FALL 2023

Michigan Family Connections Newsletter

Children's Special Health Care Services Expands To Age 26

Children's Special Health Care Services (CSHCS) is pleased to announce that eligibility for the program was recently expanded to age 26. CSHCS is a program for children and some adults with special health care needs and their families. CSHCS covers medical treatment and support services for individuals with qualifying diagnoses.

While the eligibility expansion was approved to begin October 1, 2023, it will take several months to complete the necessary computer updates and make the system operational. CSHCS understands that many individuals and families will have questions, so has prepared a Frequently Asked Questions guide which can be accessed at the following: **Link to Frequently Asked Questions**.

The Family Center for CYSHCN and MI F2F are also offering a webinar for families to explain the expansion on Wednesday, February 21, 2024 at 11:00 am. To sign up for the call please visit the link below or use QR code to register:

https://www.eventbrite.com/e/parent-connect-call-cshcs-coverage-expansion-to-age-26-tickets-745607832097

If you have any questions about the age expansion, or CSHCS in general, please visit: **https://www.michigan.gov/mdhhs/assistance-programs/cshcs**

You can also call the Family Phone Line at 1-800-359-3722.

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 Michigan Family to Family Health Information Center

Motor City Wheelz Offers More Than Basketball

Motor City Wheelz is an organization located in the Detroit tri-county area. They offer children with a permanent lower extremity disability the opportunity to play basketball. This includes, but not limited to, children with a congenital disability, cerebral palsy, arthrogryposis, amputation, spina bifida or spinal cord injury. Some children have the ability to ambulate while others use wheelchairs all of the time.

Motor City Wheelz teams practice in Sterling Heights and Southfield. They offer both Prep and Varsity level of play. Children 5 - 12 years old play on the Prep team with baskets set at 8.5 feet. The Varsity team is for children 13 - 18, and up to 21 years, who play at the regulation 10 foot baskets.

The team provides opportunities for physical fitness, socialization, team dynamics experiences, how to win and lose, a chance to be recognized for their hard work in school, travel experiences and support for parents. The team is part of the Midwest Conference of the National Wheelchair

Basketball Association and competes at Conference, Regional, and National Tournaments.

Most of the competitions are within the Midwest Conference to limit expenses for families. The biggest tournament is the National Championships which will be in Richmond, Virginia in April 2024.

Teams are open to new families that want their child to play wheelchair basketball. They have wheelchairs available for children to use. You can find them on **Facebook** or their website at **www.motorcitywheelz.org.** You can also contact Diane Winterstein, Motor City Wheelz Coach, at 1-586-212-6196.

Bookshare: An Accessible Online Library Resource

Bookshare is an ebook library that makes reading easier. They offer individuals with dyslexia, learning disabilities, visual impairments, physical disabilities and other reading barriers the opportunity to study for school, pursue careers, and read for fun.

Bookshare lets you read your way. They allow you to listen to books, follow along with karaoke-style highlighting, read in braille or large font, and customize your reading experience with ebooks in a format that works best for you.

You can read anytime, anywhere on devices like computers, tablets, smartphones, assistive technology devices and more. You can read as many books as you want, it is free for qualified students and schools, and a little over $1 a week for other members. To join, you must have a reading barrier that qualifies for Bookshare.

Visit **https://www.bookshare.org/cms/**

Tips For Alternate Funding For Medical Services

People sometimes assume that medical services or equipment is covered just because their doctor orders it. Unfortunately, this isn't always true. Your provider may see patients covered by many different types of insurance, so they may not be aware of the coverage provided by your particular company or plan.

It is important to know your health insurance benefits, work with the prescribing doctor, and know how and when to appeal an insurance decision. Even after exhausting all of these steps, some families still aren't able to get some services or items covered.

If this is the case, there may be alternative ways to cover services like therapy, medical equipment, and other items necessary for your child. There are a variety of different funding sources available, including grants.

It can take time to research what is available, gather the information to apply, and wait for a decision to be made. Here are some tips to hopefully make this process go smoother:

- Read all of the criteria and requirements carefully. That way you are not wasting your time filling out applications and the program can focus on the people who are eligible.
- Speak with your child's physician or therapist to see if a particular equipment would be helpful or if there might be another choice before applying.
- If you are chosen for a grant, follow up with a thank you letter and pictures. Many programs share these with their donors so that other children can be served.
- If you are not chosen for a grant, check out local lending closets, ask in local school groups or set up a personal fundraiser.

Here is a list of just a few alternate funding sources/assistance web sites to check out.

- Jasmyn's Voice—**https://jasmynnsvoice.org/**
- United Healthcare Children's Foundation—**https://www.uhccf.org/**
- Children with Special Needs Fund—**https://www.michigan.gov/csnfund**
- Parker Lee Project—**https://www.theparkerleeproject.org/**
- Family Hope Foundation—**https://thefamilyhopefoundation.org/**
- Needymeds—**https://www.needymeds.org/**
- Michigan State Elks Association—**https://www.elks.org/states/stateproject.cfm?state=MI**
- Jack's Place for Autism—**https://www.jacksplaceforautism.org/scholarships**
- Michigan Assistive Technology Program—**https://mymdrc.org/assistive-tech-program/**
- Varity Children's Charity of Detroit—**http://variety-detroit.com/how-we-help/variety-bikes-for-kids**
- Kellyskidz—**https://www.kellyskidz.net/**
- Aubrey Rose Foundation—**https://aubreyrose.org/financial-assistance-for-families/**

Recognizing Family Center Director Candi Bush

The Family Center for Children and Youth with Special Health Care Needs (Family Center) and Children's Special Health Care Services (CSHCS) would like to recognize and thank Candi Bush, who recently announced her decision to step down from her position as Special Advisor to the Family Center. Prior to her role as Special Advisor, Candi served Michigan families as the Director of the Family Center for over 9 years.

Candi joined the CSHCS team in 2014. Her professional experience as the Executive Director for Parent to Parent of Southwest Michigan, and her personal experience as mom to two sons with special health care needs, prepared her well for this role.

As Director of the Family Center, Candi revitalized the program by bringing in a full staff to the Lansing office for the first time in Family Center history. She created new programs and policies that would benefit families in Michigan who have children with any type of disability or special health care need.

She focused on emotional support, education and trainings, outreach, and parent-to-parent mentoring and support. She was able to broaden the net of families served by the Family Center and these programs continue today.

Over these past 9 years, Candi served on multiple boards and committees throughout the State of Michigan, as well as on the national Parent to Parent USA Board of Directors.

She was the recipient of the 2012 Exceptional Parent of the Year through the Michigan Council for Exceptional Children. In 2014, Candi was named as the Association of Maternal and Child

Health Programs (AMCHP) Family Delegate for the State of Michigan.

In 2015 Candi was accepted into the 2015 - 2016 Leadership Lab through the AMCHP Family Leadership Cohort. In 2016, Candi was honored as the Outstanding Alumni of the Year for Western Michigan University.

Since 2016, Candi made significant contributions to the implementation of Michigan's Leadership Education in Neurodevelopmental and Related Disabilities program where she also served as the family coordinator, faculty, and mentor.

Candi was also the recipient of the Association of Maternal and Child Health Programs Emerging Maternal Child Health (MCH) Professional Award for Region V in 2018.

Candi's drive, passion, and expertise will be missed. Michigan Family to Family would like to join Children's Special Health Care Services and the Family Center in wishing Candi all the best in her future endeavors!

A Kid Again Michigan Gives Quality Family Time

A Kid Again Michigan is honored to serve families who are raising children living with life-threatening conditions across the entire State of Michigan. They do so by providing cost-free, fun-filled destination events throughout the year that they call "Adventures."

Through these "Adventures", families can take a break from doctor visits and hospital stays and enjoy quality time together. Enrollment is open to families with children under 20 years of age whose diagnosis is deemed life-threatening by a medical professional.

To apply, you'll need basic info about your child as well as details about their medical condition. Your child's application will be reviewed by their Medical Advisory Committee and they'll contact you with the next steps. Enroll at: **https://akidagain.org/enrollnowform/**

November Is National Family Caregiver Month

Caregiving for a loved one or family member can be a lot of work. Caregiving is an important public health issue that affects the quality of life for millions of individuals.

Caregiving may include helping with one or more activities important for daily living. It also may involve emotional support and help with managing a chronic disease or disability.

Caregivers are often unpaid family members. Informal or unpaid caregivers are the backbone of care provided in people's homes.

Caregiving can affect the caregiver's life in a lot of ways including their ability to work, maintain good physical and mental health and engage in social activities and relationships.

The Family Caregiver Alliance website offers information, support, and resources for family caregivers. You can sign up for ***CareNav,*** a free online dashboard loaded with personalized information for your unique caregiving needs.

The Caregiver Action Network is another non-profit organization providing education, peer support, and resources to family caregivers across the nation.

This November take a moment to recognize, acknowledge, and find support for all of the important work you do!

Self-Advocacy Story Time Available For Your Class

Disability Network Southwest Michigan is pleased to continue its **"**Self-Advocacy Story Time**"** for the 2023-24 school year. Self-Advocacy Story Time is an opportunity to teach your students about living a self-determined life, and how to reach their goals by advocating for themselves. Thanks to a generous grant from the Michigan Developmental Disabilities Council, this program is FREE across the State of Michigan.

A storyteller will use ZOOM or Google Meet to virtually read an illustrated children's book about real-life kids with disabilities who advocate for themselves (see list of books below). After each reading, the storyteller will engage your students in a lively discussion on advocacy!

This program is for children with disabilities and their classmates, ages 12 and under.

You can choose from the following books:

- "All the Way to the Top, How One Girl's Fight for Americans with Disabilities Changed Everything" by Annette Bay-Pimentel

- "A Day With No Words" by Tiffany Hammond
- "Just Ask! Be Different, Be Brave, Be You" by Sonia Sotomayor
- "Completely Me" by Justine Green, Ed.D.
- "Completely Emme, A Cerebral Palsy Story" by Justine Green, Ed.D.
- "Completely Matt , An ADHD Story" by Justine Green, Ed.D.
- "Completely Toby, A Down Syndrome Story" by Justine Green, Ed.D.

Email Mary Fortney at: **fortneym@dnswm.org** to reserve your story time date!

Messages From Young Adults With Epilepsy

Epilepsy is the most common childhood brain disorder in the United States, impacting 470,000 children and adolescents aged 0-17 years.

The National Coordinating Center for Epilepsy's Young Adult Council (YAC) is a peer-to-peer empowerment and support network for young adults with epilepsy.

Members of the YAC recorded short videos related to their lived experience and what they thought was most important to know when working with young adults living with epilepsy. These videos are intended for a broad audience including providers,

other young adults with epilepsy, allied health professionals, and caregivers.

Watch their videos on the AAP's website at:

https://www.aap.org/en/patient-care/epilepsy/young-adults-with-epilepsy-share-their-story/

Michigan Rehabilitation Services Assists Teens & Young Adults with Employment Opportunities

Michigan Rehabilitation Services (MRS) provides specialized employment and education-related services and training to assist teens and adults with disabilities in becoming employed or keeping employment. MRS has 35 offices across the state of Michigan and can provide services to individuals directly in the community they live in.

One of the many services MRS provides is Pre-Employment Transition Services (Pre-ETS) for high school or college students with disabilities between the ages of 14-26. Students partner with a vocational rehabilitation counselor to outline their interests and explore career pathways that are right for them. Students receive a variety of training to provide them with the skills needed to work within their community.

Students who receive Pre-Employment Transition Services will be provided information on 5 main areas to help them become successful in their future employment:

- Job exploration counseling
- Work-based learning experiences
- Counseling on postsecondary education opportunities
- Workplace readiness training

- Instruction in self-advocacy, including peer mentoring

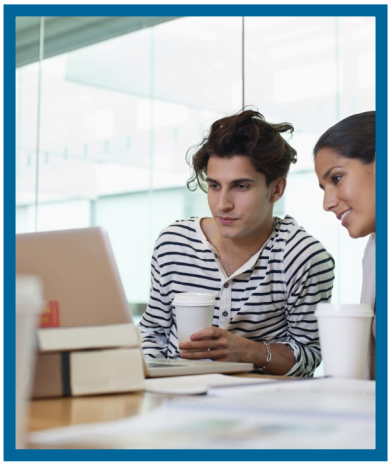
Note: Students under the age of 18 or over the age of 18 who have a guardian, will need parent/guardian permission to participate in the Pre-Employment Transition Services. The MRS-2900 – Student and Parental/Guardian Referral Consent for Pre-Employment Transition Services form will need to be completed.

If you are interested in working with MRS, you can access their office locator at **https://www.michigan.gov/leo/bureaus-agencies/mrs/orientation-intro/mrs-office-locator** to find the office nearest your home. You may also contact MRS at **Leo-MRS-CustomerAssistance@michigan.gov** or 1-800-605-6722* (toll-free, voice).

**TTY users may contact MRS by dialing 711 and providing the MRS toll-free number.*

"You can dance in the storm. Don't wait for the rain to be over before because it might take too long. You can do it now. Wherever you are, right now, you can start, right now; this very moment." — Israelmore Ayivor

Virtual Learning/Support Events



The Family Center and MI Family to Family are pleased to partner together to offer a multitude of learning and support opportunities for families and professionals. Below is a description of each offering, with the link to our Eventbrite registration page. These events are virtual, free, and open to parents of children with special health care needs or disabilities, and the professionals who care for them.

Parent Connect Calls are an opportunity for parents to connect for support and information on topics of interest. Upcoming calls include:

- **Haircuts and Dental Appointments** on Jan 17, 2024, 4 pm to 5 pm
- **CSHCS Age 26 Expansion** on Feb 21, 2024, 11 am to 12 pm
- **Self-Care/Let's Have Some Fun!** on April 17, 2024, 12 pm to 1 pm

Professional Connect Calls are an opportunity for professionals who work with families to get information on available resources, services and supports for families. Upcoming calls include:

- **Children's Special Health Care Services 101** on Nov 13, 2023, 2 pm to 3 pm
- **Children's Special Needs Fund** on Feb 1, 2024, 11 am to 12 pm
- **Introduction to the Family Center and MI Family to Family** on April 25, 2024, 11 am to 12 pm

Navigating Healthcare Workshop Series are aimed at building skills and knowledge to help families build partnerships with healthcare providers, promote shared decision making, and improve healthcare experiences. They are open to parents, caregivers, youth, social workers, medical providers, family members, etc. Upcoming topics include:

- **Appealing Insurance Denials** on Nov 30, 2023, 12 pm to 1 pm
- **Understanding the SED Waiver** on Jan 18, 2024, 12 pm to 1 pm

Growing As Leaders: A Parent Leadership Series is a collaboration with *Parent Leadership in State Government.* They are designed to support the development and engagement of emerging family leaders in Michigan to work toward meaningful parent leadership in our state. These learning sessions are open to ANY parent (you do not have to have a child with a disability/diagnosis). The series runs from Oct 2023 through August 2024. Parents can attend the full series, or just the topics that interest them. Upcoming workshops include:

- **Start With Your Why** on Dec 6, 2023, 12 pm to 1 pm
- **Identifying Interests and Passions** on Feb 21, 2024 12 pm to 1 pm
- **Sharing Your Story for Change** on April 10, 2024, 12 pm to 1 pm

To register for events, visit our EventBrite page:

https://www.eventbrite.com/d/online/cshcs-division-and-the-family-center-for-cyshcn/

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 educated decisions and supports families to partner with various professionals. They strive to make services for children and youth with special health care needs better meet their needs.

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

MI F2F Website

Like us on **Facebook**

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 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.

Disclaimer: The Family Connections newsletter includes information and links to the 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.