

# PARTNERING TOGETHER

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Lead to help your own family, support another family, or change the world!

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What does "Medical Home" mean? What is it all about?

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What you need to know and how it may affect your family



## HERE COMES SUMMER!



Summertime signals all sorts of things for families: a break from school, stressful switches in work schedules and scrambling to find something for the children to do. Summer is not just about the end of the school year. It also signifies relaxation, fun, vacations, traveling and more. What is your family doing together this summer?

Whether your family is planning to travel for a vacation, spend time exploring nature, or get to know your own neck of the woods a little better, make sure you spend time together as a family! Share with your children the same summer opportunities you took part in with your family as a child.

What is on your children's schedules this summer? Will they go to camp? Are they participating in sports? Do they want to take a class or participate in a program at the library?

Need ideas to keep your kids occupied during the summer with opportunities to meet other kids, learn, and stay active? Visit our website or check us out on Facebook and Twitter for links to resources about cool camps, sports clinics, and fun events taking place across the state.

*(Go online to [mofamilytofamily.org](http://mofamilytofamily.org) to share this newsletter and past issues with friends and family)*





# Missouri Family to Family

HELPING YOU CHART YOUR FAMILY'S LIFE COURSE

## INFORMATION PEER SUPPORT & FAMILY LEADERSHIP

Greetings from the Missouri Family to Family Resource Center (MOF2F)! Recently, MOF2F developed a publication called *Charting the Life Course*. The *Charting the Life Course* Framework was created for individuals and their families to answer their questions about life and to share with others. This publication can also be used by professionals to work with families. This document can be viewed, downloaded and printed from our website.

Each month, MOF2F continues to provide free webinars about topics that affect people with disabilities and their families in Missouri! There are 3 ways to watch the webinars! You can watch live from your computer online, attend the training at a local site, or view archived webinars at your convenience. To learn more about our webinars, visit us online!

Sharing our Strengths is continuing to expand our statewide affiliate network of organizations that provide supports to families. Organizations

can choose one of three affiliate levels: informal – disseminate information and products to individuals and families; formal– refer directly to SOS for peer mentoring; and full – access our resources and match individuals and families to peer mentors.

With our affiliate network we are able to reach out and serve in communities throughout the state, providing a more local, personal touch to those in need of support. We are also able to call on our affiliates to identify family leaders to be trained as mentors or take advantage of our leadership training opportunities. Affiliates can host our webinars and trainings and share local resources with us as well.

If you know of or are involved with an organization interested in joining our affiliate network please contact Susan Bird, Outreach Coordinator at [moddrc@umkc.edu](mailto:moddrc@umkc.edu) or 816-235-5337. ●





# FAMILY LEADERSHIP

## Is For Everyone!

*Family leaders are parents, grandparents, siblings, a foster parents, and self-advocates (people who have a disability or a special healthcare need).*

YES, you can.....be a Family Leader!

I remember, when my son was much younger (he is 21 now), if someone had suggested that I was, or that I should become, a “family leader”, I would have dismissed it. I would have thought that I wasn’t ready, or I wasn’t skilled enough, or I wasn’t the right personality to be a leader! Looking back now, I was already leading, I just didn’t know it! I still needed to learn some new skills and improve what I had already learned on my own, but I realize now that as families of children with disabilities or special healthcare needs, we are all leaders, in one way or another; we just might not always recognize it!

First of all, I want to be clear about what (or who) I am talking about when I say family leader. I am talking about “family” very broadly. A family leader might be a parent, a grandparent, a sibling, a foster parent, or a self-advocate (a person who has a disability or a special healthcare need). Parents Anonymous Inc. defines a family leader as “someone who has personal experience in using resources/ services to strengthen his or her family and speaks and acts from their perspective as a family member”.

There are different ways to be a family leader; you can think of it in terms of levels of leadership. You don’t have to start at one level and work your way “up”, you can lead at any level at any time. The first way most of us lead is within our own families. We learn quickly to advocate for our children’s needs – medical care, education, childcare, and more! Eventually, many of us feel the need to “reach back” and support other families who share similar circumstances and challenges. That is another level of family leadership; mentoring, sharing information, or facilitating a support group are all examples. Sometimes family leaders want to try to work toward changing services and systems to better meet the needs of all children, families and adults with disabilities or special healthcare needs. At one level, we might partner with organizations by participating in focus groups, reviewing products or serving on advisory boards or councils. At another level, we might partner for systems change by sharing our personal experiences with legislators or policy makers, testifying at hearings, writing letters to the editor on systems or policy issues, or even running for public office!

So remember, you might not have realized it, but you are likely already on your way as a family leader! If you want to learn more about family leadership, and learn new skills or strengthen your current skills, consider participating in the Family Leadership Certificate Series, sponsored by the Missouri Family to Family Resource Center. This series of five (5) webinars will provide training workshops in five (5) family leadership core competency areas: cultural proficiency and family dynamics; navigation, communication, decision making and problem solving, and partnerships and relationships. The series will take place at host sites around the state. For more information on how to participate, see below.

### Missouri’s Family Leadership Certificate Series

Do you want to:

- Learn skills that will enhance your ability to advocate for yourself or your family?
- Find out how to improve supports, services, & systems for families & self-advocates?
- Discover new ways to make sure your “family voice” is heard and valued?

This interactive training will help new and emerging family leaders enhance existing skills and develop new leadership skills as they strive to make a difference for other families and to make positive change in organizations, systems and policy. The series consists of five (5) monthly webinars hosted at local sites, followed by a discussion session after each webinar broadcast. Between each session, participants will be given “homework” to complete.

Expectations of participants:

- Attend all five (5) sessions at the desired host site
- Participate in ½ hour discussion/activity after each webinar
- Complete and submit homework (in person or via the online site)
- Complete an evaluation/survey before/ after each session and at the conclusion of the series

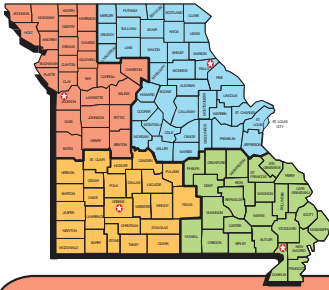
To participate, register at <http://conta.cc/familyleaders>. For more information or help finding a host site near you, call: 800-773-8652. ●

For more information on how family leaders can build their skills as leaders and learn about the five competency areas, check out our new publication,

*Core Competencies of Family Leaders: A Guide for Families and Organizations* by visiting our website at

[www.mofamilytofamily.org](http://www.mofamilytofamily.org)!





# FAMILY PARTNERSHIP

CONTACT INFORMATION | Toll-free: 1-866-809-2400 ext. 308

**NORTHWEST REGION FAMILY PARTNER**  
**STACIE WILLIAMS**  
 Phone: (816) 918-8800  
 Email: williams.stacie@sbcglobal.net

**NORTHEAST REGION FAMILY PARTNER**  
**BEV WOODHURST**  
 Phone: (573) 473-8873  
 Email: shcnfamilypartner@yahoo.com

## NORTHWEST REGION

### INCLUSION FOR CHILDREN

It's the time of year when kids are signing up for sports and summer fun! I worry about how I will keep my kids active during the summer. I have learned when you have a child with special needs, the process is more difficult and the options sometimes are limited.

I want my child to participate in activities with his peers, not segregated activities that are only for kids with special needs. I feel frustrated when the community recreation leagues offer a wide range of opportunities for kids and then a few programs specifically for kids with disabilities. Why can't kids all play together? I have found that sometimes the children are better at accommodating their peers with special needs than the adults!

If you get frustrated by this too, talk about it with your friends and neighbors! Talk to your parks & recreation departments. Get involved with organizations in your hometown that support full inclusion and can help you advocate. My experience has been that most programs want kids with disabilities to participate, they just need help from parents to figure out how to make it happen.

We can't expect that everyone intuitively understands that segregating kids because of their special needs is NOT best practice. Don't assume this summer that your child can't participate in the typical activities offered in your community. In fact, decide right now that they have just as much right to participate in whatever level they can in any of the activities offered in your community. And then go make it happen! ●



## NORTHEAST REGION

### PLANNING FOR SUMMER FUN WITH YOUR FAMILY

When looking for activities, make a list of things to consider for accommodating your family such as time frame, traveling to and from a place and how well do your family members do traveling.

One great way to spend time with your family during the summer is by going places that are free or inexpensive, such as the local zoos.

For a great guide for theme parks, water parks and zoos, you can go to [http://themeparkcity.com/USA\\_MO.htm](http://themeparkcity.com/USA_MO.htm). This website offers a lot of great activities and calling ahead can get you information on shows and accommodations such as taking coolers with your own lunch to save money.

The Recreation Council of Greater St. Louis provides information on various summer activities and camps in the St. Louis area. To access this information, visit [www.recreationcouncil.org](http://www.recreationcouncil.org)

Accessibility to different places is always good to check out. Regardless of where you are looking to go, it's always good to call ahead and check things out. Another great way to find places is to ask other parents in your area for suggestions.

Whatever you do this summer with your family, it doesn't have to cost a lot of money or take you away far from home. Missouri has a lot of great places to go and you can involve everyone in your family! ●



**SAVE THE DATE FOR THE  
 2012 FAMILY PARTNERSHIP  
 PARENT AND CAREGIVER RETREAT!**

October 19-20, 2012

More info at  
<http://health.mo.gov/living/families/shcn/familypartnership/>

# MISSOURI DEPARTMENT OF HEALTH AND SENIOR SERVICES

## BUREAU OF SPECIAL HEALTH CARE NEEDS

### SOUTHEAST REGION FAMILY PARTNER

JANIS TRAUGHBER

Phone: (573) 624-0416

Email: janis.traughber@yahoo.com

### SOUTHWEST REGION FAMILY PARTNER

KELLY BASS

Phone: (417) 833-2349

Email: klyldennis@yahoo.com

## SOUTHEAST REGION

### AUTHENTIC INCLUSION IN THE COMMUNITY

We all first hear about inclusion when our children enter school. If they have services under IDEA, we determine how much time they will be included in the regular education classroom and what that inclusion will look like. Are they going to be included for a few hours a day or all day without support staff? Will they be included with support staff for varying hours? Or will they not be included at all in regular education but may receive all their education in the special education room?

Authentic inclusion would look like inclusion without support but you should also think about it being “authentic” or meaningful. The child isn’t just present but we are allowing our child to participate and be engaged to their full potential.

With summer approaching, I am thinking about inclusion of our children in recreational activities. What can our children do and receive authentic inclusion in the many opportunities that are out there? Summer camps, baseball, dance, soccer, reading clubs, choirs, etc. How will they be included? As parents, it will be our job to facilitate their inclusion in the community and in extracurricular activities. Be encouraged to sign your child up for whatever interest they have and be willing to invest the time in supporting the activity to set your child up for successful inclusion.

Authentic inclusion will look different for each child and we as parents will know what is appropriate. An important aspect will be to make the inclusion meaningful. We may need to educate teammates, coaches, and other parents to ensure inclusion for each child. Think outside the box. Many times people say no to special considerations because they are uneducated and no one has ever asked before.

As we advocate for our children in becoming all they can be we should desire all their experiences be authentic. None of us want to just be tolerated we want to be included and wanted. Start putting a plan together now by understanding your child’s abilities and how you can support authentic inclusion in the community. ●



## SOUTHWEST REGION

### EMERGENCY PLANNING

It is that time of year when loud sirens can be heard and emergency weather reports interrupt our favorite television and radio programs.

Do *you* have an emergency plan for your family? Everyone needs to have a plan for their family, especially if they have a child with special needs. My family has some advice that might help you put a plan in place for your family. We started with an emergency kit, then devised an escape plan in case of fire, and then decided on a meeting place in case of separation.

In our emergency kit we have common supplies such as weather radio, bottled water, flashlight, and toilet paper. Since I also have a child with special needs, I had to consider everyday items such as diapers, wipes, medication, and other medical supplies that I would need to keep us going for as long as I could. This took some time and also some money but I feel it will be worth it in case of emergency. I hope I never have to use it, but in a time of crisis it would be one less thing I will have to worry about.

An escape plan is essential for small children to be able to safely get out of a burning house or one that has had severe damage due to a tornado or flood. We also have a fire extinguisher on hand and a fire ladder so we can safely evacuate our second story bedrooms.

Lastly, a meeting place is very important because when they do get out of the house they will be shaken up and need to know what to do next. In an extreme emergency someplace close would be best such as a neighbor or neighborhood community center might be safer and further away from danger.

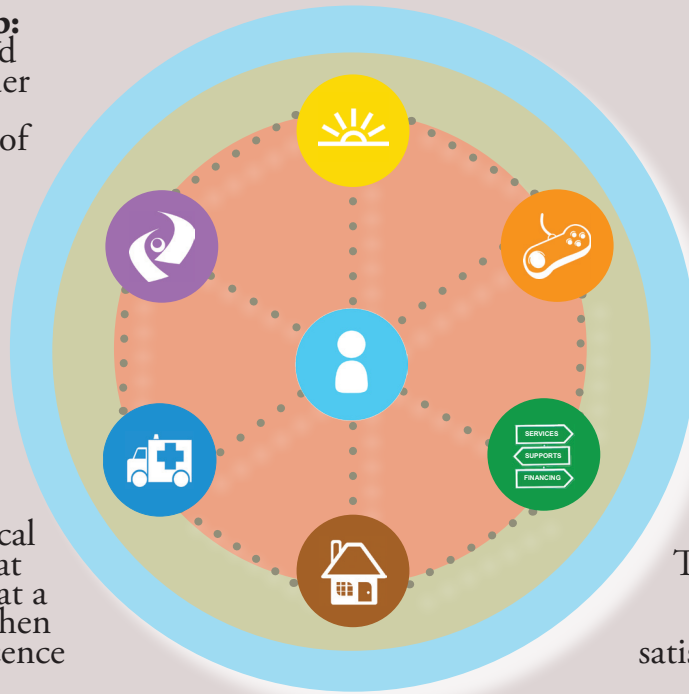
Regardless of where you live or how prepared you are, please remember to take the sirens seriously and take shelter as best as you possibly can. ●



## What does a medical home look like?

**Family-centered partnership:** Families work hand-in-hand with their main care provider to coordinate care that ensures the highest quality of life for the person.

**Transitions:** All the partners in the medical home work to make sure that the services and supports that a person needs are seamless when they transition from adolescence to adulthood.



**Community-based system:** Medical home includes partnerships not just between the patient, parent, and physician but everyone who invests in the health and well-being of the person, including schools and community resources.

**Value:** The goals of medical home are lower out-of-pocket medical costs for families, higher satisfaction with services and less use of emergency services

# MEDICAL HOME

## FOCUSING ON THE FAMILY

*The medical home is not a tangible place, but the concept points to a main caregiver – a pediatrician or care coordinator – partnering together with all involved parties to provide comprehensive medical care.*

The medical home concept was introduced by Cal Sia, a Honolulu based physician, in the late 1960's. Dr. Sia used his advocacy skills to inundate the medical community with the concept of family centered care, including communications between parents and physicians, community resources and schools.<sup>1</sup>

What does the medical home mean for you? It is a service provided to ensure your child's care is coordinated behind the scenes. The medical home is not a tangible place, but the concept points to a main caregiver – a pediatrician or care coordinator – partnering together with all involved parties to provide comprehensive medical care.<sup>2</sup>

The outcomes of a medical home model include lower out-of-pocket medical costs for families of children and youth with special healthcare needs,<sup>3</sup> fewer hospitalizations, higher satisfaction

with services and less use of emergency services.<sup>4</sup>

The American Academy of Pediatrics (AAP) recommends that pediatricians encourage and facilitate peer-to-peer support and networking, particularly with children with the same type of medical condition.<sup>5</sup> Missouri Family to Family is partnering with two clinics in Kansas City to pilot the AAP recommendation within the medical home. Pediatricians, nurses and other staff at the Children's Mercy Hospital Pediatric Care Clinic and at Priority Care Pediatrics in the northland are actively referring families to the Sharing our Strengths peer mentoring program. The two year study will assess and validate peer support as an evidence based practice and become a model for replication at local, state and national levels. You can be involved! Sharing our Strengths needs more parent peer mentors to serve more families. Contact us to volunteer! 800-444-0821 ●

1 Palfrey, Judith (2006-10-31). Child health in America: Making a difference through advocacy. ISBN 978-0-8018-8453-5.  
2 Calvin Sia, MD, FAAP\*, Thomas F Tonniges, MD, FAAP‡, Elizabeth Osterhus, MAS, Sharon Taba, MEd History of the Medical Home Concept. Pediatrics Vol. 113 No. Supplement 4 May 1, 2004 pp. 1473-1478  
3 Shirley L. Porterfield and LeAnne DeRigne. Medical Home and Out-of-Pocket Medical Costs for Children With Special Health Care Needs. Pediatrics 2011; 128:5 892-900; doi:10.1542/peds.2010-1307

4 W. Carl Cooley, Jeanne W. McAllister, Kathleen Sherrieb, and Karen Kuhlthau. Improved Outcomes Associated With Medical Home. Implementation in Pediatric Primary Care Pediatrics July 2009; 124:1 358-364; doi:10.1542/peds.2008-2600  
5 www.pediatrics.org/cgi/doi/10.1542/peds.2011-3084 doi:10.1542/peds.2011-3084 PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275)



# AFFORDABLE CARE UPDATE

The Affordable Care Act (ACA) was signed into effect in 2010. An important part of the ACA is the Essential Health Benefits (EHB) package that specifies the broad categories of benefits that must be covered by health plans selling insurance through the state Exchanges. It is important for families and children and youth with special health care needs and/or disabilities to understand these parts of the ACA and how they are affected by them.

Each state will have an exchange which is designed to expand health insurance coverage, improve quality of coverage, and reduce costs. The exchange will work as a marketplace for people buying health insurance and give choices for health coverage by offering a variety of certified health plans as well as providing information and educational services about options. If the state chooses not to set up its own exchange the federal government will set up the exchange in that state. In Missouri, legislation to implement the health insurance exchange is pending. The Senate has set up a committee to study a state based exchange. The governor also has a council working on planning efforts. The exchange means that insurers can no longer refuse to sell policies to people with pre-existing

conditions and says that all policies have to cover certain services. There will also be limits on out of pocket expenses and deductibles. The exchange must be in place by 2014.



The Essential Health Benefits (EHB) package must be covered by plans sold by the exchange. This plan must be selected by October 1, 2012. It is crucial for people with a special health care need and/or disability, caregivers, and family members to look at the benefits and make sure that the plan will work for them or their family.

The ACA already prohibits insurance companies from denying coverage to children under age 19 based on pre-existing conditions and people cannot be dropped from coverage because they made a mistake when applying. The lifetime benefit cap for children and adults has also been removed. The ACA allows children to stay on their parents' policy until age 26. In 2014, Medicaid coverage will expand eligibility requirements and provide coverage for former foster children until age 26. ●

## RESOURCES

Go to [www.mofamilytofamily.org](http://www.mofamilytofamily.org) to read this issue online and get connected to the resources below!



### SUMMER FUN

Check out our website for links to guides, listings and resources related to summer camps, travel, and family fun!



### AFFORDABLE CARE

Go to the Affordable Care Act section of our website to find the latest news, tools, and websites that will help you understand how the ACA affects your family.



### FAMILY SUPPORT

Check out our newest publication, Charting the Life Course online at our website and find out what our new icons are all about!



**FRIEND US**



**FOLLOW US**

Friend us on Facebook and follow us on Twitter for news 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!



# PARTNERING TOGETHER

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## 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

[www.tips4kids.org](http://www.tips4kids.org)



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

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.

800-452-1185

[www.ihd.umkc.edu](http://www.ihd.umkc.edu)

### UMKC - IHD

The Institute for Human Development, located within the



### The Department of Health and Senior Services

The DHSS serves the citizens of Missouri by working to improve the health and quality of life

for Missourians of all ages. Within DHSS is the Special Health Care Needs which provides services for children and adults with disabilities, chronic illnesses, and birth defects. The services available from SHCN depend on the condition or illness of the individual and include diagnostic and treatment services, service coordination and Adult Head Injury Rehabilitation Services.

800.451.0669

[www.dhss.mo.gov/SHCN/index.html](http://www.dhss.mo.gov/SHCN/index.html)



### 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

[www.mpcdd.com](http://www.mpcdd.com)



### 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.

866-809-2400 ext. 308

[www.dhss.mo.gov/FamilyPartnership/](http://www.dhss.mo.gov/FamilyPartnership/)



### Missouri Family to Family Resource Center

At the MOF2F, we offer Missouri individuals with disabilities and/or special health care needs of all ages, their families and professionals support, connections and opportunities to strengthen leadership skills and participate in program & service decision-making. When you connect with us, you are linking directly with self-advocates, parents, caregivers and family members whose lives are touched daily by healthcare or disability celebrations and challenges. Because of our experiences, our information is offered in a person-centered, easy to understand, and culturally friendly way.

800-444-0821

[www.mofamilytofamily.org](http://www.mofamilytofamily.org)