

Michigan Family Connections Newsletter

FALL 2021

CSHCS EXPANDS COVERAGE FOR SICKLE CELL

Children's Special Health Care Services (CSHCS) is pleased to announce an eligibility expansion for adults ages 21 and older with sickle cell disease effective 10/1/2021. CSHCS will cover services directly related to the sickle cell diagnosis. CSHCS also helps with copays and deductibles, transportation, care coordination, access to CMDS clinics, and case management.



As an individual with sickle cell and a mother of three children with sickle cell disease, Kefaia Alsaaid, had this to say about the expansion of coverage.

"Acute painful episodes, organ infraction, chronic organ damage and a significant reduction in life expectancy are all related to having sickle cell disease. It is a gene disorder that cannot be cured. Medications are given to modify disease severity and to help treat the symptoms. Children's Special Health Care Services is one of the programs that provides benefits for children with sickle cell up until the age of 21. However, the disease

is a lifelong battle even with a mild form. Growing into adulthood increases the cost of healthcare, therefore, having Children's Special Healthcare Services as lifelong coverage is essential to Individuals with sickle cell disease."

Initial Adult Enrollment: Enrollment in CSHCS begins with the provider submitting a medical report related to the sickle cell diagnosis. If you have recently lost CSHCS coverage, you may be eligible to re-enroll. The initial medical eligibility period is two years if the initial medical report is not from a hematologist. If the initial medical report is received from a hematologist, the medical eligibility period is up to five years. Clients who do not have Medicaid will need to complete an enrollment application.

For more information regarding CSHCS or the enrollment process, contact your Local Health Department or the CSHCS Family Phone Line at: 1-800-359-3722

Children's Special

Health Care Services



*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 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

MICHIGAN INNOVATIONS IN CARE COORDINATION PROJECT

The Michigan Innovations in Care Coordination project (MICC), funded by the Michigan Health Endowment Fund, aims to improve workforce capacity and access to coordinated care for children with or at risk for Autism Spectrum Disorder (ASD)/ Developmental Delays (DD) in Wayne County, MI.

The MICC project team and partners developed a series of educational videos and other resources that are available for families and providers to help them navigate screening, evaluation, and accessing early intervention resources when they have a child at risk for ASD.

By directly engaging providers and the parents of children with ASD throughout the community, the resources developed by this project are useful for parents and can help guide them through the complex ASD system of care.

Resources include:

[Is my child at risk for Autism?](#)

[Autism Evaluation and Applied Behavioral Analysis Services](#)

[Significance of Early Intervention](#)

[ASD Diagnosis: Next Steps](#)

[Insurance & Autism Evaluation Guidance Document for Parents & Professionals](#)

These resources and others can be found on their website: <https://www.mphi.org/our-teams/center-for-strategic-health-partnerships/micc/>.

To learn more about the MICC project, please email the MICC Project Coordinator, Danielle, at dbaumgar@mphi.org.



NEW RESPITE AND PLAY CENTER OPENING IN WAYNE

Scheduled to open in November, Vonnie's World is a new out of home respite activity and play center. The center will provide hands on fun, recreational, educational, and developmental adaptive activities and adventures for people with intellectual or physical disabilities through independent play.

Activities include, physical play, exercise and movement, arts and crafts, sensory and visual stimulations, parties, music, science, dances, media, and technology. Toys and materials are ADA approved.

Founder/owner, Saunda Cunningham, is a EMT and a licensed Nurse in the State of Michigan, holds a CDA degree in child development, and an early childhood education and administration certificate. She has three children, including her daughter Savona (or Vonnie for short). She personally understands the hurdles and challenges of having a child with special needs.

She created Vonnie's World to be a solution for other families looking for somewhere enjoyable to take their child. There is a fee for services, but the center

accepts Medicaid respite care vouchers and works to offer assistance to families in need.

Vonnie's World also supports wellness

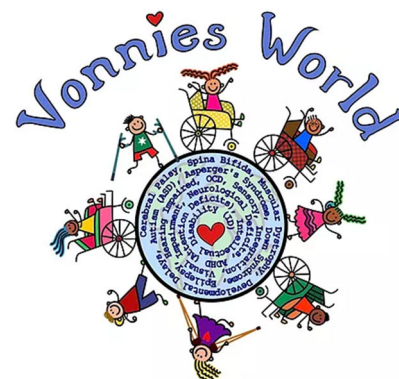
community events such as health screenings, CPR trainings, and parent support & enrichment classes.

Children with all disabilities and syndromes are welcome to come and play. They are encouraged to reach their full potential with the professional staff and quality adapted environment, toys, and equipment.

The center will be hosting an Open House event on November 20th, from 10 am to 6 pm.

<https://www.vonniesworld.com/>

<https://www.facebook.com/aspecialplacetoplay>



CONNECT WITH MICHIGAN FAMILY VOICES

Michigan Family Voices is a grassroots collaborative that exists to identify and mobilize current and new family member and individual leaders. They have worked to create a network across the state that will impact and effect positive change in policy, and other policies relevant to families, children and youth with special health care needs and disabilities.

Its statewide network of leaders informs, builds relationships, and works in partnership with decision-makers at all levels.

Michigan Family Voices' goals are :

- Shared leadership.
- Families driving the system, not just commenting on it.
- Family experiences shaping the system from the ground up, not at the edges.
- Unbiased family voice. Not a system voice. Families are true consumers not working in or for an agency.



[MichiganFamilyVoices.org](https://michiganfamilyvoices.org)

Michigan Family Voices strives to ensure that state and federal policies:

1. advance the health and well-being of children with special health care needs and their families,
2. promote family-centered health care,
3. and reflect the voices of families,

by providing information about current policy proposals and facilitating the recommendations and participation of local family leaders on state and national level committees, task forces and workgroups.

Michigan Family Voices is recruiting family leaders for its Advisory Body and Leaders Network.

For more information contact by phone:

800-292-7851 extension 472 or

email: info@michiganfamilyvoices.org.

FAMILY CENTER UPCOMING EVENTS

Parent Connect Calls

Topic: Family Center Camp Scholarships, Wednesday, December 1, 2021 at 11:00 AM - 12:00 PM EST.

Registration for this event can be completed at: <https://www.eventbrite.com/e/parent-connect-call-camp-scholarships-tickets-180352748927>

Professional Connect Calls

Topic: Family Center 101, Thursday, November 18, 2021 from 3:00 to 4:00 pm EST. via Microsoft Teams. This will be an informative presentation/discussion for **professionals** to share insight into the Family Center and discuss ways to partner together to provide support to families.

Registration for this event can be completed at: <https://www.eventbrite.com/e/professional-connect-call-fc-101-tickets-180327774227>

Parent Mentor Trainings

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.

Virtual Parent Mentor Training will take place from Tuesday, December 7, 2021 to Thursday, December 9, 2021 starting at 9:00 am EST on Microsoft Teams.

Registration for this event can be completed at: <https://www.eventbrite.com/e/virtual-parent-mentor-training-tickets-180349479147>



SIBLING INTERACTION STUDY OPPORTUNITY

Interested in participating in a study on social interaction between siblings with and without developmental disability? A Michigan State University grad student is seeking typically developing siblings and their sibling with a developmental disability between the ages of 5-12 to participate in a fun training to increase social interaction. If interested, or you have questions, contact Atikah Bagawan at:

575-567-9142 or email bagawana@msu.edu

Participation includes:

- Caregiver completes initial assessments about both siblings
- Typically developing sibling will receive training to implement social interaction strategies
- Recording of 2-3 sessions each week via Zoom. Video equipment provided if needed
- Amazon gift card will be provided to all participants (\$30-\$40)

Disclaimer: MI F2F and the Family Center cannot endorse or influence families to participate in this study. This information is provided for your information only and we encourage you to do your research before participating in any research studies.

PROTECT YOUR CHILD FROM FALL ASTHMA AND ALLERGIES

Every September, asthma hospitalizations and doctor visits increase. During this time, more people have asthma attacks. The third week of September is the worst and it continues through the fall.

It is important for everyone with asthma to take extra precautions during this time. There are many reasons September is hard for those with asthma and allergies. Ragweed (the most common Fall allergen), mold from falling leaves, and increased contact with respiratory illnesses occur when children go back to school. It is also the start of the flu season. With all this happening at the same time, kids are exposed to a lot of asthma triggers.

The best way to deal with illness or asthma attacks is to prevent them before they begin. The following tips come from the [Asthma and Allergy Foundation of America](https://www.asthmaandallergy.org/) website:

1. Stick to your Asthma Action Plan. Take your long-term control medicine as prescribed by your health care provider. If you move into the Yellow Zone of your plan, take action early so you can get back in the Green Zone.
2. Get the flu shot – It takes two weeks to take effect in your body, so now is the time to protect yourself.
3. Avoid your asthma triggers. If you are allergic to ragweed or mold, take steps to reduce your exposure to those allergens:

- Remove shoes before entering your home.
 - Keep your windows and doors closed during peak pollen times.
 - Use a certified asthma and allergy friendly air filter on your home's furnace/heater.
 - Shower and wash your hair before bedtime. Consider using a saline nasal rinse.
 - Talk with your allergist about possible treatments for your allergies.
5. Practice steps to avoid getting sick. Wash your hands often and for at least 20 seconds. Don't touch your eyes, mouth and nose. Stay away from people who are sick.
 6. Get plenty of sleep, eat healthy, stay hydrated and eat well. Take action to keep your stress levels down.

Be sure to work with your child's doctor to make sure their asthma is under control this fall.



FIND LOCATIONS FOR CAR SEAT SAFETY CHECKS

We all want our children to travel safely in cars. Many older children with special health care needs still require a car seat in order to ride in a car safely. Learning how to properly install any car seat can be a challenge for caregivers of children of any age.

Safe Kids can connect you to child passenger safety (CPS) technicians in your community who can check to make sure your car seats are installed correctly and teach you how to use and install a car seat on your own.

Working with a CPS technician will be a one-on-one learning experience. When you leave, you should be confident that your child's seat is installed correctly and feel comfortable reinstalling it on your own. This may be the most important thing you learn.

The National Child Passenger Safety Certification Training Program (CPS certification program) certifies people as child passenger safety technicians. Many technicians are trained health and safety professionals, others are parents, and some are



volunteers. They all have one thing in common: they care about kids and want to make sure they're safe.

You can find a child passenger safety technician in your area through the National CPS Certification Program. Simply fill in the online form and search by location, language or special needs training.

<https://cert.safekids.org/get-car-seat-checked>

NORD RARE CAREGIVER RESPITE PROGRAM AVAILABLE

Caring for a loved one with a rare disease demands significant time, attention, patience and dedication. The National Organization for Rare Disorders (NORD), launched the Rare Caregiver Respite Program, a program aimed at providing caregivers of rare disease patients much-needed respite.

NORD's Rare Caregiver's Respite Program provides financial assistance to enable the caregiver a break to attend a conference, event, or simply have an afternoon or evening away from caregiving.

Through the program, NORD provides financial assistance to eligible caregivers up to \$500 annually. This money can be used for respite care for a loved one. The patient for whom care is being provided must have a confirmed rare disease diagnosis. The grant may be dispersed throughout a calendar year or be used in a single award.

Awards are granted on a first come, first served basis. A NORD Patient Services Representative will guide the



applicant through the process, including verifying - financial eligibility using an Electronic Income Verification System.

The application decision process can take as few as five minutes over the telephone. Applications completed and submitted via email, fax or US mail will be processed within three business days of receipt. There is no fee to apply.

For more information, go to https://rarediseases.org/wp-content/uploads/2019/05/NRD-1182-RespiteCare_SS_1up_FNL_NoCrops_Fixed.pdf

or contact NORD AT: 203.616.4328 or email CaregiverRespite@rarediseases.org

ASAN OFFERING VACCINE FACT SHEET AND VIDEO

COVID-19 is especially dangerous to people with intellectual and developmental disabilities — but too often, the facts about COVID-19 are not shared in ways that are accessible. That's why Autistic Self Advocacy Network (ASAN) has released a fact sheet about the COVID-19 vaccine. This fact sheet answers questions like:

- Why should I get the COVID-19 vaccine?
- What will getting the vaccine be like?
- Is the vaccine safe?
- When can I get the vaccine?
- Do I still need to wear a mask after I get the vaccine?

The fact sheet is available in two versions: Easy Read version and

Plain Language version. The Easy Read version uses pictures and large text, and has more white space. The Plain Language version does not have any graphics. It is available in both English and Spanish.

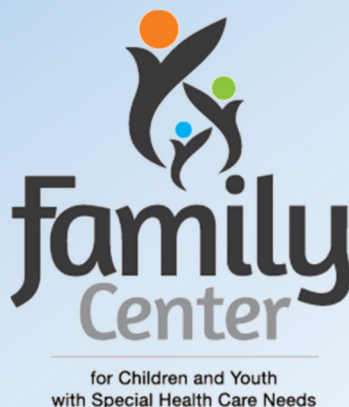
They also made a video that talks about the COVID-19 vaccine. It explains how the vaccine will help and what getting the vaccine will be like. You will find these resources and more at:

<https://autisticadvocacy.org/resources/covid-pl/vaccine/>



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

www.michigan.gov/familycenter

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.