

Michigan Family Connections Newsletter

Spring 2022

MDHHS Invites Public Comment On Title V Block Grant Application

The Michigan Department of Health and Human Services (MDHHS) invites the public to comment on the Title V Maternal and Child Health (MCH) Services Block Grant application. [\(Link to application here\)](#)

Title V of the Social Security Act of 1935, as amended, provides funding to states to improve the health of mothers, infants and children, including children with special health care needs. Michigan's Title V application is for services from Oct. 1, 2022, to Sept. 30, 2023, and includes a report on activities and services provided in fiscal year (FY) 2021.

Title V state action plans address the following priority areas for the current five-year cycle (FY 2021-2025) to improve the health of the MCH population in Michigan:

- Low-risk cesarean delivery
- Breastfeeding
- Infant safe sleep
- Bullying prevention
- Transition for youth with special health care needs to adult health care
- Oral health care for women and children
- Childhood lead poisoning prevention
- Immunizations for children and adolescents
- Medical care and treatment for children with special health care needs
- Healthy and intended pregnancy
- Behavioral and mental health services

These MCH priorities address needs across five federally identified population domains: women/maternal health, perinatal/infant health, child health, adolescent health, and children with special health care needs.

MDHHS welcomes comments on the application by 5 p.m. on June 10, 2022. Comments can be submitted to MCHBlockGrant@michigan.gov



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

A National Health Systems Research Agenda for Children and Youth with Special Health Care Needs: Supplement to Academic Pediatrics

Nearly 20% of U.S. children have special health care needs. Because of their increased need for health care services, they tend to be the most vulnerable to problems with health systems, including quality and access to care.

A national group of researchers aims to improve how health systems work for this population through the establishment of a family-centered national research agenda for children and youth with special health care needs (CYSHCN).

In a supplement to Academic Pediatrics released March 2, 2022, CYSHCN^{*} provides a blueprint of research priorities aimed at improving health outcomes and the wellbeing of CYSHCN and their families/caregivers.

The supplement includes seven papers that explain each of the agenda's priority topics plus

an executive summary paper. The research topics were identified through a rigorous process known as the RAND/UCLA Appropriateness Method (RAM).

Through this process, a diverse group of stakeholders, including youth and family caregivers, identified the following priorities:

- Child health and social determinants of health, to examine how the places people live, learn, work, and play impacts health
- Family health and how to support the adaptability of families with CYSHCN
- Telemedicine and supporting families living in rural areas
- Caregiving and at-home support
- Principles of care, to better understanding the keys to successful care management
- Health care financing, including payment models and value outcomes
- Youth-to-adult transitions and how gaps in support impact outcomes

The articles can be accessed on the

[Lucile Packard Foundation for Children's Health website](#)



^{*}About CYSHCN

Children and Youth with Special Health Care Needs National Research Network (CYSHCN) is a national group of expert investigators, family leaders, and early-career researchers. Our vision is to improve the health, wellbeing,

and quality of life of children and families by creating and promoting research excellence. The network partners with families and collaborates to share findings and train early-career investigators.

Simply Sayin' App from Phoenix Children's Hospital

Simply Sayin' is an educational app created by the Child Life team at Phoenix Children's.

The app helps you find the right words or phrases to explain and talk about an illness or injury, medical procedures or other areas of interest or concern.

The app's user-friendly layout includes:

- Ready access to an large glossary of medical terms with simple explanations that are easy for kids to understand
- A script feature to prepare children for surgery, with details about specific procedures and photos of medical equipment that may be used.



- Interactive drawing boards for various body systems to help kids become familiar with areas and approaches to treatment
- English and Spanish translations

The app is available free of charge in the iTunes or Google Play stores.

For more information and other resources, visit:

[Phoenix Children's Hospital Website](#)

Lori's Voice Expands Van Assistance Statewide

Lori's Voice is an all-volunteer organization that was founded to enrich the lives of children with neuromuscular and degenerative diseases.

Lori's Voice provides financial assistance to support the cost of items such as adaptive equipment, therapies, barrier-free rooms, wheelchair accessories and accessible vans.

These essential items are critical to one's wellbeing and quality of life and are not always covered by insurance.

Accessible Vans represent a huge cost for caregivers that insurance does not cover. Lori's Voice recently expanded their "van assistance" to cover the entire state of Michigan, reaching even more families in need. This assistance is limited, and families are expected to use other resources to provide additional funds necessary for this type of purchase.

As permitted by resources and determined solely by the Board of Directors, Lori's

Voice may provide financial assistance to children who:

- Are under 21 years old,
- Have a neuromuscular or degenerative disease (typically with mobility issues) and
- Have a financial need.

This organization exists to help as many families and children with special needs as possible. For more information or to complete an application, please visit

[Lori's Voice Website](#)



Children with Special Needs Fund

Do you know a child who could benefit from a therapeutic tricycle? Are you a family who struggles to move their child from a wheelchair to their vehicle? The Children with Special Needs Fund can help!

As a program of Children's Special Health Care Services (CSHCS), the CSN Fund provides family-centered support for children in Michigan with special health care needs by helping with the purchase of equipment to promote the child's mobility, health, and well-being.

Children under 21 who are enrolled in CSHCS (or medically eligible to enroll) can apply for help from the CSN Fund.

The CSN Fund helps families purchase items not covered by insurance or other state or federal programs. Part or all of the costs may be covered for the following items:

- Adaptive recreational equipment
- Air conditioners
- Ceiling/stair lifts
- Electrical service upgrades
- Therapeutic tricycles
- Transit options
- Vehicle accessibility devices
- Weighted blankets/vests
- Wheelchair ramps

In addition to helping with equipment, the CSN Fund provides funding to the Family Center for Children and Youth with Special Health Care Needs for conference scholarships, camp scholarships, parent mentor trainings, and Sibshop trainings.

All requests are made by filling out an application and providing the required materials.



Applications are available at:

www.michigan.gov/csntfund

or families can call (517) 241-7420 or

email csntfund@michigan.gov to request one.

CSHCS staff at local health departments can also assist families with their applications.

The CSN Fund was created in 1944 when co-founder of Dow Chemical, Dr. James T. Pardee, and his wife, Elsa Pardee, made a generous bequest of Dow Chemical Company stocks to the State of Michigan to support children with special needs.

While the Pardee's gift makes up the largest portion of the Fund, many other organizations, businesses, individuals, and families have contributed over the years, making the fund a privately funded program without using any tax dollars.



Communication is Key, AAC

Communication is Key AAC is a Michigan non-profit organization that believes that every individual has the right to be able to communicate.

Their mission is to improve access to communication for those with complex communication needs by increasing training for Speech pathologists, teachers, support staff in schools and the community, and families, and increasing opportunities for those with complex communication needs to meet others with similar needs.

Communication is Key was founded by families who were frustrated with the support (or lack thereof) their children were receiving from local schools and therapy facilities.

People with complex communication needs have a right to communicate, and a lack of trained staff who can help them learn to communicate effectively is an impediment to achieving their goals.

Their goal is to improve services to those with complex communication needs, and their families, in order to help them reach their communication potential.

They have awarded families, schools, therapy centers, teachers, speech paths, and more a variety of things from playground communication boards, AAC literature, access to conferences, and more.

For more information, visit :

[Communication is Key website](#)



Her Power, Her Pride Camp Returns Summer 2022

After two years of prioritizing the safety of campers and staff, Michigan Disability Rights Coalition is excited to announce Her Power, Her Pride camp will be back this summer.

Her Power, Her Pride works directly with teen girls ages 14 - 19 with disabilities through a unique, four-day event designed to promote critical thinking about society's messages, eliminate shame, develop leadership skills, and encourage self-acceptance.

This event is grounded in disability pride and emerging research in female development and goes beyond a self-esteem program to provide a venue for real self-empowerment.

Registration for Her Power 2022 is now open.

Dates: July 28th—31st

Where: Camp Fish Tales, Pinconning, MI

Link to register:

tinyurl.com/HerPowerHerPride2022



The Michigan Assistive Technology Program

The Michigan Assistive Technology Program (MATP) is a program for people with disabilities, by people with disabilities. It is made possible due to the Assistive Technology Act.

Assistive technology is any tool, software, or app that can help people with disabilities, including older adults, do what they want to do. This may include recreation, sports, education, employment, activities of daily living and more.

The Michigan Assistive Technology Program is housed at Michigan Disability Rights Coalition and provides services for people with disabilities, family members, and others to know more about, have better access to, and help to find ways to obtain assistive technology devices.

They offer demonstration activities to provide opportunities for people to become familiar with specific types of AT. They can help compare the functions and features of devices through hands-

on exploration guided by a knowledgeable professional. They also allow individuals to borrow AT for a limited time period to try out and determine if a device will meet their needs before a purchase is made.

For more information, visit the [Michigan Disability Rights Coalition Website](#).



Kid's Cove New All-Inclusive Playground Coming

Kid's Cove located in Mattson Park in Marquette, Michigan, was an outstanding community endeavor completed in the summer of 1996. It has been a fixture for the Marquette community and has been a great gathering place for families.

Now, after thousands of children have climbed its towers and slid down its slides, the existing playground at Mattson Park needs to be replaced because it is 25 years old, outdated, and filled with equipment that needs to be replaced.

With safety, inclusion, and fun being top priorities, the Marquette Playgrounds for All

Committee, the Community Foundation of Marquette County, and the City of Marquette are working with the community on the creation of a new playground made of child-friendly material and equipment.

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Kid's Cove Playground (continued)

The playground will be built so it is easy to use, understandable, and safe for all users. A playground for the widest spectrum of users and one that meets the concepts of all-inclusive design.

This playground will build togetherness, understanding, and respect that children of all abilities would not achieve if separated. In other words, this playground is not just for children with disabilities, but is for ALL kids.

The fundraising goal for the playground is

\$1.4M. The committee is asking community members/foundations/corporations, etc. to donate toward the \$400k to reach that goal and make the dream a reality.

Community fundraising is ongoing with ground-breaking planned for Fall of 2022, and construction in Spring/Summer 2023. Once completed, the playground will delight children and families of all abilities for years to come.

For more information, visit the [Kid's Cove Marquette Website](#)

OpenSpot Celebrating 10 Years Of Accessible Theatre

OpenSpot Theatre began in Metro Detroit in 2012 as 4th Wall Theatre Company. Co-Founders Katie Mann and Annie Klark created the company based on the idea that the performing arts should be accessible to ALL people.

Their dream of Theatre for All spread quickly through the Southeast Michigan area, and in 2020 Katie and Annie decided to expand the company, providing arts opportunities to students across the United States. Thus, OpenSpot Theatre was born!

OpenSpot Theatre's mission is to provide a fun, creative, and inclusive arts experience that is accessible to all people. Through their rehearsal and performance process, students will experience personal affirmation, empowerment, and build important life skills.

OpenSpot's theatre program is specifically designed for everyone, from students with developmental disabilities to seniors looking for a fun, new adventure. Participants explore the three pillars of theatre (singing, acting, and

dancing), theatre games/activities, and for their younger students, life skills (eye contact, manners, etc).

The founders believe musical theatre can be applied to educate all ages of theatre students about different aspects of themselves and with our younger students; real world skills.

Each class is led by trained theatre professionals and culminates in a live performance for family and friends. The process of learning about the theatre and rehearsing a live show promotes teamwork, cooperation, belonging, work ethic, memory, leadership, social skills and maybe most importantly; it's fun!

For more info on upcoming classes/events:

[OpenSpot Theatre Website](#)



Trainings And Other Events

Parent Connect Calls

- Topic: Oakland Mediation Center, Wednesday, June 8, 2022, from 11:00 am to 12:00 pm EST.

[Parent Connect Call Registration](#)

Professional Connect Calls

- Topic: Children's Special Health Care Services (CSHCS) Thursday, June 16, 2022, from 3:00 pm to 4:00 pm EST. [Professional Connect Call Registration](#)

Parent Mentor Trainings

Weekday Virtual Parent Mentor Trainings:

- Tuesday – Wednesday, 9 am – 11:30 am and Thursday, 9:00 am – 12:00 pm EST.
- June 14 - 16, 2022

[Weekday Parent Mentor Registration](#)

Saturday Virtual Parent Mentor Trainings:

- Saturday from 9:00 am to 3:30 pm EST on Microsoft Teams.
- June 25, 2022

[Saturday Parent Mentor Registration](#)

Bereavement Virtual Parent Mentor Training

- Tuesday, June 28 and Wednesday, June 29, 2022, 9:00 am – 12:30 pm EST.

[Bereavement Parent Mentor Registration](#)

Navigating Healthcare Training for Families of Children with Epilepsy

An online, interactive, medical advocacy training created to provide families with the information, tools, and resources needed to help navigate healthcare systems. This training will have a special focus on supporting families of children with a diagnosis of epilepsy (seizure disorders).

- Open to any parent (bio, adoptive, foster, step, kinship, etc.) with a child (birth to 18) with epilepsy in Michigan.
- Dates: July 27th and 28th or August 17th and 18th.
- Training is from 9:30 am to 12:30 pm on both days.
- Parents who complete the training are eligible for a \$100 stipend.

[Navigating Healthcare for Families of Children with Epilepsy Registration](#)



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.



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 work to make services for children and youth with special health care needs better.

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 517-241-7630

CSHCS Family Phone Line 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.