

PARTNERING TOGETHER



HEALTHY LIVING THROUGHOUT THE LIFE COURSE

Living a healthy lifestyle and learning healthy habits begins early and continues throughout the life course. Health and wellness are very important and can positively or negatively impact a person's ability to go to school or work, live as independently as possible and participate in their community.

From wondering whether your baby is meeting developmental milestones to facing the extra challenges of entering school with special health care needs or helping your child transition to adult medical care, health and wellness are major factors to consider in everyday life.

It can be challenging to see beyond the needs of our children to the possibilities of living a healthy, active, and stimulating lifestyle.

By being active in the community, our children become ambassadors, break down barriers around special health care needs and disability, and add to the health of the community as a whole.

Explore this issue of *Partnering Together* to learn about developing natural community supports, communicating with your school to provide a successful educational environment for your child and helping your child learn about and manage their own medical care. Look beyond needs and see possibilities to live a healthy family lifestyle.

See page two for an exciting opportunity to connect with families just like yours in your area to learn how to make a good life for your family! ●

Log on to mofamilytofamily.org for previous issues of *Partnering Together*.



LIVING THE GOOD LIFE

Charting the Life Course for Families

What does a good life look like for your child who has special needs?
How will they live a good life as an adult?

Attend a free workshop with families just like yours from your area to get ideas, resources and tools to help create a vision and support your child in living the good life.

SE

WHEN: SEPTEMBER 9, 2014 @ 10am - 2pm
WHERE: BLACK RIVER COLISEUM, POPLAR BLUFF, MO
CONTACT: crystal@mofamilypartnership.org

NE

WHEN: SEPTEMBER 20, 2014 @ 10am - 2pm
WHERE: DELTA GAMMA CENTER, ST. LOUIS, MO
CONTACT: pat@mofamilypartnership.org

SW

WHEN: SEPTEMBER 23, 2014 @ 10am - 2pm
WHERE: HENRY COUNTY LIBRARY, CLINTON, MO
CONTACT: beth@mofamilypartnership.org

NW

WHEN: SEPTEMBER 24, 2014 @ 10am - 2pm
WHERE: KANSAS CITY HEALTH DEPARTMENT, KANSAS CITY, MO
CONTACT: information@mofamilypartnership.org

Register for each event at mofamilytofamily.org. Lunch provided.

FOR QUESTIONS ABOUT OR HELP WITH REGISTRATION, CONTACT
information@mofamilypartnership.org | (800) 779-8652

The Family Partnership is an initiative with the Missouri Family-to-Family Health Information Center, housed at the UMKC-Institute for Human Development, UCEDD and Special Health Care Needs within the Missouri Department of Health & Senior Services and funded by the MCHB Title V Block Grant.

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CHARTING THE LIFE COURSE

This and future issues will include articles and resources to help you think through topics from our guide, *Charting the Life Course*.



Daily Life & Employment

What you do everyday- school, employment, volunteering, routines



Community Living

Where and how you live- housing options, transportation, modifications



Healthy Living

Managing health care and staying well- medical, dental, behavioral, prevention



Safety & Security

Staying safe and secure- emergencies, guardianship options, legal issues



Social & Spirituality

Having relationships and fun- hobbies, personal networks, faith communities



Self-Determination & Advocacy

Making decisions and having choices in your life, standing up for yourself

View and download the guide at
mofamilytofamily.org

ASKING QUESTIONS ABOUT...

HEALTHY LIVING



Early Childhood (3-5)

Do you know if I qualify for special health care or disability services? ★

Eligibility-specific supports are not the answer to everything—all of us use many different types of supports to make it through our daily lives and to accomplish our goals.

The birth of a child brings many changes both to the family unit as a whole and the parents individually. A new parent begins to address these changes to help them manage their lives by looking at all the supports that seem to exist naturally: grandparents, friends, and neighbors all offer to pitch in. However, with the birth of a child with special needs, extended family members, friends, and neighbors may shy away from a situation they don't understand or may drift apart or not know what kind of help to offer.

Building natural supports should be the first focus for any family in providing a good life and quality health care. For a child with special needs, these supports may not be obvious. Perhaps extended family and friends would benefit from education regarding the child's diagnosis and planned visits to learn about your child's daily life. Offering information to others in a positive manner can often help them to understand your child's needs and make them feel more comfortable with helping the family. The same may apply with the grocery store clerk or the librarian. Taking a few extra steps in the community can increase awareness and form supports needed throughout life. Contacting local emergency service providers to educate them on your child's needs can provide extra security in emergencies. Often simply inviting neighbors over for coffee may prove to be fruitful in building much needed supports.

While the idea of enlisting the support of family, friends and community sounds great, there are also times when a family needs more formal supports. Fortunately, there are programs that provide the support needed for these families and children with special health care needs. In-home supports, personal care assistance, private duty nursing and respite are just a few of the services that can be obtained through the DHSS Bureau of Special Health Care Needs or the DMH Division of Developmental Disabilities. Although formal services can never replace the love and care that a family member or friend can



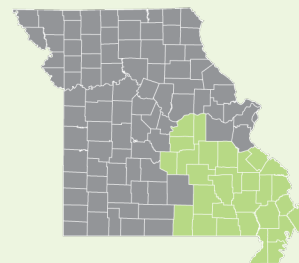
give, they can be a great supplement to the support network of the family. Other organizations offer specialty programs or supports – some specific to a diagnosis, others more general to special needs. Connecting with them is a great way to learn about their community, build advocacy skills and grasp a vision of hope for the future.

The important things to remember are to develop natural community supports, don't be afraid to ask for help, and use the supports you do have wisely. Raising children is hard enough. Raising children with special needs can seem impossible, but it can be done successfully when a family learns to lean on others and envision a bright future. ●



CRYSTAL BELL | SOUTHEAST FAMILY PARTNER
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Crystal is the mother of two boys with special health care needs. She is excited to help families that deal with the daily challenges of supporting an individual with special needs and connecting families to each other and resources in their local area.



ASKING QUESTIONS ABOUT...

HEALTHY LIVING



School Age (6-13)

What do you need to tell the school staff about my needs? ★

Communicating your child's medical needs is essential for success in school. Communicating with school staff is just one way of being proactive in case an issue or emergency pops up. Families and school staff have to work together to make sure that the child's needs are met – it's a partnership.



Do you worry about your child when they are not with you? By preparing ahead for what may happen, we can put our minds at ease and set our child's life on a smoother path.

Schools are the place children spend the most time away from their families. It only makes sense for key personnel to know your child's unique needs to help shape a successful school experience.

Nursing care, including prescription management, can be a huge part of caring for a child with special needs. Work with your school to form an individualized health plan for your child and keep the communication open between the school, yourself and your child's health care providers.

Behavioral concerns, meltdowns, triggers and sensory sensitivities will be greatly reduced if school personnel can anticipate what to look for and how to avoid these issues.

Simply changing a seating arrangement or discovering new ways to communicate may lessen frustration.

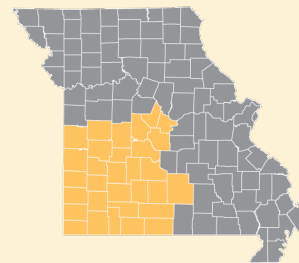
Often parents feel anxious when it comes to IEP and/or 504 meetings. Learning about the process, disability law and getting to know your child's team will help you be more prepared. Work as part of the team for your child's best outcomes. Consider taking someone else with you to the meetings to take notes; the process can move quickly and it can be difficult to remember all that was said and decided.

Remember to be positive and communicate often with key people at your child's school. Encourage the staff, teachers, nurse, therapists, and librarian – anyone who interacts with your child. Take the time to show your appreciation to them for their efforts to work toward your child's healthy and well-rounded school experience. ●



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Beth is the mom of three children, one of which lives in the home and has a special health care need. She is knowledgeable about Autism, Fetal Alcohol Syndrome, Post Traumatic Stress and Sensory Disorders.



ASKING QUESTIONS ABOUT...

HEALTHY LIVING



Transition (14-22)

Are you helping me know the symptoms, triggers, and side effects of my disability or health care need and how to get help or interventions? ★

Learning about and exploring about all the options for where a person lives after they graduate high school can help youth envision what is possible for their own future. When youth know more about what is available to them and what they might like to try, they are better equipped to plan their path toward future goals.

Part of growing up and becoming independent is learning about yourself: who you are, what you believe and how to care for yourself. In the case of a child with special needs, self-awareness about their diagnosis, use of medications, symptoms of their conditions and treatments is crucial. It's important he or she feels it is a normal part of life to discuss and understand challenges.

Encourage your children to take an interest in their own medical care. Help them hone communication skills to make it possible for them to make their wishes known. Lead them to become strong self-advocates in all areas of their life, but especially when it comes to medical care.

Open communication is the key. Here are a few tips to think about when visiting a health provider:

- Your medical provider is a person just like you. Don't be intimidated because they are professionals. Having a medical degree does not make them unapproachable.
- Be open and honest about your feelings and health concerns. Speak up about issues that you feel are important. Sometimes the smallest things are related to a larger medical condition.
- Ask questions, especially if you get an answer you don't understand. Again, speak up.
- Build a trusting relationship with your provider. If you are uncomfortable, intimidated or have a personality clash, you may want to seek different medical personnel. That is okay. Not everyone gets along.
- Make a list of your concerns and prioritize them. Make sure the 3 most important issues to you are at the top of your list. If there are time constraints you will have covered those first. If other issues are pressing you might ask for a longer appointment time to cover all your concerns.
- Know your medications and what you take them for. If you are having side effects take time to tell your medical professional about them. They may need to make changes to your medicine.



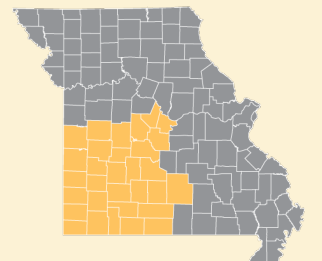
Everyone desires to have control over decisions that affect their lives. Even if they need someone else to assist them with some information and decision making, they should be at the center of the process and comfortable with their treatment options.

Let's raise our children with special needs to grow up to be capable of taking ownership of their medical care as they transition into adulthood. ●



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Beth is the mom of three children, one of which lives in the home and has a special health care need. She is knowledgeable about Autism, Fetal Alcohol Syndrome, Post Traumatic Stress and Sensory Disorders.



ASKING QUESTIONS ABOUT...

HEALTHY LIVING



Adulthood (23+)

Am I being supported to help with managing my own medications, talking to my doctors and other medical professionals, and participating in making medical and health decisions? ★

Adults have to learn how to manage and access health care on their own. Part of managing your health as an adult is knowing your health conditions and their symptoms so you are ready in case of an emergency.

As my daughter is packing up to go away to college, I worry about her getting sick while she is so far away. Have I given her the right tools and skills to manage her own health? Sure, I have taught her to eat right, exercise and get plenty of rest, but does she know when to call the doctor? Does she know how to order a new prescription or call in a refill?

Whether or not your children have special health care needs, it is important to teach them skills they will need to advocate for their own health care as they transition to adulthood and seek more freedom. The first step in helping them advocate for their own health care is to make sure they understand their diagnosis. If they have questions that you can't answer, make a list to ask at the next doctor visit.

Speaking of doctor visits, does your child know how to schedule an appointment? If not help him/her to schedule the next one. If your child sees multiple specialists help by making a list of all the doctors, what types of doctors they are, and their phone numbers. Include when the last appointment for that doctor was and when they are to see them next. You may also want to include a picture of the doctor next to the name to help your child put a name and face together. I also make a list of my child's therapists.

If your child receives medication or special treatments, make a list of them. Include what the medicine is for, the concentration, and the dosage. Make sure your child updates them with each change in treatment or medication. This is great information to take to doctor appointments. (I have one for myself. I no longer have to try to remember what medications I'm taking. It makes my visits less stressful.) Don't forget to include over-the-counter medications like vitamins, aspirin, etc.

Putting everything into a three ring binder is helpful for easy access and quick updates. Just pull out the old list and replace with a new one. Not only will this help your child have the tools to advocate for his/her own needs it is valuable in an emergency. If you or



your child are unavailable to let first responders or other health care personnel know what your child's current health care needs and treatments are, it is there for all to see. Make sure the book is somewhere accessible by all. Taking it to all health care related appointments saves time and helps avoid delays in treatment.

Other things to think about putting in the notebook:

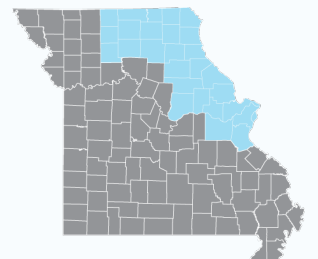
- A copy of the health insurance card,
- doctor's orders,
- hospital discharge papers,
- emergency contact information and
- information on your child's diagnosis.

In our house the three ring binder is red and we call it the "Red Book." I need to go check to make sure my daughter packs it on top for quick and easy access when she gets to school. ●



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Pat is the mother of three children. Her youngest, Patrick, was diagnosed with both special health care needs and developmental delays. She has been involved with the Delta Gamma Center, Missouri Blind Task Force, the Special School District in St. Louis, and Missouri Family to Family as an SOS mentor.





HEALTH INSURANCE MARKETPLACE UPDATE

Open enrollment for 2014 coverage is over, but you may still have options to get health coverage. Go to healthcare.gov to find out if you qualify for a Special Enrollment Period so you can buy a private health plan through the Marketplace.

If you are eligible to apply for Medicaid and the Children's Health Insurance Program (CHIP) — you can do this any time, all year. If you qualify you can enroll immediately.

There is also an online screening tool you can access to see if you qualify to get coverage outside Open Enrollment.

If none of these options work for you, the Open Enrollment period for 2015 coverage begins on November 15, 2014.

Connect with Cover Missouri at covermissouri.org to find tools to assist you in educating yourself about and getting help with navigating the exchange. Go online to calculate your savings, read and download informational materials, connect with educational and enrollment events, and find one-on-one assistance near you. ●



COVER MISSOURI

From Healthcare.gov and Cover Missouri covermissouri.org

Sign up for e-mail updates about the Family Partnership and Missouri Family to Family, including when the latest issue of Partnering Together is available online!

Visit mofamilytofamily.org today to sign up!



FEATURED RESOURCES

Partnering with your Local EMS Professionals to Support Your Family

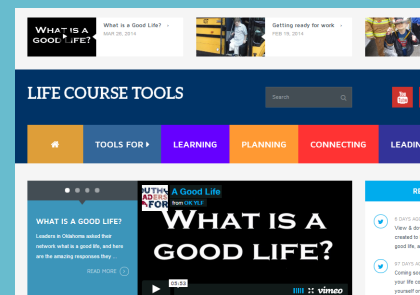
This free, archived webinar is available to help you

- get familiar with Emergency Medical Services,
 - learn how you can work with your local EMS providers to make sure your family's needs are understood if an emergency situation occurs, and
 - make a plan for your family so you can be ready!
- View or download the webinar at mofamilytofamily.org.



Lifecoursetools.com

Lifecoursetools.com is a new, one-stop resource for individuals with developmental disabilities or special health care needs, their families, the professionals who serve them, and organizations that support them. Visit the new resource and be part of its development at lifecoursetools.com.



Charting the Life Course: A Guide for Individuals, Families and Professionals

Do you know what you need to know? Do you know what questions to ask?

This guide was created to help people with disabilities or special health care needs and families think about what they need to know, identify how to find or develop supports, and discover what it takes to live the lives they want to live. View and download the guide at mofamilytofamily.org.



Connect with us online for news, contests, events and even more resources!

Need info in an accessible format or in Spanish? Call us to get the information you need!



Look inside on Page 2 for information about upcoming networking events in your area!

MISSOURI FAMILY TO FAMILY •

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 | tips4kids.org



Department of Health & Senior Services, Special Health Services

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

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



Family Partnership

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

800-779-8652 | mofamilypartnership.org



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

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

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

UMKC IHD

The Institute for Human

Development, located

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

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



Missouri Developmental Disabilities Council

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

800-500-7878 | moddcouncil.org



DMH Division of Developmental Disabilities

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

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

Missouri Family to Family is housed within Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) at the University of Missouri - Kansas City Institute for Human Development. It is the state's HRSA Family to Family Health Information Center, and is a Parent to Parent USA Alliance Member. This newsletter was developed in partnership and with support from the Missouri Department of Mental Health, Division of Developmental Disabilities; the Missouri Department of Health and Senior Services, Bureau of Special Health Care Needs; the Missouri Developmental Disabilities Council (PL106-402); and the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs (#H84MC09484).