

PARTNERING TOGETHER



PAGE 3 A PARENTS' GUIDE

Working with Emergency Medical Services

PAGE 4 OUR COMMUNITY

Updates from the Family Partnership Initiative

PAGE 6 READY IN 3

Three Steps to Prepare for an Emergency



ARE YOU READY FOR EMERGENCIES?

What do you do to get prepared for an emergency? An emergency can happen at any time, anywhere, and to anyone. You can prepare for emergency situations so that you are ready before they happen.

One of the first things you can do is make a plan. There are many resources including Ready in 3 that can help you plan for emergencies. It is also helpful to meet with your emergency medical service (EMS) providers to introduce your child and talk about your family's needs.

You may need to get your home ready for winter cold and summer heat. There are things you can

do yourself to seal openings and make your home tighter. If you need assistance there are community agencies that may be able to help.

You also need to be ready for emergencies when you travel. Getting prepared includes making sure that you have everything you need and knowing your route. When you pack make sure that you are packing for the season and have supplies to keep warm or cool down.

By preparing for an emergency before it happens, you will be ready no matter what the situation is. ●
(Go online to moddrc.org and share this newsletter and past issues with friends and family)





M•O•D•D•R•C

MISSOURI'S FAMILY-TO-FAMILY HEALTH AND DISABILITY RESOURCE CENTER

SHARING OUR STRENGTHS PEER MATCHING NETWORK

Missouri's Family to Family Health and Disability Information Resource Center continues to grow as it provides information and peer support. The family partners, with the Bureau of Special Health Care Needs Family Partnership Initiative, have joined forces with our Sharing Our Strengths peer matching network and we continue partnering with the Thompson Center in Columbia, Cardinal Glennon Autism Center in St. Louis, and Children's Mercy Hospital in Kansas City to connect families to more trained parent and peer mentors. With our partners and you we are able to increase the number of families using the Sharing Our Strengths network to meet their needs and help other families.

Parents who have received mentoring describe it as an invaluable resource because they are talking with someone who has been in their shoes. It is exciting to hear the comments from these parents and know that they are receiving the emotional and social support necessary to problem solve and

feel connected. In a time when resources for direct services are dwindling, providing a family with the emotional and social support necessary to problem solve and feel connected can make a world of difference, a value we believe in.

Sharing Our Strengths is a one-to-one mentoring opportunity allowing you to support another individual or family with similar life situations to your own. Your experience is all you need to support to someone else. Are you the parent of a child with special health care needs or developmental disabilities? Did you wish that you could have talked to another parent who had been there when your child was first diagnosed? Are you willing to share your experience to help another parent? What you have to offer is priceless! If you would like to be the voice on the other end of the phone that provides a listening ear and a positive perspective to a family needing an affirming connection with someone who has been there, please call us at 1-800-444-0821. ●



A PARENTS' GUIDE WORKING WITH EMERGENCY MEDICAL SERVICES

Emergency Medical Services (EMS) is a system providing emergency medical care by supplying personnel, facilities, and equipment to effectively coordinate delivery of emergency medical services in your geographic area. It includes many people and agencies who work together in order to provide fast emergency response, treatment, and transportation to people in need of immediate medical attention. Emergency medical services may look different depending on where in the state of Missouri you live, but there are things that you can do to be prepared no matter who is providing services. In an emergency it is hard to think of everything. We recommend meeting with the EMS providers in your area to introduce yourself and discuss your needs so that they have necessary information before they arrive if called for an emergency.

It is also important that you keep your medical information up to date in either a hard format such as a binder or electronically on a flash drive. You can work with your doctor to create an emergency care plan. Your plan should include your child's: age, allergies (medication and food), medical condition(s) and relevant past medical history, current medications, typical physical and vital findings (pulse, blood pressure, respiration, communication, etc.), a family protocol of the procedures you follow that best meet your child's needs, and contact information. This information should be kept in a safe place at home and school or other locations where your child may be receiving care.

When working with EMS it is also important that you work together with your school. This way, if there is an emergency at school or during a school activity, EMS service providers and school personnel can work together and be prepared to meet the needs of your child. When traveling to and from school it may be helpful to pack a "manual" with information about him/her that contains emergency phone numbers, familiar things (a family picture, a photograph of your home, etc.), doctors' information, and current medication information. By using plastic sleeves it is easier to make changes to the necessary pages without starting over on the manual.

Meeting with your local EMS workers for the first time may feel scary, but it doesn't have to be. At this meeting you can give service providers information about your specific family needs and ask questions that you may have for them. EMS workers have knowledge and training in dealing with emergencies. You have knowledge and

experience in caring for your child. Together you can be prepared for an emergency. The first step is finding out who to contact. In some areas there is one provider for everyone, while in other areas services are provided at the local level. You may need to call a local fire chief to learn who provides EMS services in your community. Once you know who to contact, call and set up a meeting. Include your children in the meeting so that they can see the ambulance, fire truck, and police cars as well as meet the workers. This way it is more likely that the people responding in an emergency will be familiar with and to your child. It is helpful to invite EMS workers to your home so that they can get familiar with the area, your child's room, and location of stored supplies. Since some children's disabilities or health care needs are not visible, provide a picture of the child who may need assistance so that they know where to go first. It is also helpful if you are able to provide EMS workers with a floor plan of your home that includes the location of equipment, such as where oxygen is stored, and where the individual needing the greatest assistance is in your home.

In an emergency situation you may need to call 911. It is important to know how, when, and what to tell the dispatch operator. Following the instructions listed can save time and allow needed help to arrive more quickly.

- Try to stay as calm as possible.
- Listen to what the dispatch operator is asking you.
- Speak slowly and in a clear voice.
- Answer all of the questions from the dispatcher.
- **STAY ON THE PHONE** with the DISPATCHER until emergency help arrives to continue passing vital information that can be shared with providers in route to your location.
 - Do not leave your child alone to be on the phone, either bring your child to the phone or the phone to your child so that you can monitor his/her condition and speak with the dispatcher at the same time.
- Be ready to answer the questions the dispatcher will ask you about the emergency.

Working with EMS providers before an emergency happens can be life changing. It will help you and your family be more prepared for the situation and can ease anxiety for family members. Service providers will also have familiarity with your family dynamics and needs regardless of the type of emergency or where it occurs. ●

For more information on working with Emergency Medical Services (EMS) contact the Missouri Family-to-Family Health and Disability Resource Center (MODDRC) at (800) 444-0821 or www.moddrc.org.





FAMILY PARTNERSHIP

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

NORTHWEST REGION

STACIE WILLIAMS

Phone: (816) 918-8800

Email: williams.stacie@sbcglobal.net

SOUTHWEST REGION

KELLY BASS

Phone: (417) 833-2349

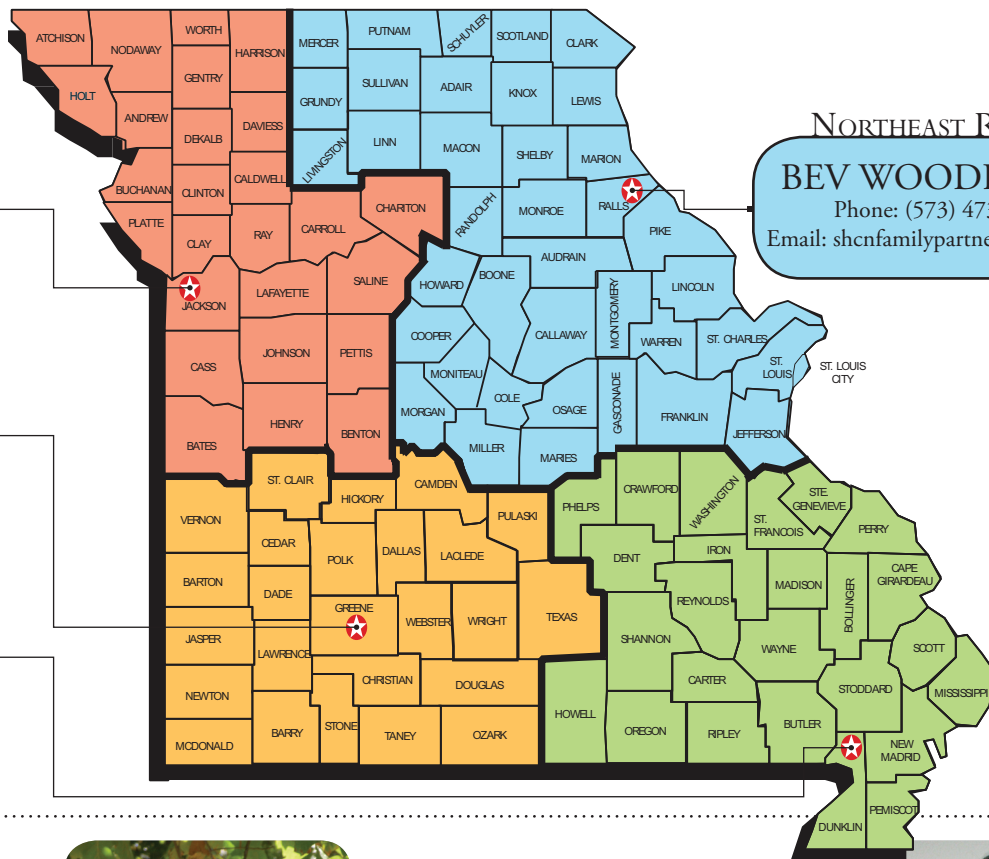
Email: klydennis@yahoo.com

SOUTHEAST REGION

JANIS TRAUGHBER

Phone: (573) 624-0416

Email: janis.traughber@yahoo.com



NORTHEAST REGION

BEV WOODHURST

Phone: (573) 473-8873

Email: shcnfamilypartner@yahoo.com

SOUTHEAST REGION

**Hello Southeast Missouri.
I am the new Family Partner for
your region.**

My name is Janis Traughber and I reside in Dexter, Missouri with my wonderful husband and twins that are 23 years old. I have had a variety of life and work experiences that I believe will help me serve this region in a positive way. My resume may not be very impressive but what you should know is I have been there – done that. My daughter has a dual diagnosis of cerebral palsy and autism and is presently still living at home as we continue to work on skills and behaviors to help her become more self reliant and self determined. I also have seven years of experience working for MPACT, Missouri Parents ACT, as the Southeast Regional Coordinator. I hope that experience brings me knowledge that will help serve your families with school related issues. If you asked my friends about me they would probably say I am a good listener, honest, responsible, a good mother, and a fun person to be with. I trust we will build relationships through the coming years that will be meaningful and strengthening for us all. I look forward to meeting and assisting you and your family. If you would like to email me, you can reach me at janis.traughber@yahoo.com. ●



SOUTHWEST REGION

Colder Weather Higher Utility Bills ...

The leaves are turning and the north wind is blowing and like many of you the high cost of heating is also on my mind. Every year I dread the news that my utility bill is even higher than last year. So, what can I do if I am unable to pay my bill, aside from getting loan assistance which seems impossible to come by? Every year I hear about Federal assistance or grants that Ozarks Area Community Action Committee (OACAC) receives. So, how can OACAC assist you?

OACAC is a not-for-profit agency that is working to end poverty in the Ozarks. OACAC provides information and supplies to low income families in 9 counties in Southwest Missouri. OACAC began sponsorship of the Energy Crisis Intervention Program (ECIP); this program provides energy assistance, fans, and air conditioners to needy families and the elderly. So, how can you receive help this winter? First you must have utilities in your name, second you must meet income guidelines, and third you must call your local community office. In Greene County you can call 417-862-4314. To find the community action agency serving your area, go www.communityaction.org/ or call (573) 634-2969. ●



MISSOURI DEPARTMENT OF HEALTH AND SENIOR SERVICES

BUREAU OF SPECIAL HEALTH CARE NEEDS

NORTHWEST REGION

Know where you are.

If you experience an emergency situation it's really important to know where you are. Sounds simple right? We recently had an experience, driving home from a family reunion in Illinois. Somewhere along I70, in Illinois, our son had a seizure or stopped breathing; to this day we are unsure what really happened. We pulled off the road and my Dad, who is a medical professional, went around to the back seat to try and revive Gabe. After doing an initial assessment of vitals my Dad told me to call 911. So there along the interstate I dialed 911 on my cell phone. The first thing I was asked, "what is your location?" I didn't know. Heading West Bound on I70 there were no mile markers, no exit signs and we couldn't recall how far past Mount Vernon we were, it was the last town my Dad remembered seeing. I was then transferred to several different ambulance services, all with the same questions that I could not answer.

"What County are you in?"

"How far outside of Mount Vernon are you?"

"Are you close to Greenville?"

I had mistakenly thought that they would be able to "ping" my cell phone and would be able to pinpoint my exact location. But it doesn't work that way. By the time I was dispatched to the 3rd ambulance service I was all but screaming into the phone for someone to help us but the fact of the matter was, that because I did not know where we were, they could not get to us to give us the help we needed. Finally, I had the wherewithal to turn on the GPS and discovered that there was an exit a couple miles ahead that would take us to a hospital. Once I was able to relay that information to the ambulance driver, they were able to tell me how quickly an ambulance would reach us. They determined we could get there faster if we drove. All of this probably happened within a span of 6 or 7 minutes, but when you are dealing with what seems like the life or death of your child, minutes feel like hours.

So the lesson is, always take note of where you are, especially when traveling outside of where you are familiar. Missouri has mile marker signs every quarter mile along the interstate, however, other states do not. Several weeks ago we went on our family vacation before school started, because of our previous experience with our son, you could have asked me at any point along our journey and I could have told you where we were, what we had just passed and what was coming up. It isn't difficult it just takes a little extra vigilance and the understanding that if you don't know where you are, no one else will if you need help along the way. ●



NORTHEAST REGION

Winter will be here soon enough. If you're like me, traveling when the kids were little meant a lot of packing and preparing. For some of parents, that holds true even when our kids are grown up and traveling with us.

My son had two major life changes with his health last year that caused me to think long and hard about how to prepare for any kind of travel but cold weather is the worst. Make sure you make a list of things that you would need on a regular outing and then add to it, for weather related issues. Here is my list of things to take along. Maybe I have things you didn't think of or you might need things for your child that I don't. Whatever the case, don't wait until the snow hits to make your list. Remember we are in Missouri and it could snow in October! When traveling anywhere out of town it is always good to let others know where you are going and the route you intend to take (ex. doctor appointment and a potential time to be back).

1. Cell phone (fully charged and take along car charger too)
2. Water and extra food or snacks (in our case, water and extra supplement)
3. Medication (even if your trip is an hour and meds are given at the end of the day take along extra)
4. Feeding pump/suction machine/nebulizer (and batteries and/or ac adapter to plug in car)
5. Hand sanitizer
6. Extra clothes, diapers/undergarments and Ziploc bag of wet wash clothes for spilled food, sticky fingers etc.
7. List of emergency phone numbers.
8. Battery powered electric blanket or extra heavy blanket.

If you don't need these items, pack what would be needed should your schedule change because of weather. If you don't have a cell phone call someone before you leave and let them know what time to expect you back. Most doctor offices/businesses don't have a problem letting you make the call especially when you are traveling with children. ●



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





READY IN 3

THREE STEPS TO PREPARE FOR AN EMERGENCY

Emergencies can strike anytime. Missouri families, communities, businesses and schools need to take steps today to prepare for an emergency. Preparing today can save lives! Coping with emergencies and power outages is a challenge for everyone, but the problems are more complicated for families with children and youth with special health care needs.

The Ready in 3 program is part of the Missouri Department of Health and Senior Services ongoing efforts to keep Missouri ready to respond to natural or man-made disasters. They recently launched new web pages for the program, www.dhss.mo.gov/Ready_in_3, with resources to help individuals and families plan for and respond to emergency situations. The new resources include a checklist specific to the needs of individuals using oxygen. It encourages people to designate multiple places they could go to obtain back-up power, including at least one out-of-town site and recommends that you contact your local power company to be added to the priority reconnection service list. The new information is part of the resources and tools from the department's Ready in 3 disaster preparedness program. This information was shared with hospitals, clinics, home care services, as well as other health care providers.

Missouri's Ready in 3 Family Safety Guide details how to prepare for a wide range of emergencies and includes a family plan outline that can be adapted to individual situations. "In an emergency, several days might pass before vital services are restored and roads are cleared," Margaret Donnelly, director of the Missouri Department of Health and Senior Services said. The Ready in 3 resources provide critical information for Missouri families that they can use to plan and prepare for all types of emergencies. According to Donnelly, "Being prepared to act quickly, and having plans and supplies in place can help you ride out a disaster."

The Ready in 3 Family Safety Guide provides comprehensive information on the three steps in preparing in advance of any emergency and is available in English, Spanish, Bosnian and Braille. The Ready in 3 program reminds families of three simple steps they can take to prepare for and deal with all types of emergencies.

1. Create a plan.
2. Prepare an emergency kit.
3. Listen for information.

Mary Kramer of Rich Fountain knows first-hand the importance of having an emergency plan and practicing that plan with her family. Mary's 9-year-old daughter, Emily, relies on

supplemental oxygen regularly because of heart and lung complications. "Most days we live our family's emergency plan," Mary said. "With Emily in and out of a St. Louis hospital so frequently, my other children are separated at times and need to know how to reach each other or us at the hospital quickly." Kramer has prepared by identifying people who can help during emergency situations and by gathering supplies for long, unexpected trips to the hospital. She also has designated alternative locations for the family to meet during power outages so that Emily has oxygen when she needs it. "Emily could need medical attention at any time," Mary said. "So having our emergency supplies and knowing what to do and how to care for her when we are two hours from her hospital is vital. Coping with the stress of the situation is easier knowing my family has worked through our plan."

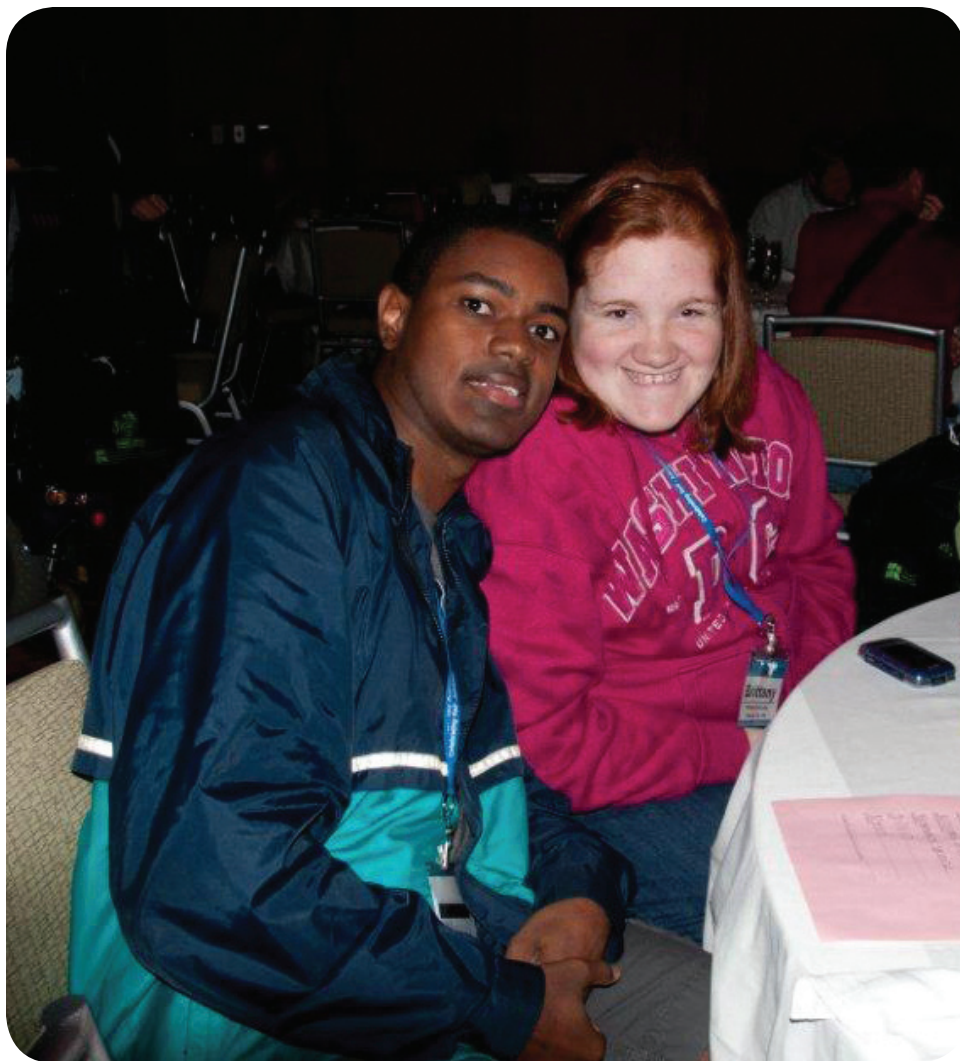
It is important that you identify who can help during an emergency. Make sure these people know where you keep your emergency supplies and give someone you trust a key to your house or apartment. Medical alert tags or bracelets also help identify your health care needs if you require medical attention. It is also recommended that you create a supply kit that includes:

- A list of prescription and nonprescription medications and dosages
- A list of allergies
- Extra eyeglasses and hearing aid batteries
- Extra wheelchair batteries or other special equipment
- A list of the brand, style and serial numbers of medical devices
- Copies of medical insurance and Medicare cards
- A list of doctors
- A list of emergency contacts and family
- Telephone numbers of close neighbors who can help

Once you are armed with the necessary resources, prepare an emergency kit and use the Family Plan and Personal Healthcare Information checklist to create a plan. Place a copy of your completed Family Plan and Personal Healthcare Information in your emergency kit and in your care agency's service binder. It is also important that you are familiar with the emergency response plan and procedures in your area.

While staying in a well-prepared home is often the best approach for you to get through a crisis, evacuation may be required. It is important that you consider evacuation as early as possible, so that you can meet the unique needs of your family. Remember to take your emergency kit including medicines and medical equipment with you if you evacuate. In addition, notify your care agency with your evacuation or relocation information so they can continue services, if necessary. ●

For more information on Missouri's Ready in 3 materials visit www.dhss.mo.gov/Ready_in_3 or call the Missouri Department of Health and Senior Services at 573-526-4768. You can also contact your regional family partner or the Missouri Family-to-Family Health and Disability Resource Center (MODDRC) at (800) 444-0821 or www.moddrc.org



THE YOUTH ADVISORY COUNCIL

The Youth Leadership Council for the Missouri Partnership for Integrated Community Services for Children and Youth with Special Health Care Needs has had some very productive meetings so far this year. We are currently working to develop our medical transition web site, which will soon include a version of our medical transition training, links to information, and personal “testimonials” about issues related to medical transition – right from our own youth council!

Recently members of the team participated in the SABE (Self Advocates Becoming Empowered) National Conference in Kansas City where they participated in break-out sessions and learned about self-advocacy and self-determination. They also co-presented during the break-out sessions.

The Youth Advisory Council plans to continue addressing needs related to transition as well as participate in leadership opportunities at a variety of levels. At our next meeting, we’re going to discuss medical transition & insurance, plus fine-tune what we want on the site. By the end of the year we are looking to finalize the look, feel & supply of information on our web page – and have most of the “testimonials” up as well. ●



RESOURCES

Preparing for emergencies can save lives. Missouri families, communities, businesses, and schools can take steps to prepare for an emergency. Visit the **Ready in 3** web site: www.dhss.mo.gov/Ready_in_3 for information and resources about how you can be ready for any emergency.

- **Missouri Association for Community Action** is a statewide association of 19 community action agencies that fight poverty in every county in Missouri. One of the services they offer is weatherizing homes to reduce energy costs. For more information visit www.communityaction.org/
- **The American Academy of Pediatrics** developed an Emergency Information Form for you plan for emergencies. For a copy of the form go to: www.aap.org/advocacy/blankform.pdf
- **The Kaiser Family Foundation Medicaid Primer** is a guide to answer your Medicaid questions and can be found at www.kff.org/medicaid/7334.cfm ●



PARTNERING TOGETHER

VOL. 1, ISSUE 5 • WWW.MODDRC.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

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 Developmental Disability Resource Center/Family-to-Family Health Information Center

At the MODDRC/F2F, 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.moddrdc.org