

PARTNERING TOGETHER

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Developing new partnerships
to help others

COLLABORATING
IS EVERYTHING



CREATING PARTNERSHIPS

How are you involved in your community? There are many ways to make partnerships to meet the needs of your family, help others, and be involved in changing policies and systems. You can become more involved by volunteering in community activities, acting as a peer mentor, and participating in school organizations, in focus groups, or on local advisory boards. All of these activities may improve your skills, build your confidence, and can introduce you to new people who may become friends.

Partnerships start with your family. In order to partner at any level, you first need the ability to meet the needs of your own family. This includes learning

from your successes or failures, finding and using resources for yourself or your own family, prioritizing your needs, building relationships, and speaking up for your own family's needs. After you are able to partner for your own services or needs consider partnering to help others, for quality improvement, or for systems change.

When you partner for others and to change policies or systems you use the same skills that you use for your own family to help others and create change. ●

(Go online to mofamilytofamily.org to share this newsletter and past issues with friends and family)





M • O • F • 2 • F

MISSOURI FAMILY-TO-FAMILY DISABILITY & HEALTH RESOURCE CENTER

At the **Missouri Family-to-Family Disability & Health Resource Center** we value our volunteers. Have you been looking for ways to share what you have learned from your experiences? Perhaps you will find that outlet in our volunteer opportunities.

Help others by becoming a **Sharing Our Strengths** peer mentor. As a mentor you are matched to another individual based on their request. You decide how long you will act as a mentor in each case and how often you are matched; mentoring is flexible in time commitment based on the type of match and request. Mentors attend a one-time workshop that usually lasts 1½ hours. Some mentors serve as trainers to reach more people across Missouri.

You can also help us by becoming a display assistant who shares information and materials about **Missouri's Family-**

to-Family Disability & Health Resource Center. This requires a short training session at an event you attend with a trainer. We then will ask you if you available for events in your area, which allows you to attend for free.

Missouri's Family-to-Family Disability & Health Resource Center provides quality information and resources, help by reviewing our products or writing products with us. Other groups across the state may have opportunities for you on their committees and boards. Through our volunteer and leadership network we can connect you to these opportunities.

Through our volunteer and leadership network we can connect you to these opportunities. If you are ready to share your time and talent contact us at 1-800-444-0821 or by e-mail at moddrc@umkc.edu and get started today. ●

PARTNERING FOR YOUR FAMILY

WHILE MEETING YOUR OWN NEEDS

Partnerships start at home. You make many partnerships when meeting the needs of your family. These include working with your doctor(s), teacher(s), and family members to problem solve, prioritize needs, and build effective relationships. You may want to join a parent group or listserv and attend conferences so you can learn about the issues that impact your family.

You know your family best. Do you know how to share your story? It is important that you are comfortable sharing your experiences so that you can meet your own needs. Frame your messages and requests so that they are clearly understood. Everyone has their own communication style, so recognize yours and know what works for others so that you are effective when speaking up for your family's needs to ensure that they are met. Remember to stay positive when working with others to get services and accept your own strengths and weaknesses.

You are an essential partner in any service your family accesses including medical, education, and community services. Communication is vital to building relationships, navigating systems, and problem solving. You are the expert on your family, be ready and willing to share your experiences and what works for your family. Ask questions and get the information you need in a way that you understand. It is okay to ask again if you don't understand something. Involve your child in his/her services as appropriate so that he/she develops relationships and skills.

When asking questions and advocating for your own needs be clear, honest, concise, and courteous. Be assertive for what you need and believe you're entitled to, without becoming aggressive. Write down possible questions in advance. Remain confident and in control of your feelings during the meeting or conversation. Carefully listen to answers you're given, and ask questions if you don't understand the response. Get the name of the person to whom you are speaking, and ask them to spell it if necessary. Write down the date and time of the conversation for future reference. If you are given a personal/negative comment, write it down. Then read it to the speaker asking if the words match their statement. If necessary obtain assistance from a supervisor and report the incident. It is appropriate to practice the conversation before you make a call or have a meeting so you are comfortable with what you need to say. If you need advocacy assistance, help is available. Contact the Missouri Family-to-Family Disability & Health Resource Center or your Family Partner and we will connect you with the right person or group.

Meeting your own needs and those of your family is the first step. Once you can help yourself, you can begin partnering with others to help them meet their needs and work with service providers. You can also develop partnerships to make a difference in your school, community, state, or the nation. For more information on partnering for your family, others, or for change visit www.mofamilytotfamily.org or call 1-800-444-0821. ●



Everyone has their own communication style, so recognize yours and know what works for others so that you are effective when speaking up for your family's needs to ensure that they are met.

Above: LaRenda Hutt & family of St. Louis, Missouri



FAMILY PARTNERSHIP

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

NORTHWEST REGION

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SOUTHWEST REGION

KELLY BASS

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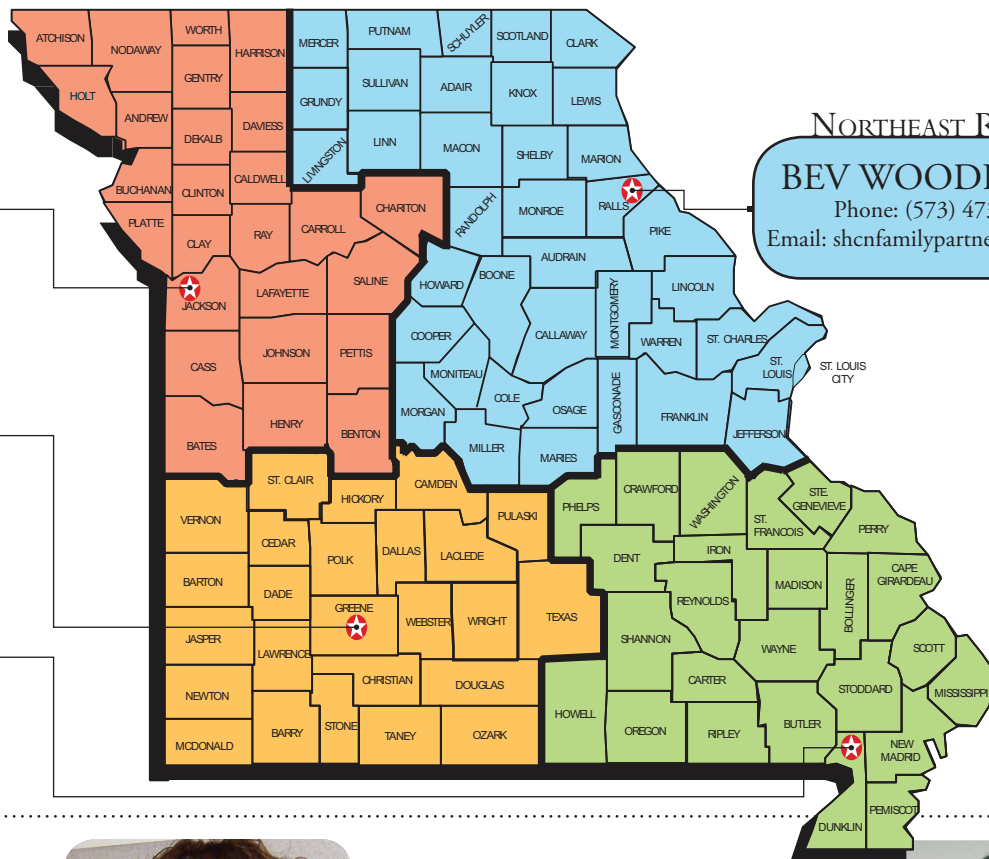
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NORTHEAST REGION

When we venture into the world of parenthood, regardless of how we became parents, we also venture into areas we may have never imagined we would be.

When we are blessed with our exceptional children, we also need to understand how important our role is; not only in our daily lives, but as a part of preparing for their future. This includes, but not limited to, volunteering at school, booster club/school organizations as well as government appointed panels and boards. The best way for you to know where to start, is by asking the groups that provide any type of service to your child/family. Inquire about providing personal experience, your background knowledge and anything else that might be beneficial in helping improve the programs not only for your family, but for the families yet to come. Government appointed panels are all accessible on the internet and have scheduled meetings that are open to the public. This may be a way to get yourself out there.

One thing to always remember, regardless of the needs of your family, there is now and always will be a need for parental input. Your experience and knowledge is invaluable! ●



SOUTHWEST REGION

PARTNERING FOR INFORMATION

Sometimes finding information can be difficult and once you do find the information it can be overwhelming. So where do you go to get the information for you and your family? I like to start with my child's health provider I believe it is important to partner closely with them and to build a solid relationship. Sometimes we forget that we are working for the same outcome, we have information that they need and they have the information that we need. However, when they don't seem to have the answer we want or need then where can you go? I, like many, instinctively turn to the internet for information. This can be tricky determining what is correct and what isn't. There are also many peer groups you can turn to for answers such as the Family Partner in your area or the Missouri DDRC/Family to Family Health Information Center, just to name a few. It's always a good idea to pair up or partner with someone who can give you a different perspective on the same idea. So, when you feel completely overwhelmed just remember you are not alone. Just take a deep breath and write down your questions and tackle one thing at a time. ●



MISSOURI DEPARTMENT OF HEALTH AND SENIOR SERVICES

BUREAU OF SPECIAL HEALTH CARE NEEDS

I think that sometimes the things that stress us the most aren't always the things we can go get help with, but if we think creatively, a ready solution presents itself.

Stacie Williams, Northwest Region

SOUTHEAST REGION

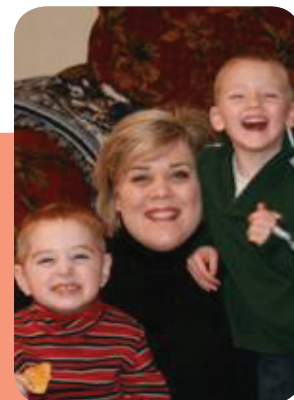
PARTNERING – WHAT DOES THAT MEAN?

As we all begin the life of learning how to support our family member with a special health care need we may experience “Where do I begin?” I believe we begin with human relationships and through those relationships we find cooperative relationships between people or groups who share a common interest, have a specific knowledge, or can be effective in helping us attain a specific goal. Now you may still be thinking, “That sounds good but, where do I begin?” We begin by accepting the roll of advocate for our family member or individual we are supporting and understand that we must become their voice. We must learn to ask questions about things we don't understand, become knowledgeable about an endless list of disability issues, and we learn to keep a notebook or binder that documents hundreds of conversations and materials we receive from various sources. A great place to start is with other parents. There are support groups that are full of parents very willing to share their experiences. Partnering with them and building a relationship with them can save parents hours of time. Learning to communicate effectively with individuals and professionals is another form of partnering that can lead us to groups who share a common interest and can connect us with other partners. No matter how insignificant you think your question is, always ask it. You never know what door to a new partner it may open. Sometimes it becomes like a family tree or flow chart before you get to the partner that can help you attain certain goals and get to the door that you did not even know you needed to consider. Being a parent of a child with special needs is a lifelong learning experience. The network or partnerships you develop will strengthen your family and give you hope when you feel you've exhausted your knowledge base. Partner with people who care and will help you along your journey. This is the roll of the Family Partner in your area so please don't hesitate to contact us and allow us to assist by partnering with your family. We can each share our experience and how we have learned to partner. ●



NORTHWEST REGION

As a parent I have come to understand that there is not always a formal service or support for everything that I sometimes need for my children. I suppose if money were no object it might be easier, but that isn't realistic. Recently, my 7 year old son has been having some significant issues keeping up with his school work. He gets easily frustrated, gives up and doesn't even want to try. This makes homework in the evenings a challenge. Some of the issues are clearly due to the fact that his brain just works differently. However, I still want him to keep striving to reach his potential. But, God help me, it's a battle every night. And part of the problem is that after many conversations with his teachers, I know how far behind he has become and I sense that panic within me, because I know it won't get any easier. Then a few weeks ago, I was talking to my other son's babysitter, and for whatever reason the subject of nightly homework came up and I broke down into tears. I felt like no matter what I had tried in the last week, homework became a battleground of defiance and frustration. My babysitter empathized. She has a daughter a couple years older than my son who also can bring her to tears at the prospect of homework. Jokingly, I said, “Wanna swap kids tonight, I'll take yours, you take mine.” She laughed and responded “Absolutely.” And then all at once we looked at each other and realized we had just solved our own problem. As the parent, it's hard to work with your own child sometimes. Now, a couple nights a week, we do what we call “homework swap.” I think that sometimes the things that stress us the most aren't always the things we can go get help with, but if we think creatively, a ready solution presents itself. Partnering with other parents experiencing similar circumstances is a great place to start. ●



BUREAU OF SPECIAL HEALTH CARE NEEDS

P.O. Box 570
Jefferson City, MO 65102-570
Toll-Free: (800) 451-0669



MILLER COUNTY HEALTH CENTER

P.O. Box 2
Tuscumbia, MO 65082
Toll-Free: (866) 809-2400 ext. 308





PARTNERING

TO HELP OTHERS

You can share information and resources, while being a listening ear for another person whose family is going through something you have experienced.

As you understand the needs of your own family, consider the needs of other families. Think about how you can make a difference in lives outside of your own family and build relationships that support others. There are many opportunities for you to use what you have learned from your own experiences to help other families. If you are concerned about others believe that anyone can learn and improve and each person has their own strengths and weaknesses, and are willing to share your personal experiences consider using your partnerships and developing new partnerships to help others.

If you are involved in a parent group, you may want to share information about a certain issue that impacts your family and other families in the group. If you prefer to work individually with others consider serving as a peer mentor. In this role you can share information and resources, while being a listening ear for

another person whose family is going through something you have experienced.

Another way you can help others is by letting providers know when you appreciate them or when you are not satisfied. Be specific so that they can continue providing quality services to your family and others. Some service providers have advisory groups, which allow you to provide feedback on policies, resources, and services. You may also want to volunteer at your child's school to help teachers or other students. Ask your child's teacher how you can help.

Remember that everyone is valuable regardless of their abilities. Just as you have strengths and weaknesses, so do others. It is also important that you are sensitive to the choices of others and respond appropriately to different cultural and socioeconomic backgrounds, remaining respectful and non-judgmental of the attitudes, practices, and beliefs of others. ●



PARTNERING FOR CHANGE

TO IMPACT YOUR COMMUNITY

As a family leader you offer a unique perspective that strengthens your community. You have the ability to identify gaps in current services, while suggesting possible solutions. You are vital at all levels of policy development and ensure that the voice of the family is valued.

You can work with other families and service providers to make service systems more responsive to the needs of families. You may choose to focus on quality improvement for an organization of work towards change in a service system, policies, and/or legislation. Use your story to promote change. Your experiences and knowledge helps support other families and can be used to improve policies and systems serving families. By engaging in awareness activities, you can unite to increase numbers and have a presence at events, show support for an idea or change in policy, or visit the capital to share the voice of the people with law-makers.

You have the expertise and experience, use your skills to influence systems change. Meeting with public officials provides an opportunity to discuss issues and concerns and may include providing testimony that shapes the way systems serve families. You also know the impact of policies and legislation on how your family and others receive support. Work with others to create a common vision for the future. ●

RESOURCES

- **Missouri Family-to-Family Disability & Health Resource Center** is available to provide you or your family information and individualized emotional support for your family. We can also connect you with other families or organizations if you are interested in volunteering or serving in a leadership role. For more information visit our Web site www.mofamilytofamily.org or call 1-800-444-0821.
- **AmeriCorps** is an opportunity to make a difference in your life and the lives of others. It is a chance to apply your skills and ideals toward helping others and meeting critical needs in the community. For more information about the benefits of AmeriCorps and ways to serve visit <http://www.americorps.gov>.
- **Partners in Policy Making (Partners)** teaches leadership skills and the process of developing positive partnerships with elected officials, school personnel and other individuals who make policy decisions about services that you and/or your family use. It is about systems change – creating, working towards, and achieving a vision of shared values about people with disabilities. For more information visit <http://www.mpcdd.com>.
- **The Arc of the United States Missouri Chapter** is a grassroots organization working to support and empower persons with intellectual and developmental disabilities and their families through advocacy and education, expanding individual choices and promoting community inclusion. The Arc works in partnership with individuals and their families regardless of level of disability or membership in The Arc. For more information visit <http://www.arcofmissouri.org>.
- **The Family Partnership** provides support and information to families and an opportunity for families of individuals with special health care needs to connect with each other. The family partners provide information and resources to local members and serve as the Partnership's contact person for their designated areas. They plan, schedule, and facilitate the Family Partnership meetings. For more information contact your regional family partner or visit <http://www.dhss.mo.gov/living/families/shcn/familypartnership/index.php>.
- **MPACT** is a statewide parent training and information center that serves parents of children with all disabilities. Our primary goal is to assist parents in their effort to effectively advocate for their children's educational rights and services. For more information visit <http://ptimpact.org>. ●



UMKC Institute for Human Development
215 W. Pershing Road, 6th floor
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• THE MISSOURI FAMILY-TO-FAMILY DISABILITY AND HEALTH RESOURCE CENTER •

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



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



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/



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

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

UMKC - IHD

The Institute for Human Development, located within the University of



Missouri Planning Council For Developmental Disabilities

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



Missouri Family-to-Family Disability & Health 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