

# Michigan Family Connections Newsletter

Fall 2018

## FAMILY STORY AND VIDEO SUBMISSIONS

Are you a parent or individual with special health care needs with a story to tell? Now is your chance. Michigan Family Connections Newsletter is preparing for our annual Family Stories edition in early 2019.

Each year, we ask our readers to share their experience with us. This year, we are making it even better. Not only can you share your written story or poem, we are also accepting short, original video stories.\*

Our next newsletter will feature six of the stories and videos sent in. All of the entries will be shared on the MI F2F website or YouTube channel. The six chosen to be featured in the newsletter will also win a \$50 gift card. Submissions must be received by **December 31st, 2018**.

Feel free to get creative. We love to hear about the challenges and joys in your life. Submissions must be your original work, and previously unpublished or featured. Some topic ideas include: grief and acceptance, inclusion, transition to adulthood, sibling or family relationships, mental or behavioral health, or experiences as a youth or young adult living with a disability.

Written stories can be submitted to the following link:

<https://f2fmichigan.org/family-stories/submit-your-story/>

Videos can be submitted to [f2fmichigan@gmail.com](mailto:f2fmichigan@gmail.com).



\*Original video stories can be created in a variety of ways. Some free, easy to use ideas include the following: Adobe Spark, Google Picasa, and PowerPoint.

For an example, check out MIF2F's YouTube channel:

[https://www.youtube.com/watch?v=5I\\_R3EvHVZs](https://www.youtube.com/watch?v=5I_R3EvHVZs)



*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 quarterly 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 CENTERS FOR INDEPENDENT LIVING

Did you know there are fifteen Centers for Independent Living (CILs) in Michigan? They are community-based, inclusive organizations focused on promoting independence for all persons with disabilities.

The goal of CILs is to ensure that persons with disabilities have what they need to participate in all aspects of their lives, to the fullest extent possible. All of Michigan's 83 counties are serviced by one of the fifteen CILs.

The CILs provide a variety of services, including community development activities and direct services.

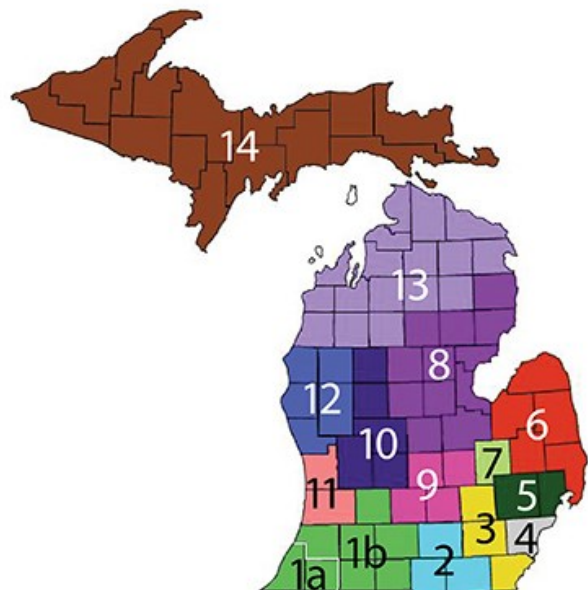
Community development activities include community needs assessments, systems advocacy, community outreach, and technical assistance.

Direct services include advocacy, transition services, peer support, independent living skills support, and information and referrals.

Each CIL also may provide other services unique to their community's and consumers' needs. People with disabilities of all ages and

characteristics are eligible for independent living services.

Visit [www.dnmichigan.org/cil-directory](http://www.dnmichigan.org/cil-directory) for a list of all fifteen CILs and a CIL county service map. Contact information and websites for each CIL are also provided for further information.



## FAMILY HEALTH HISTORY

The Center for Disease Control (CDC) encourages you to celebrate Thanksgiving Day as Family Health History Day as well.

A tool has been developed called *My Family Health Portrait*. It helps organize your family health history. You can learn about your risk for conditions that run in families and you can save it and update it over time.

With the holidays approaching and families gathering, it's a great time to ask them questions that could be vital for your health care practitioners to provide better care for you.

The "My Family Health Portrait" is an internet based tool that makes it easy for you to record your family health history. It assembles your



information and makes a family tree that you can download.

It is completely private and does not keep your information. It gives you a health history that you can share with family members or send to your health care practitioner.

For more information visit the CDC website: <https://phgkb.cdc.gov/FHH/html/>

## WHEN THE PATH ISN'T ALWAYS CLEAR BY SCOTT NEWPORT

When Evan came into our family, I didn't know how his life would be.

The first words I heard from medical staff was, "We would give him a fifty, fifty chance of survival."

After about four month in the NICU they said, "He may live a long time, he may die tomorrow. The path isn't always clear for kids like Evan."

By the time we left the hospital there was a name for his condition but no cure. It wasn't till I started to investigate palliative care that I knew I may be able to start being more of a dad instead of a nurse.

With our palliative team added to the list of caregivers, our family quickly discovered we didn't have to take Evan to the hospital every time he got sick. We were even able to do blood draws at home instead of loading up the car with his equipment. Our new supportive team was just a phone call away. Sometimes an email or text would work.

Linda, our palliative social worker, helped me to understand it was ok to be sad but also take joy in teaching Evan how to ride a bike. Noah, Evan's big brother could make it to more soccer games too.

We kept all our other doctors but the palliative team helped keep life a bit more manageable, as they tend to think outside the box.

The other day I was thinking about the first time I heard the words palliative care from one of my favorite nurses, Maureen Giacomazza from the Stepping Stones Palliative Care Program at C.S. Mott Children's Hospital. I decided I would write her and ask, "Maureen, what are the words, you use today, to tell families about the work you do?"

Her response was kind of how I remembered it back when Evan was just a newborn.

*"Palliative Care is a program that provides additional support to patients and families who are facing a serious illness. We can help with pain & symptom management, communication between their specialty care providers, identification of additional resources*

*in the hospital and home that might help them live the best quality of life. We provide medical decision-making support when new treatments (or surgeries) are proposed. Our ultimate goal is to make sure that all the care the families are receiving aligns with the values, hopes and goals for their child."*

Even though Evan is gone, his journey has given me the privilege of helping other families on the path. Just last week I was working with a mom at the hospital as a mentor. She said, "Of course, I appreciate our conversations, because I know you get it."

Palliative care may not be the answer for every family but it was for ours, especially when the path was not always clear.



### Palliative Care

Palliative care (pronounced pal-lee-uh-tiv) is specialized care for patients with serious health conditions. It focuses on providing relief from the symptoms and stress of ongoing medical treatment.

Palliative care involves clinicians from different areas, such as medicine, nursing, social work, child life, spiritual care and different kinds of therapies.

Palliative care strives to provide comfort for you and your child. It improves quality of life: physically, psychologically, socially, emotionally, and spiritually.

There are no time restrictions. Palliative care can be received by patients at any age, any time, at any stage of illness, whether or not it is life-limiting.

Many insurance plans, including Medicaid, cover palliative care.



## NATIONAL SURVEY OF CHILDREN'S HEALTH DATA

The Health Resources and Services Administration (HRSA) has released data from the 2017 National Survey of Children's Health (NSCH). The NSCH provides annual national and state level estimates of measures of children's health and well-being.

It includes physical and mental health status, health insurance, access to and utilization of health care services, medical home access, early childhood information, transition into adult health care services, access to community-based services and impact on child's family. The voluntary survey is administered by HRSA's Maternal and Child Health Bureau and the U.S. Census Bureau.

The 2017 National Survey of Children's Health fact sheet, which includes a snapshot of some of the data collected, can be accessed at: <https://mchb.hrsa.gov/sites/default/files/mchb/Data/NSCH/NSCH-factsheet-2017-release.pdf>.

For those interested in the full 2017 NSCH data, please visit <https://mchb.hrsa.gov/data/national-surveys>.



"I will love the light for it shows me the way, yet I will endure the darkness because it shows me the stars." ~Og Mandino

## IDEAS FOR YOUR FAMILY BOOKSHELF

Dr. Laura Jimenez, Boston University Wheelock College of Education and Human Development, specializes in inclusive books. She has given us some recommendations for your family:

**Rain Reign** by Ann M. Martin: Rose Howard has OCD, Asperger's Syndrome and an obsession with homonyms. Hearts will break and spirits will soar for this powerful story, brilliantly told from Rose's point of view. (Upper elementary to middle school age)

**Annie Sullivan and the Trials of Helen Keller** by Joseph Lambert: Annie Sullivan, a young woman who was herself visually impaired, was hired as a tutor when Helen was 6 years old. Annie broke down the barriers between Helen and the wider world. The author and illustrator examines the powerful bond between teacher and pupil. (Third grade and up)

**Handbook for Dragon Slayers** by Merrie Haskell: This middle grade fantasy adventure mixes magic, mythical creatures, thrilling action and a wonderful cast of characters. Political upheaval sends Princess Tilda fleeing her kingdom, but the princess never had any interest in chasing dragons. The princess finds herself doing things she never imagined and finds qualities in herself she never knew she possessed. (Upper elementary to middle school age)

**You're Welcome, Universe** by Whitney Gardner: When Julian finds a slur about her best friend scrawled across the back of the Kingston School for the Deaf, she covers it up with a beautiful graffiti mural. *You're Welcome, Universe* introduces audiences to a one of a kind protagonist who is unabashedly herself no matter what life throws in her way. (Upper middle school age)



## PARENT MENTOR TRAINING

The Family Center for Children and Youth with Special Health Care Needs is Michigan's statewide Parent-to-Parent Support Network. The Family Center offers Parent Mentor trainings throughout Michigan. The training locations are updated quarterly on our website – <http://michigan.gov/familycenter>

We greatly encourage you to attend our face-to-face Parent Mentor trainings, however, we understand this may be difficult for some families. We also offer an online training option – <http://courses.mihealth.org/PUBLIC>. Once you register, you'll select the Family Center's Parent Mentor Training.

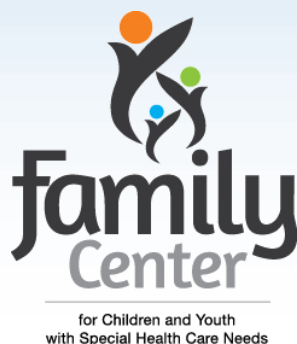
Please call the Family Phone Line at 800-359-3722 if you would like more information about the trainings, services and/or resources provided by the Family Center.



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](http://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**

**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.