

PARTNERING TOGETHER

PAGE 3
A PARENT'S GUIDE
to partnerships at school

PAGE 4
TRANSITION STORIES
from the Family Partners

PAGE 6
GUARDIANSHIP
know your alternatives & options
before you act



YOU ARE NOT ALONE IN TRANSITION

Starting a new school year is a sign that summer is over. Students are excited to see old friends, make new ones, meet their teachers, and learn about the upcoming school year. Parents are thinking about buying school clothes and supplies and hoping their students will do well as they enter the classroom for the first time or after the summer break. Back to school may be a time of transition for some families. For others, their children are not going back to school but are starting a new phase in life such as a new job, volunteering, or living on their own.

Transitions happen throughout life. It occurs when our babies become toddlers, with the start of preschool, kindergarten, or a new school year. Transition happens when we change doctors or teachers. It also includes events such as graduation, going to college, getting a job, or getting married.

You are not alone during times of transition. Sometimes transitions are smooth, but at other times they take you through the storm. It is important to prepare yourself and your child for the change coming. There are others who are sharing your experience, or they have been there and can share tips to help you through the process. You can talk to the new people as well including, but not limited to, new teachers, doctors, and service coordinators. Throughout our families' lives, our needs may change, but we will always need information and support. There are many ways to find information so it is important that we know how to get it and what to do with it when we have it.

For more information about transition or to talk to someone who has been there contact your family partner, or connect with us at the Missouri Family-to-Family Resource Center at (800) 444-0821 or online at www.mofamilytofamily.org. ●



M • O • F • 2 • F

MISSOURI FAMILY TO FAMILY RESOURCE CENTER

The Missouri Family-to-Family Resource Center is here for you. We want to make sure you do not feel alone. Through Sharing Our Strengths (SOS) we can help you connect with other parents, family members, caregivers, and self-advocates who have had similar experiences. Trained SOS mentors are supportive and help you with whatever is happening in your life because they've been there too. We are also a one stop resource to provide you with the information or organization you need to meet your family's needs.

We partner with different organizations across Missouri so you can get the services you need and spread the word to other families. The Thompson Center in Columbia, Children's Mercy Hospital, and Cardinal Glennon Hospital all can match you to SOS mentors through our partnership. We work with the Missouri Planning Council

for Developmental Disabilities (MPC), one of our funders, to ensure that quality services are offered that meet the needs of Missouri's families. We also partner with BSHCN Family Partnership and your local regional offices in many ways. One way to get connected is through our monthly, Brown Bag Webinar Series. You can watch these on the fourth Wednesday of each month online at home, at work, or with others at one of our host sites. For more information on our webinars, visit www.mofamilytofamily.org.

Missouri Family-to-Family can also connect you to leadership opportunities. Volunteer with us by sharing your personal story, reviewing products, or hosting displays. You can also become a peer mentor or watch for ways to participate in policy and service development. To get involved, connect with us! ●

A PARENT'S GUIDE TO PARTNERSHIPS AT SCHOOL

Partnerships go beyond working with your child's teachers.

A new school year is a great time to think about partnering with your child's teacher(s) and other members of the school staff. Building a relationship with your child's teacher helps to start the school year out right. Your child spends a large part of the day at school. Partnering with your child's teacher can help your child do better in school. It also helps your teacher understand your child's individual needs, which means your child can be more successful. As a parent, you are the most important person in building strong, lasting relationships with school staff.

Meeting your child's teacher is the first step in building a successful relationship, so go to "Back to School" or "Meet the Teacher" night. Even if you have been in past years, every teacher is different. Back to school nights give you a chance to meet your teacher and get an idea of what the school year will be like. It also gives you a chance to get noticed and involved in the classroom. Ask your teacher how you can help. Volunteering sends a message that you value the school and the work they do, while giving you the inside look at day-to-day life at school. This is also a great time to connect with your school's parent-teacher organization and get involved school-wide.

Communicate with school staff. Make sure your teachers and school staff know you look forward to working together. Ask your teachers how they prefer to communicate, phone or e-mail, and give them your feedback. Communicate regularly, this is a great way to share your child's strengths and struggles. You can give the teacher positive feedback and talk about your concerns. It is important to communicate honestly. Open and honest communication helps school staff understand your perspective. You are the expert on your child--share information teachers may not learn during the day such as your child's favorite books or movies and interests. Remember to listen too so you can learn from school staff. If you have questions ask them and keep asking until you understand. If you disagree with the teacher address your concerns directly first. If that doesn't work go to the principal before

taking your concern to the district level. At the same time remember to say thank you and share your appreciation with administration when your teacher or other school staff helps your child succeed.

When school staff understands your child's needs they can take better care of your child and teach better. Building relationships with all of the staff interacting with your child improves your child's education and care. Your school nurse and counselor can be an important part of your team, connecting school to home. They can explain the school's medicine policy and can be a partner if your child's health care needs impact the school day or attendance. They can also help you learn more about school-based health care and the services available to your family. If you choose you can give permission for your health care providers to talk to your education providers. Remember that only you can give this permission and any information remains confidential. They can also answer questions if your child needs a health or behavior plan and the policies for getting plans in place as well as making sure that necessary staff and you are part of making and implementing the plan.

Partnering with school staff can also help you connect with the community. These connections will be helpful throughout your child's school career, and may be more useful during transition planning as your child is exploring options for after high school. The school nurse, counselor, or other staff can connect you with resources and activities in the community. Talk to your teacher about what you can do at home to reinforce what is being taught at school. Work with the teacher to make sure that you and your child understand the homework policies and work together to keep assignments organized. It is important for you to keep organized too. Keep good records of conversations, evaluations, and IEPs or 504 plans. Get regular reports on how things are going, especially for behavior plans. Be a part of all school meetings. Ask that they be held when you can be there. ●



As a parent, you play the most important role in building strong, lasting relationships with school staff.

For more information on partnering with your school in Missouri contact Missouri Family-to Family at (800) 444-0821.

Additional information is available from The Health Care System (HSC) Foundation in Partnering with Your Child's School: A Guide for Parents.

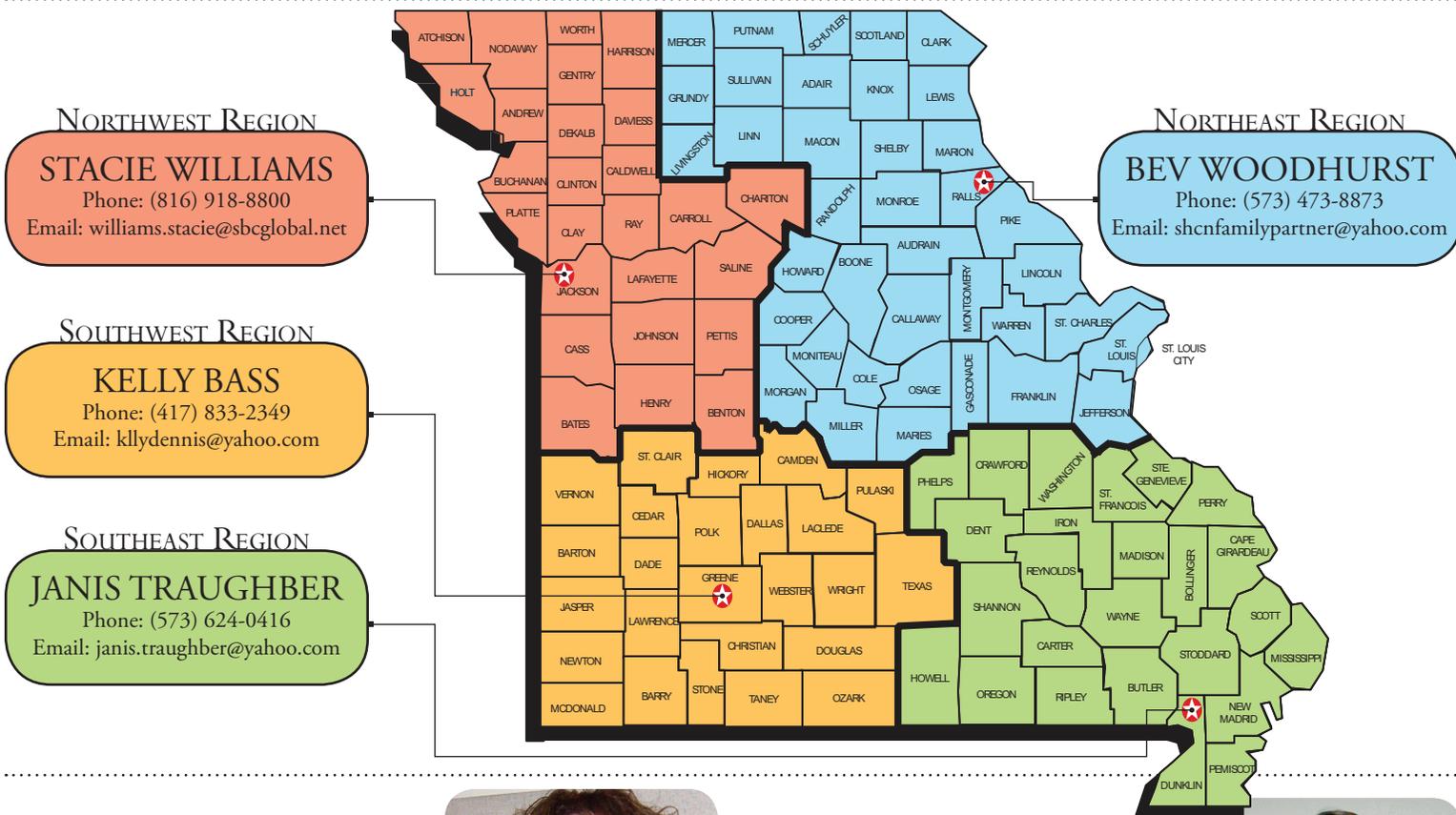
Visit www.mofamilytofamily.org to download!





FAMILY PARTNERSHIP

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



NORTHEAST REGION

TRANSITIONS IN LIFE

Transition begins as we start with a newborn and each day they grow and change. As our children get older, we are constantly transitioning on to new things. They go from crawling to walking, babbling to talking and from finger foods and messy high chair trays to utensils and a clean shirt when meal time is over.

No matter what the changes life brings, transition is always taking place. There are several keys to remember during these times. No matter what life is handing you, think things through, do your research, talk to other parents and most of all, share with extended family. As our kids go from early childhood into pre-k or kindergarten, there are new things to think about. Different settings, different people and being away from home all day! For some of us, that's harder for the parents than it is the kids! When you know you are getting close to another change, prepare your child for the things to come. Talk to people that will be involved on a daily basis.

As our children get older, their needs will change; not only medical issues, but school, social networking, and types of supports. There is a huge world of information out there to be accessed, but we have to know how to get to it and what to do with it when we get it! Remember, no matter the age of your child, we all have different experiences to share, but have the same goal, and that is to give our children an amazing quality of life and the supports they need to get there! ●



SOUTHWEST REGION

TRANSITION...

When I hear that word I tend to shut down. When thinking about transition, I often think, what does this have to do with me? My child is only four! I am still contemplating pre-schools and what school system I want her to be in. So where do I begin, could this be my transition? Transition from my baby to my big girl...

After much investigation, all signs directed me to our local OACAC (Ozarks Area Community Action Corp) Head Start program. To my surprise there was a waiting list! I couldn't believe it! Didn't every child get into preschool? Well, apparently four year olds take precedence over three year olds and their actual age depends on when their birthday is. If their birthday falls after the cut-off then they may be four yet considered three!

I guess I should've started sooner, because now my child is still at home with me and on the waiting list a year later. These are things that seem relevant to me when it comes to transition and I hope it helps someone else not feel so anxious the next time someone mentions "transition." ●



MISSOURI DEPARTMENT OF HEALTH AND SENIOR SERVICES

BUREAU OF SPECIAL HEALTH CARE NEEDS

SOUTHEAST REGION

EDUCATIONAL TRANSITION FOR YOUNG CHILDREN

We know transition or changes occur at numerous times throughout a child's life - bottle to sippy cup, cereal to baby food, crawling to walking, and baby talk to putting sentences together. Educational transitions also happen numerous times, and families with children that have developmental disabilities and/or special healthcare needs know all too well about the difficulty of transitions. Families experience transition of new staff, teachers, therapist, doctors, service coordinator, and more.

From birth to three years of age, we see children served through the First Steps program with Individualized Family Service Plans (IFSP). These IFSP's are written to address the needs of the child and the family and is a collaborative process. These services end at the age of three. Six months prior to the child's third birthday, parents should expect a transition meeting with team members that have knowledge of the child's developmental progress and needs. A transition plan will be written and the child will be referred to their local Early Childhood Special Education (ECSE) services in their district or there may be other options in the community that may be appropriate. Parents should be diligent in gathering of information at this meeting to truly understand what supports all professionals that have been working with the child believe will continue to be areas in need of on-going support as the child transitions out of First Steps services.

ECSE looks strictly at delays that are educationally relevant and parents need to be able to express the child's needs as they relate to an educationally setting. Some parents have stated First Steps felt like "warm fuzzies" and moving to the next transition was a scary time as they moved into the unknown of the "real school world." DESE (Department of Elementary and Secondary Education) and MPACT (Missouri Parent's ACT) created a wonderful transition tool named *Transition from Early Intervention: A Guide for Parents* that does a great job breaking down the process. This guide can be viewed online (find it on the MOF2F website!) or by calling DESE at 573-526-4757 or MPACT at 1-800-743-7634.

Children will continue to deal with transition issues all throughout the educational process. For parents to be successful in advocacy they need to become knowledgeable of IDEA and how to effectively communicate their child's needs. Although transition can be uncomfortable, it will become less stressful when parents have the tools they need to be informed and involved. ●



NORTHWEST REGION

WHEN TRANSITION DOESN'T SEEM TO BE WORKING

Transition is a process. It doesn't just happen overnight. Sometimes transitions are smooth and easy, other times they are kind of messy and chaotic. This year we have had a rough transition with school. Even though as we have been struggling and trying to make things work, I have to acknowledge that I have learned a lot.



Here are just a few of those things:

1. Just because it feels like things aren't working, that does not mean that your child isn't getting some benefit from the service. While our school year has felt awful and wrought with anxiety, my son has still learned a lot. He might not be where his team thought he might be as far as achievement is concerned but in terms of where he started, he's still learned a lot this year.
2. Don't give up. Keep talking and seeking out those who can help you. I didn't find many advocates within the classroom; however, I did find one person, the school counselor, who listened to me and understood and validated my concerns. She has been a great resource for my kiddo when things aren't going so well. He has an ally so when his classroom is too stressful; he knows he has someone in the building who cares.
3. Don't let your emotions get the best of you. There were nights at our house where both my son and I were in tears. This didn't help either of us. While it's difficult, I have learned the value of finding the positive even when the situation seems negative. Focusing on those little glimmers of progress really helped us.
4. TAKE GOOD NOTES. It is imperative to keep track of all the incidents that don't go well and the things that do. Conversations you have, phone calls that aren't returned, specific issues that are problematic, situations or days that go really well-- all of it is important. You might be surprised to find out when you take good notes you may start finding patterns. "Why are Tuesdays better than Thursdays?" Those insights can hold the key to a solution you didn't even know existed.
5. Find an outlet! When one aspect of our life isn't going well it consumes a lot of our energy. Remember that there is more to life than the things that aren't going so well. Have fun, play games, and spend time together as a family. ●



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





GUARDIANSHIP

KNOW YOUR ALTERNATIVES AND OPTIONS BEFORE YOU ACT

When children are young, parents are their legal guardian. We make decisions on their behalf – medical, financial, living arrangements, etc. When they turn 18, even if they have a special healthcare need or a disability, they become a legal adult and are assumed capable of making their own decisions.

Whether or not to pursue guardianship is a personal decision for each family. A lot of people think that just because someone has a disability or special healthcare need, they automatically need to have a guardian when they turn 18. However, there are many ways to continue to support your young adult in making choices and decisions without becoming their legal guardian. For our family, we put off thinking about it until we received a letter from my son Ben's school, encouraging us to get guardianship so we could continue to be involved in Ben's educational decision making.

There are ways to give a person the support and protection they need without taking the drastic step of making them a ward of the court and appointing a substitute decision-maker (which is what guardianship does). A person with guardianship loses many rights which most of us take for granted such as the right to vote, to obtain a driver's license, to consent or object to medical care or to enter into contracts like marriage or home ownership. Individuals who have a guardian may not get to decide where they live, who they live with, where they may go in the community or how their money is spent.

Every family has to make the decision that is right for their own loved one, but it's so important to know and understand the person's needs for decision making support, know that there are alternatives to guardianship, and to explore if they will meet the support needs of your loved one.

The first thing that our family did was to think about what our greatest concerns were for supporting Ben in his adult life. For us, it was Ben's medical care and school related issues. Because Ben has a number of medical diagnoses (cerebral palsy, epilepsy, scoliosis, osteoporosis, ADHD), a cognitive disability, and takes regular medications, we wanted to make sure we could help him with making medical decisions and if needed, give consent for treatment. We wanted his doctors to be able to talk to us about any medical issues that might come up, so we could help Ben understand. We also wanted to stay involved in helping Ben through his transition process at school, and continue to be part of his IEP team.

We were fortunate to be able to utilize the *MO Guardianship: Understanding Your Options & Alternatives* "stoplight tool" to help us figure out in what areas Ben would need support and protection,

and then explore the alternatives to guardianship that might meet those needs. We sat down as a family, including Ben, to talk about what he could do on his own and what he needed some help or support with. We discovered there were some areas where Ben was in the "green" column of the tool – he could do those things without support, such as deciding what kind of job he would like or deciding what he liked to eat and when. Just like a stoplight, he was "good to go" in those areas.

With other things, it was clear he would need some help – looking for and applying for a job he might like (reading the want ads, filling out applications, transportation to interviews, etc.); taking care of his finances (shopping, banking, keeping track of benefits); keeping his meds straight (taking the right dosage at the right time); healthcare decisions and medical care (what doctors to go to, whether or not to have surgery or specific treatments). Those were areas where he was in "the yellow" on the tool. We had to slow down, think about what his needs were and explore what might work for him in those areas.

We then looked at the different options and alternatives that were available to see what might work for the areas where Ben needed support. Ultimately, we were able to find an alternative to guardianship for all the areas that Ben was in the yellow column on the tool. As a family, we felt that guardianship (the "red" column) was just too restrictive of an option and wouldn't be in Ben's best interest. Many of Ben's needs right now are met by family and friends, such as helping him with job searching or with personal care. Other alternatives that have worked for Ben include obtaining a power of attorney, which has allowed us to still participate in school meetings and decisions, and to help Ben with making healthcare choices and decisions. Ben and I have a joint bank account, he has a debit card and is learning to use his PIN to go shopping at Wal-Mart and the grocery store, and going out to eat. Sometimes using the alternatives to guardianship takes a little more work on our part, such as making sure that doctors and other medical professionals will "accept" the power of attorney, or setting up limits on the bank account to make sure Ben isn't overspending or isn't possibly being taken advantage of financially. We are also trying to plan ahead so when he no longer lives at home with us he will still have the support that he needs without needing a guardian. The supports we have put into place are not only helping Ben to learn new life-skills, but are helping him to be more independent in the community and to live life in the way that HE chooses. What more could we ask for our son? ●

You can learn more about guardianship options and alternatives by visiting www.mofamilytofamily.org.

Every family has to make the decision that is right for their own loved one, but it's so important to know and understand the person's needs for decision making support, know that there are alternatives to guardianship, and to explore if they will meet the support needs of your loved one.

THE TOP 5 THINGS

YOU SHOULD KNOW ABOUT THE AFFORDABLE CARE ACT

1. **Your child under 19 can not be denied or limited coverage or benefits because of a “pre-existing condition.”**

In the past, insurance companies were able to deny or limit coverage to families based on a child’s “pre-existing condition.” If you have insurance that was created after March 23, 2010, this rule applies to you. In 2014, this rule will apply to all Americans, despite any disability or gender.

Parents should know however that many insurance companies in Missouri have dropped their child-only plans due to the requirement to cover children with pre-existing conditions. You may find it hard to find a plan. Of course, come 2014 they you be able to find a plan within the Affordable Insurance Exchange.

2. **Preventative services are now free for many families!**

Many important preventative care services are at no cost if you have insurance that was created after March 23, 2010. Some examples of services (depending on age and other factors, for details visit healthcare.gov) are blood pressure, diabetes, and cholesterol tests, routine vaccinations against diseases such as measles, polio or meningitis, counseling, screening, and vaccines to ensure healthy pregnancies and regular well-baby and well-child visits, from birth to age 21.

3. **Medicaid is expanded to cover more Americans who can not afford healthcare.**

Beginning in 2014, Medicaid rules will be simpler and more people will be eligible. Almost all adults under 65 with individual incomes up to about \$15,000 per year will be able to get coverage through Medicaid in each state.

4. **Health coverage has been expanded for young adults.**

Under the ACA, children will be allowed to stay on their parent’s plan until they turn 26 years old. This means you can insure them if your policy allows for dependent coverage. The only exception to this rule is if you have an existing job-based plan, and your children can get their own job-based coverage.

If you are a parent with children transitioning into adulthood, you may be able to find coverage in the federal high risk pool at www.MHIP.com. The ACA implemented high risk pools. Missouri had one, but it was not affordable. As a result of the ACA they have a second high risk pool (Federal High Risk pool). The premiums were recently lowered to make it more affordable.

5. **Health insurance exchanges arise to make insurance more affordable for those who aren’t covered by their jobs.**

Starting in 2014 if your employer doesn’t offer insurance, you will be able to buy it directly in an Affordable Insurance Exchange. The exchange would provide affordable options which can be easily compared, apples to apples. Missouri is currently working on developing its exchange. ●

Adapted from healthcare.gov

RESOURCES

TRANSITION RESOURCES

Catalyst Center

The Catalyst Center is a national center dedicated to improving health care coverage and financing for Children and Youth with Special Health Care Needs (CYSHCN). For more information visit <http://hdwg.org/catalyst/>

Got Transition?

Got Transition? is a national resource for health care professionals, families, youth, and state policy makers focusing on a young adult’s transition from pediatric to adult health care. Transition tools and tips and other resources are available under each of the main categories of Youth, Family, Providers and States. These resources will grow and develop so visit us often. For more information visit <http://www.gottransition.org/>

MPACT

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. MPACT staff and volunteers are located throughout Missouri and work with public and private agencies, parent groups, professional organizations and advocacy groups to achieve that goal. <http://ptimpact.org/>

AFFORDABLE CARE RESOURCES

Healthcare.gov

Check out the US government healthcare portal on the web! YOU can learn about and get recommendations about insurance options that might meet your family’s needs, compare doctors and other providers, learn more about the Affordable Care Act, and get information about healthcare and the provisions of the ACA tailored to your life situation.

Healthreform.kff.org

Check out the Kaiser Family Foundation’s health reform hub! You can watch “Health Reform Hits Main Street,” a great video that will help you understand the basics of the ACA, view an interactive timeline of the changes that will be coming to our healthcare system, and more!

MissouriDCHR.org

Check out the Disability Coalition for Healthcare Reform if you want to get involved in the movement for affordable and accessible healthcare for all Missourians. Go to their website for some great information and to learn more about DCHR!



• THE MISSOURI FAMILY TO FAMILY RESOURCE CENTER •

PARTNERING TOGETHER

VOL. 2, ISSUE 1 • WWW.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

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 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