

PARTNERING TOGETHER

PAGE 3 WE NEED YOU!

Become a F2F Volunteer and help other families!

PAGE 5 CHARTING THE LIFE COURSE

Webinar Series

PAGE 7 AFFORDABLE CARE

What you need to know about the Health Insurance Marketplace



DISCOVERING AND NAVIGATING TOGETHER

Four years ago Missouri Family to Family partnered with Special Health Care Needs to bring you the first issue of *Partnering Together*. Since then, *Partnering Together* has become just one of many tools available through MOF2F that connects you to information and resources available in your area, Missouri, and across the country.

This magazine is for you. It is written by families, for families. Each issue contains news about supports and services, relevant and practical information about life topics like transition and insurance coverage, profiles of Missouri families of children with special healthcare needs, and new ways to network with other families.

Over the years we have armed you with information about building partnerships and communicating effectively, making a difference in your community, being prepared for emergencies, easing the transition from one life stage to the next, and much more. We are excited to keep bringing you what you want and hope to include your stories in the resources we share. Do you have news to share? Do you have pictures of your family living life to share? Would you like to contribute to *Partnering Together*? Connect with us at mofamilytofamily.org or by e-mail at mofamilytofamily@gmail.com for more information about opportunities to partner together. ●
(Visit mofamilytofamily.org to share this newsletter and past issues with friends and family)





PARTNERING TO HELP OTHERS

Parents and family members become natural leaders within their own families. Eventually many parents feel the desire to “reach back” and help other families and try to change services and systems to better serve all families. You can use your expertise and passion to transform policies and the systems you use to help create change and make things better for your own and other families.

Have you ever wanted to serve on an advisory board or council? Are you already a family leader who wants to build your skills? You can enhance your skills by participating in the Family Leadership Certificate Series hosted at local sites across Missouri. The series is made up of five training sessions hosted monthly. These sessions include a discussion and an activity after each broadcast. The webinars cover topics such as communication, navigation, cultural and family diversity, partnerships and collaboration, as well as problem solving and decision making. The series is designed to help

you enhance and develop leadership skills as you strive to make a difference for other families and to make positive change in organizations, systems and policy.

There are many ways you can partner to meet the needs of your family and help others at the same time. You can become more involved by volunteering in community activities, talking to other parents or people with special health care needs/developmental disabilities as a peer mentor, and participating in school organizations, on focus groups, or on local advisory boards. All of these activities can introduce you to new people who may become friends and make a difference for yourself or someone like you. MOF2F can help you channel your passion and find the right opportunity. Connect with us online at mofamilytofamily.org to attend the Family Leadership Series or find out how you can help us make a difference for families in Missouri! ●



Above: The Heavenly Angels of Kansas City, a parent group, who spent a Saturday helping us prepare Welcome packets for new families!

WE NEED YOU!

MOF2F is growing and we need your help! Check out just some of the many ways you can connect with us to make a difference in the life of another family or make an even bigger impact.

HELP OTHER FAMILIES



Help us with our mission of providing information to families

Spread the word about MOF2F

Do you like attending conferences, fairs, and networking with others? Become a display assistant! Display assistants share information and MOF2F materials at events. This requires a short training session at an event you attend. We will then ask you if you are available for events in your area.

Help us create family-friendly products

Do you have stories to share about finding employment, accessing health care, or exploring options for a new living space? Are you creative? Do you like to write or take photos? We always need individuals and families to help us develop products that will be helpful to families!

Tell us what you think about MOF2F materials

We always need individuals and family members to review products (like websites, MOF2F publications, and flyers) to ensure they are useful, accessible and family-friendly.



Become a lifeline for another parent with Sharing Our Strengths

Become an SOS Mentor

Did you wish when your child was first diagnosed that you could talk with another parent with a similar situation? Become an SOS mentor and provide comfort, guidance, and a listening ear for other parents. Being a mentor is easy and flexible: volunteering is usually done over the phone, via email, or even on social media! You decide when and how often you would like to be matched with another parent who needs help.

Serve as an SOS "Caller"

Have you ever been a secret shopper? We need secret "callers" for Sharing Our Strengths to help new mentors feel comfortable getting ready for their new role.

Train SOS Mentors in your area

We can come to you and teach you how to train SOS mentors so you can recruit and train mentors in your own area. Please contact us to find out more!

TRANSFORM POLICIES AND SYSTEMS



Become a voice for other families through the MOF2F Family Leadership & Volunteer Network

Speaker's bureau

Are you confident telling your story in front of others? MOF2F is often approached by organizations that need individuals with disabilities and/or special health care needs and their family members to give a testimony, share their story with a reporter, or write an editorial.

Serve on a board or committee

Have you ever wanted to serve in a position of leadership? Organizations and systems that provide services must have people on their board that represent the population they serve. We often get requests for family members to make sure that families' voices are heard!

Sign up as a volunteer and join a network of over 500 volunteers across Missouri who are passionate about supporting families! Go to mofamilytofamily.org for more information or call 800-779-8652.





FAMILY TO FAMILY NETWORK

supporting families across the lifespan

We want to live in a world where everyone is valued and treated with respect, fairness, and equality; included in their communities; and given opportunities to dream, achieve success, and change the world.

Explore and download resources, learn about upcoming opportunities, and connect with others at mofamilytofamily.org

Missouri Family to Family is a statewide resource for individuals with disabilities or special health care needs and their families. We link families to information and support so they are well informed, hopeful, connected with their communities, and know they are not alone in their experience. MOF2F believes in supporting families throughout the entire life course. We envision a world where everyone is valued and treated with respect, fairness, and equality; included in their communities; and given opportunities to dream, achieve success, and change the world.

MOF2F is a one-stop resource that arms you with the information or connections you or your family needs. One of our core supports is offering customized information about needed resources and supports, navigating the maze of systems and services, as well as options to make their vision for their life possible. You can get connected online or by calling our toll-free number.

In addition, each month MOF2F offers a new webinar on issues that are important to you. Webinars are archived online and can be viewed at any time. You can also connect with others at local host sites where you can watch the webinar, discuss how the topic affects your life, and learn from shared experiences.

Our network has grown to include over 90 partnering organizations and systems and we are still growing. We partner with statewide

and family organizations to make sure you have access to the information and support you need. Our partnering organizations (affiliates) connect with the F2F Network to link you to other families through Sharing Our Strengths, host Life Course Webinars, and connect you to local and statewide information.

MOF2F partners with the Department of Mental Health-Division of Developmental Disabilities to enhance the statewide network supporting families. It is crucial to them that families have quick access to information and resources and have an opportunity to talk with another family member with similar experiences. The Division partners with us to make a personal connection available to you. The Family Support Coordinators in each region host the Life Course webinars every month. They can also provide you with information about alternatives to guardianship in Missouri and connect you with opportunities to make an impact in your area.

Through our ongoing partnership with Special Health Care Needs, Family Partners are another example of families who are here to help. The four Family Partners are parents of individuals with special health care needs who provide information and connect families to other families through one-on-one support and local events. Family Partners can arm you with tools and information to create the life you want for your family. They are just an e-mail or phone call away! ●



CHARTING THE LIFE COURSE Webinar Series

Missouri Family to Family presents monthly webinars about topics that are important to people with disabilities and their families as well as professionals that work with families. Below are topics featured in past Charting the Life Course Webinars. If you have an idea for a webinar that you would like to see in the future, contact us!



Daily Life

- Assistive Technology: Independence, Inclusion, and Access
- The Golden Years: Thinking About Aging and Retirement
- Focusing on Employment
- Everyone Can Serve: Volunteerism & Service for People with Disabilities & Special Healthcare Needs



Community Living

- Focusing on Housing: An Array of Options
- Focusing on Housing: Housing in Missouri
- Companion Model: A Shared Home, Shared Life Approach



Healthy Living

- Understanding Health Reform
- Surviving the Transition to Adult Medical Care
- Partnering with your Local EMS Professionals to Support Your Family



Services & Supports

- Navigating the Maze: Mapping Supports for Your Life Course
- Focusing on Families: A Priority of DMH's Division of Developmental Disabilities



Social & Spirituality

- What Are You Doing this Summer?



Safety & Security

- MO Guardianship: Understanding Your Options and Alternatives



Advocacy & Family Support

- Self-Advocacy: Not Just a Buzz Word
- The F2F & You
- Disability History & Awareness
- Transition to Adulthood: The Self-Determined Life
- Learning about Family Leadership: Leading to help other families and change systems
- Moving Along the Timeline: Past, Present & Future of Disability
- Uncharted Waters: Moving Beyond What We Know As Family Support

THERE ARE TWO WAYS TO WATCH!



VIEW AN ARCHIVED WEBINAR

Visit mofamilytofamily.org and click on Charting the Life Course Webinars to sign in to the webinar archives!



ATTEND A HOST SITE

Go online to our website and find out how you can watch the webinar in person with other families and professionals in your area at a local host site.



NAVIGATING THE EXCHANGE



The Affordable Care Act, passed in 2010, is now three years old. So far the law has made it illegal for insurance companies to:

- deny coverage to children because of a pre-existing condition (in 2014 discriminating against anyone with a pre-existing condition will be illegal)
- place a lifetime cap on how much care they will pay for if you get sick, and
- cancel your coverage when you get sick by finding a mistake on your paperwork.

The law also increases your access to free preventative services and screenings. Preventative care includes things like screenings and assessments, immunizations, well child exams, well woman exams, and more.

Beginning in October of 2013, you will be able to shop for health insurance and compare plans through the Health Insurance Marketplace. This is a way to offer you new access to affordable health insurance coverage. The Marketplace is designed to help you find the health insurance that fits your needs and budget. At The Marketplace you will complete one application and see all of the programs for which you qualify. In Missouri, the marketplace is being set up by the federal government so we don't know what Missouri's Marketplace will look like. The federal government requires four levels of coverage: bronze, silver, gold, and platinum with each level having different plans and insurers for you to choose from.

As you begin looking at your health insurance needs it is important to:

- Learn about different types of health insurance available
- Make a list of questions you have before you pick your health plan
- Make sure you have a firm grasp on how insurance works
- Organize information about your household income and other important documents
- Set your budget
- Find out if your employer offers health insurance at your workplace
- Explore your current choices for health insurance coverage

The Marketplace will also have navigators and in-person assistance. Navigators are not connected with any specific plan and they aren't on commission, so the help they give is unbiased. Family Voices, an organization that advocates on behalf of families with special health care needs, submitted comments on a proposed rule on standards for navigators in states not running their own exchanges like Missouri. Family Voices wanted policymakers to know that it is important that navigators are trained to understand the needs of children and youth with special health care needs and disabilities.

If you have questions concerning your family's health care and want to talk to another family to think through your options, contact MOF2F. We are here to help. ●

EXCHANGE NAVIGATORS: GUIDING YOU THROUGH THE MAZE



Are you confused about the Marketplace and worried about figuring it all out? Once the exchange is up and running, navigators will be available to guide you through the various facets of the new health care environment if you need help. Navigators will assist families with things including shopping around in the Health Insurance Marketplace, identifying a qualified

health plan that fits their family's situation, and accessing public programs like Medicaid and the Children's Health Insurance Program. Navigators will be able to help you one-on-one and at community events. Stay tuned to mofamilytofamily.org and we will keep you informed about how you can get connected to a Navigator in your area! ●



FAMILY LEADERSHIP CERTIFICATE SERIES

ARE YOU READY TO MAKE CHANGE?

- Do you have valuable family experiences you want to share with others?
- Do you want to learn more about how to advocate for yourself and others?
- Have you ever wanted to serve on a board or council but didn't know how to get started?
- Are you already a family leader and wish to enhance your skills?

Missouri's Family Leadership Certificate Series (FLCS) is for you! A family leader has personal experience in issues affecting children and families, and speaks and acts from their perspective as a family member.

The FLCS will help new and emerging family leaders enhance and develop leadership skills as they strive to make a difference for other families and to make positive change in organizations, systems and policy.

The Family Leadership Certificate Series is a series of FREE interactive webinar training workshops! The series consists of 5 monthly webinars hosted at local sites, followed by a discussion or activity after each broadcast. The webinars will cover topics such as communication, navigation, cultural & family diversity, partnerships & collaboration, and problem solving/decision making.

Register and find out more at mofamilyleadership.org! ●

RESOURCES

The screenshot shows the HealthCare.gov homepage with navigation tabs for 'Find Insurance Options Now', 'Prepare for the Health Insurance Marketplace', 'Health Insurance Basics', 'The Health Care Law & You', and 'Prevention, Wellness & Comparing Providers'. A main banner features a 'Need health insurance? Learn more & get ready.' section with an email input field and a 'Get Email or Text Updates >' button, alongside a 'Get Prepared' section with a 'Learn More >' button. A photo of a smiling couple is visible on the right.

Healthcare.gov

See what preventative services are covered, sign up for email updates about the exchange, get help understanding insurance coverage and more. Information is available in Spanish as well.

The screenshot shows the HealthIT.gov homepage with navigation tabs for 'Providers & Professionals', 'Patients & Families', and 'Policy Researchers & Implementers'. A main banner features a quote: "I no longer have to fill out the same forms again and again." and text stating 'Health IT can free you to focus on your family's health instead of the everyday hassles of managing your health care.' with a 'Learn More >' button. A photo of a sleeping child is visible on the right.

HealthIT.gov

Learn about how information technology is changing the way we interact with our health care providers, making managing our health easier, and working to make systems more seamless. A fun feature of this website is that families can enter contests to share health care-related stories.



Friend us on Facebook and follow us on Twitter for news, contests, events and updates of interest!

Want a printed version of our resources? Need information in an accessible format or in Spanish? Call us at 800-444-0821 and we will connect you to the information you need!



MISSOURI FAMILY TO FAMILY •

PARTNERING TOGETHER

VOL. 2, ISSUE 5 • MOFAMILYTOFAMILY.ORG

OUR PARTNERS

TIPS



For Kids

TIPS for Kids

Training in Interdisciplinary Partnerships and Services (TIPS) for Kids is the Leadership Education in Neurodevelopmental and Related Disabilities (LEND)

training program in Missouri. The LEND program provides intensive training for advanced graduate students and post-doctoral fellows in the field of neurodevelopmental and related disabilities.

573-882-0757 | tips4kids.org



Department of Health & Senior Services, Special Health Services

Provides statewide health care support services, including service coordination, for children and adults with special health care needs who meet eligibility requirements. Programs include: Children and Youth with Special Health Care Needs, Healthy Children and Youth, Medically Fragile Adult Waiver, and Adult Brain Injury.

800-451-0669 | health.mo.gov/living/families/shcn/



Family Partnership

The Family Partnership was formed by Special Health Care Needs (SHCN), of the Missouri Department of Health and Senior Services, to enhance the relationship between SHCN and the families they serve. The Family Partnership also serves as a means to provide support and information to families of individuals with special health care needs and identifies ways for families to connect with each other.

800-779-8652 | mofamilypartnership.org



INSTITUTE FOR HUMAN DEVELOPMENT
A University Center for Excellence in Developmental Disabilities (UCEDD)

UMKC Institute for Human Development

The Institute for Human

Development, located within the University of Missouri - Kansas City, is an applied research and training center for human services. It exemplifies the University's goals of academic excellence and a campus without borders by helping people, agencies, and the community reach their fullest potential.

800-444-0821 | www.ihd.umkc.edu



Missouri Developmental Disabilities Council

MPCDD is a federally-funded, 23-member, consumer-driven council appointed by the Governor. Its mandate under P.L. 106-402, the Developmental Disabilities Assistance and Bill of Rights Act, is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration in all aspects of community life.

800-500-7878 | moddcouncil.org



DMH Division of Developmental Disabilities

The Division of Developmental Disabilities (DD) serves individuals with developmental disabilities such as intellectual disabilities, cerebral palsy, head injuries, autism, epilepsy, and certain learning disabilities. Such conditions must have occurred before age 22. Services are coordinated through 11 regional offices.

dmh.mo.gov | 1-800-364-9687

Missouri Family to Family is housed within Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) at the University of Missouri - Kansas City Institute for Human Development. It is the state's HRSA Family to Family Health Information Center, and is a Parent to Parent USA Alliance Member. This newsletter was developed in partnership and with support from the Missouri Department of Mental Health, Division of Developmental Disabilities; the Missouri Department of Health and Senior Services, Bureau of Special Health Care Needs; the Missouri Developmental Disabilities Council (PL106-402); and the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs (#H84MC08005 and D70MC09834).