

# Michigan Family Connections Newsletter

Spring 2024

## Sibshop Training Coming Soon!

Sibshops are celebrations of the many contributions made by siblings of children with special needs. Sibshops acknowledge that being the sibling of a person with special needs is for some a good thing, for others a not-so-good thing, and for many, somewhere in between. They reflect a belief that siblings have much to offer one another – if they are given a chance. Sibshops are an opportunity to participate in a spirited mix of new games, new friends, and discussion activities.

If you would like to learn more and/or become a certified Sibshops facilitator, join us on August 15th and 16th in Okemos. After the training, grant applications will be available from the Family Center to individuals who are interested in running a Sibshops in their area.

For more information or to be notified when registration opens, contact the Family Phone Line at 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



**Sibshops**

## SAVE THE DATE!

### SIBSHOP TRAINING

**INTERESTED IN BECOMING A SIBSHOP FACILITATOR OR JUST WANT TO LEARN MORE ABOUT SIBSHOPS?**

**Join us in Okemos on Aug 15 & 16, 2024**

Open to parents, caregivers, service providers, educators, community partners, and local health department staff

**Thursday, Aug 15th – Introduction to Sibshops** – Anyone who would like to learn more about sibling issues, but not interested in running a Sibshop, should attend day one.

**Friday, August 16th – Facilitator Training** – Anyone who is interested in becoming a certified Sibshop facilitator should attend both days.

Cost \$35/one day \$60/both days. A limited number of scholarships are available. Interested in being on the **Adult Sibling Panel** or have a sibling (8-13 years old) of a child with special health care needs interested in participating in a **Demonstration Sibshop** on day two? Contact the Family Phone Line at 800-359-3722.

Brought to you by the  
Family Center for Children and Youth with Special Health  
Care Needs within Children's Special Health Care Services

**MDHHS**  
Michigan Department of Health and Human Services  
Children's Special Health Care Services



## SCDAA Inc. Speaks About Gene Therapy Approval

On Dec. 8, 2023, the Food and Drug Administration (FDA) approved two cell-based gene therapies for sickle cell disease (SCD), Casgevy from CRISPR/Vertex and Lyfgenia from Bluebird Bio. These are the first treatments of their kind available to individuals with SCD in the United States.

The Sickle Cell Disease Association of America Inc. welcomed the approval of these potentially curative therapies which mark major advances in the treatment of sickle cell disease; however, there are valid concerns about accessibility and the potential for adverse effects. In a statement issued by Dr. Lewis Hsu, chief medical officer of the SCDAA, he said:

“We at the Sickle Cell Disease Association of America Inc. celebrate that two gene therapies are approved for sickle cell disease by the FDA today, Dec. 8. This double milestone was a long



time coming, and sickle cell disease now joins the ranks of other genetic diseases with gene therapy treatments. These two gene therapies mark a big step forward for sickle cell disease research and treatment.”

To read more of Dr Hsu’s statement and learn more about gene therapy for SCD, visit: [SCDAA Statement About Gene Therapy Approval - Sickle Cell Disease Association of America Inc.](#)

## Camp and Conference Scholarships Available

Did you know that the Family Center for Children and Youth with Special Health Care Needs at Children’s Special Health Care Services offers both Camp and Conference Scholarships?

These programs are just one of the many ways the Family Center provides supports to families. These programs are available to families regardless of enrollment in Children’s Special Health Care Services. Specific eligibility criteria must still be met.

Camp Scholarships applications are available starting in February and are accepted as long as funding is available. The Family Center is still accepting applications at this time. Conference scholarships are available year round, and can



be used to help a parent and youth attend a conference related to the child’s diagnosis or disability.

More information, eligibility criteria, and applications are available at: [The Family Center for Children and Youth with Special Health Care Needs \(Family Center\) \(michigan.gov\)](#)

## Preschool Learning Resources from Build Up MI

When many preschools closed because of the pandemic, hundreds of thousands of Michigan children didn't have access to the vital resources they needed to meet important developmental milestones.

That's why early childhood educators from across Michigan created **Thrive From Home**, a statewide program to help parents and caregivers support their 3- to 5-year-olds with at-home activities and resources.

Families are encouraged to watch videos on Build Up Michigan's website and then practice activities with their preschooler at home using household items. There are a wide range of skill-building activities that take only a few minutes a day.

If parents are concerned about their child's development, they can find additional information on Build Up's website and contact a local Child



Find coordinator to request an evaluation.

Children who are not meeting developmental milestones or are struggling to learn may need additional supports through local districts to help them prepare for kindergarten.

Intervening as early as possible helps to develop skills to strengthen the child's foundation for future learning. The videos and other skill building resources are available at: [Thrive From Home Resources | Build Up Michigan](#)

## New Issue Brief on Paying Family Caregivers

Paying family caregivers for services covered by Medicaid for home- and community-based services has risen in popularity over the past several years. This is due to a shortage of providers and increased utilization during the COVID-19 public health emergency.

While many families and individuals may want this option, not all states have authorized it. Although there are some Medicaid restrictions, paying family caregivers is possible for many home- and community-based services.

This issue brief from the National Health Law Program discusses the Medicaid options for paying family caregivers. It covers some of the policy considerations that can help protect

individual choice, support caregivers, and overall increase the availability of support.

To download a copy of the issue brief, visit:

[Paying Family Caregivers: State Options, Limitations, and Policy Considerations - National Health Law Program](#)





# 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 youth 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 lived 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 openings in Regions 1, 2, 3, 7 and 8. A map of the regions is below:



**Family Leadership Network members (from left to right) Marisa Van Zile, Essie Brown, Genevieve Moore, Denise Crumbey, Ann Livingston, Nikki Sprague, Amy Nierenberger, Amethyst Crawford, Tisha Wowianko, and Samantha Oard at the annual meeting in April.**

This April, ten of our current members met in Okemos for our annual in-person meeting. They spent two days together learning about parent leadership, developing a vision statement for the group, and doing strategic planning for moving forward.

While the purpose of our annual meeting is to work together and plan for the upcoming year, the time spent together was also an opportunity to get to know the other members, build relationships, and share their experiences.

If you are interested in applying for an open position, more information is included in the Family Leadership Network application packet available on the MI F2F website at:

**[Family Leadership Network – Michigan Family to Family \(f2fmichigan.org\)](https://www.f2fmichigan.org)**



## New Transition Website For Youth With IDD

According to the National Survey of Children's Health (data from 2020/2021), 7% of youth aged 12-17 have intellectual and developmental disabilities (IDD). Eventually, they will need to transition from pediatric to adult health care services. But only 14% of youth with IDD received health care transition preparation and guidance from their doctor. Teens and young adults with IDD can make this transition smooth with support from their health care providers, families, and supporters.

The Center for Transition to Adult Health Care for Youth with Disabilities, a national center funded by the Administration for Community Living (ACL), is launching a new website to help young people and their families take the lead in health care transition.

The accessible site was developed for and by youth with intellectual and developmental



disabilities. The site features tools and resources for youth and their families, as well as resources for health care professionals who are supporting these families through health care transition.

Visit [www.MovingToAdultHealthCare.org](http://www.MovingToAdultHealthCare.org) to learn more!

## Supported Decision-Making Toolkit Available

People with disabilities and their families often ask, "What will happen to me when I am older or, to my son or daughter when I am gone?" As young people approach adulthood, families often question whether to pursue guardianship.

These conversations are made more difficult by lack of information and tools people can use to support loved ones.

Members of the Supported Decision-Making Coalition created a resource designed for all people, that recognizes their uniqueness and individuality and helps them, their families, and those who support them, throughout their lifespan to make decisions.

This toolkit is for all people, including people with multiple disabilities, intellectual disabilities, developmental disabilities, mental health disabilities, physical disabilities, substance use disorders, and aging adults.

The toolkit is available at [Supported Decision-Making Toolkit \(michigan.gov\)](http://SupportedDecision-MakingToolkit(michigan.gov))





## 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 current offerings 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.

### Growing As Leaders: A Parent Leadership Series

is a collaboration with *Parent Leadership in State Government*.

They are designed to develop and engage emerging family leaders in Michigan who are interested in working 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:

- **#5 Leadership Opportunities and your Role**, June 6, 2024, 12 noon to 1 pm
- **#6 Mentors and Networking**, August 7, 2024, 12 noon to 1 pm

To register for upcoming events, visit our Eventbrite page:

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



## We Want To Hear From You!



The Family Center and Michigan Family to Family are busy planning the next six months of learning opportunity events. This includes our Parent Connect Calls, Professional Connect Calls and the Navigating Healthcare Workshops. Is there a topic you are interested in learning more about? Please submit your ideas to the Family Center email at: [cshcsfc@michigan.gov](mailto:cshcsfc@michigan.gov).

## 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



### Children's Special Health Care Services

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.