Michigan.

MI F2F also works with health and other professionals. MI F2F helps families make informed decisions and supports families to partner with professionals.

For more information and resources, look for us on Facebook or visit our website.

MI Family to Family Website



*This project is supported by the Health Resources and Services Administration (HRSA). The contents are those of the Michigan Family to Family staff and do not represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. The sharing of resources is for your consideration only. Use at your own discretion.

The Family
Center for
Children and
Youth with
Special Health
Care Needs



Children's Special Health Care Services

(Family Center) is the statewide parentdirected 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, behavioral, developmental, or emotional conditions.**

Family Center Direct Line 1-517-241-7630 CSHCS Family Phone Line 1-800-359-3722

Family Center Website

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