



# MICHIGAN FAMILY CONNECTIONS NEWSLETTER

## NEW FACES AND NEW PLACES!

There have been some exciting staff changes at the Family Center for Children and Youth with Special Health Care Needs in the past few months. The Family Center has welcomed new staff as well as made changes to existing staff work assignments. First, please join us in welcoming Kristen Reese and Sandy LaPrad to the Family Center!

Kristen Reese accepted the position as Family Engagement Analyst and started in April. Some of you will recognize her as the former project director for Michigan Family to Family at Michigan Public Health Institute. Kristen has over 16 years of experience working with diverse families of children with special health care needs. She is excited to use what she has learned in her own parent leadership journey to support family involvement in programs and policy development.

Sandy LaPrad is the new Parent Peer Support Tech. She worked as a CSHCS nurse in Midland County for the last sixteen years. In addition to her work at CSHCS, Sandy comes to the Family Center with many years of experience with family-focused organizations including, Newborn Screening, Early Hearing Detection and Intervention, the Children with Special Needs Fund, and the PKU Association, to name a few. Sandy is parent to two young adult daughters and is passionate about helping families of children with special needs.

In addition to Kristen and Sandy joining the team, the Family Center has also transitioned some current staff to new positions. Ayanna Eggleston accepted a new position as Family Systems Specialist, and Aleisha Leavitt as Parent Information and Referral Support Tech.

We are excited for all of these changes and are looking forward to working with new and existing families.



Kristen Reese



Sandy LaPrad

## SUMMER 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*



# AUGUST IS NATIONAL IMMUNIZATION AWARENESS MONTH – IS YOUR CHILD UP TO DATE?

During the COVID-19 pandemic, there was a concerning drop in routine immunizations for children and adults. Routine vaccination numbers are recovering but it has been uneven and varies among some groups of people.

Many children and adults that delayed vaccination during the pandemic are still behind schedule. It is crucial that steps are taken to help get everyone back on schedule with their routine immunizations



Parents can use their child's back to school doctor appointments to schedule any of their missing immunizations.

Did you know that your child may qualify for free vaccines? The Vaccines for Children (VFC) program provides free vaccines to children who qualify. Children are eligible if it is before their 19th birthday and they:

- Qualify for Medicaid
- Don't have insurance
- Are American Indian or Alaska Native

Children whose insurance doesn't cover some or all recommended vaccines can also receive VFC at a Federally Qualified Health Center or Rural Health Clinic.

For a fact sheet on this program.

[Did you Know Your Child can Get Free Vaccines? – Factsheet \(cdc.gov\)](#)

## SUPERIOR ALLIANCE FOR INDEPENDENT LIVING (SAIL)

Superior Alliance for Independent Living (SAIL) is one of fifteen Centers for Independent Living in the State of Michigan. SAIL is located in Marquette, Michigan and supports individuals with disabilities in all fifteen counties of the Upper Peninsula.

SAIL has been serving individuals with disabilities and their families in Upper Peninsula communities since 1998. Their staff provides information, resources, referrals, and support services to people of all ages with a wide variety of disabilities, both visible and invisible.

SAIL's core pillars of service are advocacy, transition, independent living skills development, and peer support.

They also work on a larger scale, helping local businesses, and other organizations



to make changes that improve life for everyone in the community.

Connect with them to learn more about the wide variety of services they offer, including an Assistive Technology program, Transition Supports, Health and Wellness activities, and more.

Their website can be found at [Home - UP SAIL Disability Network](#)

# ARE YOU PREPARED FOR A SUMMER EMERGENCY?



For people with disabilities and their families, it is important to consider individual circumstances and needs to effectively prepare for emergencies and disasters. It is important to create a personalized emergency plan and kit that addresses your family's unique needs.

Here are some suggestions:

- Create a support network of people who can help. Keep a copy of your contact list in a watertight container in your emergency kit.
- Let your support network know where you keep your emergency supplies, and how to access them.
- Plan ahead for transportation if needed. Check with local transit providers as well as local emergency management agencies to identify accessible options.
- Many city and county emergency management agencies maintain voluntary registries for people with disabilities to self-identify in order to receive assistance during an emergency event.
- If you require life-sustaining medical treatment, such as dialysis, know the location and availability of more than one facility that can help.
- Organize and stock enough necessary prescription medications to prepare for an emergency.
- Wear a medical alert tag or bracelet and keep pertinent medical information in a safe place.
- Consider creating printed cards to inform first responders how to communicate with individuals with a communication disability.

- If you use medical equipment that relies on electricity, explore options about how to keep it running during a power outage. You can ask if your power provider can put you on a list for priority power restoration.
- If you use assistive devices, plan how to evacuate with them or how to replace equipment if lost or destroyed in an emergency event.
- Plan for individuals who may have difficulty in unfamiliar or chaotic environments. Have a comfort item available in your emergency kit if possible.
- Plan for animals' need for food, water and supplies. If you need to evacuate, find out if available shelters allow pets. Many shelters only allow service or support animals.

For additional emergency planning needs as well as information on building an emergency kit, visit the following:

[MIREADY \(michigan.gov\)](https://michigan.gov/miready)

[Mobile App \(michigan.gov\)](https://michigan.gov/mobileapp)

[People with Disabilities | Ready.gov](https://ready.gov/people-with-disabilities)

[Emergency Kit Checklist: Children with Special Healthcare Needs | CDC](https://www.cdc.gov/emergencykitchecklist/childrenwithspecialhealthcareneeds/)

[6 ways families of kids with special needs can prepare for emergencies \(michiganmedicine.org\)](https://michiganmedicine.org/6-ways-families-of-kids-with-special-needs-can-prepare-for-emergencies/)

[Welcome - Emergency Preparedness \(do1thing.com\)](https://do1thing.com/welcome-emergency-preparedness)





# NEW REPORT ON YOUTH AND YOUNG ADULTS WITH DISABILITIES AGING OUT OF MEDICAID, CHIP, SSI AND TITLE V PROGRAMS

The National Alliance to Advance Adolescent Health and Got Transition released a new report on the significant challenges and inequities that youth and young adults with disabilities face when aging out of Medicaid, CHIP, SSI, and Title V Programs.

Low-income youth with disabilities are at risk of losing coverage, supports, and continuity of care when they transition into adulthood. When they age out, many become uninsured, face worsening poverty levels, and experience



disruptions in care. Many also report additional worries and pressures.

This report is one of the results of a two-year effort to bring new attention to the challenges and inequities faced by this vulnerable population during such a difficult time in their lives.

With funding from the Lucile Packard Foundation for Children's Health and the WITH Foundation, and guided by a National Advisory Committee, the national report presents detailed recommendations to address gaps, complexities, and disparities for each of the public programs studied.

You can access the report at the following link from the Got Transition website:

[A National Report: Youth and Young Adults with Disabilities Aging Out of Medicaid, CHIP, SSI, and Title V Programs \(gottransition.org\)](https://gottransition.org/reports/a-national-report-youth-and-young-adults-with-disabilities-aging-out-of-medicaid-chip-ssi-and-title-v-programs)

## HELPING KIDS TRANSITION TO BACK TO SCHOOL

While it may seem early for parents to begin preparing their children to go back to school, it is important to plan ahead, especially if your child has a disability or other special needs.

One big difference between summer and the school year is the change in bedtime and wake up routines. Tackling this early can help avoid an abrupt change. Easing into a new routine will help the process of starting back to school much easier.

It is also helpful to recognize the strong emotions and anxiety that can come with starting a new school year. New teachers, new buildings, and being away



from home can be an adjustment for even older, more experienced students.

There are things you can do to make this transition easier for both parents and children. For helpful tips, visit: [11 back-to-school tips for parents of kids with special needs \(care.com\)](https://www.care.com/articles/back-to-school-tips-for-parents-of-kids-with-special-needs)

# FAMILY CENTER CONFERENCE SCHOLARSHIPS HELP FAMILIES LEARN AND CONNECT WITH OTHERS

The Family Center for Children and Youth with Special Health Care Needs has been helping families attend conferences related to their child's disability for over 30 years.

The conference scholarship program is open to any parent in the State of Michigan of a child (birth to 26 years) with special health care needs or disability, including those not enrolled in Children's Special Health Care Services. Youth (ages 14-26) can also attend a conference related to their own diagnosis with a parent or on their own.

One recent conference scholarship recipient, Shannon, shared about her experience. "Going to the conference allowed me to talk to drug developers and researchers one-on-one who are working on treatments and possible avenues to a cure for my daughter's disease."

"I was able to sit in courses and presentations given by multiple specialists, including epileptologists,



gastroenterologists, endocrinologists, neurologists and many more."

She also shared that, "Beyond listening to experts and learning from them, meeting other families is the best part for me. Being around people who understand our daily struggles and the challenges we face is very comforting and fulfilling. It is a feeling I can't properly explain."

Just since 2014, over 200 parents and 34 youth have attended conferences thanks to the conference scholarship program.

For more information on eligibility and an application, visit:

[The Family Center for Children and Youth with Special Health Care Needs \(Family Center\) \(michigan.gov\)](https://www.familycenter.org/michigan.gov)

## MI FAMILY TO FAMILY OFFERS RESOURCE REPOSITORY

One of the goals of Michigan Family to Family is to provide health related resources and information to families in Michigan with a child with a disability or special health care needs.

In order to maximize their outreach, MI F2F has invested considerable effort in building a resource repository on their website, [www.f2fmichigan.org](http://www.f2fmichigan.org). This online resource repository was created to help families find information on resources in their area. Families don't always know what resources exist to help meet the needs of their child.

Resources are searchable by name, keywords, or topics. They can be sorted

by county to identify resources in your specific area of the state.

There are also resources available in Spanish, and "Tip Sheets" created to help families on a variety of topics, including Finding a New Doctor, or How to Advocate for Your Child. You can also find great information and resources by exploring our past newsletters listed on the website as well.



## LEARNING OPPORTUNITIES

The Family Center and MI Family to Family partner together to offer various learning and support opportunities for families and professionals. Our current offerings are below:

### Growing as Leaders:

#### A Parent Leadership Series

To register for our next webinar visit:

[Growing as Leaders-Networking and Relationship Building Tickets, Wed, Aug 7, 2024 at 12:00 PM | Eventbrite](#)

More opportunities are coming soon.

To sign up for emails visit:

[Michigan Dept of Health & Human Services – Sign up for our Family Connections Newsletter \(govdelivery.com\)](#)



## FAMILY PHONE LINE

The Family Center offers a dedicated phone line for parents to call if they need information, support, or resources.

The Family Phone Line is open Monday – Friday, from 8:00 am to 5:00 pm. You can ask to speak directly with an experienced parent who can help!

**800-359-3722**

## 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 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, 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.