

PARTNERING TOGETHER

PAGE 3 WELL CHILD EXAMS

Ensuring the health of children as they grow!

PAGE 6 HEALTH MATTERS

Do you know you should be asking about your family's health?

PAGE 7 ACA TURNS THREE!

What's happened so far and what is going to change?



YOUR FAMILY'S HEALTHCARE



Day after day, we are flooded by information about our health from medical providers, insurance companies, the media, friends, and family. Being responsible for our health means we take information in and use it to make good decisions about medical care. It is important that you are educated about and take care of your own health, especially if you are responsible for supporting the health of another person.

A child's health care needs begins before he or she is born and they continue to be central to quality of life across the lifespan. Before giving birth, mothers must make sure they stay healthy and receive good prenatal care. When a child is born, federal and state laws mandate that he or she is screened for health conditions. As children grow, they should

see the doctor regularly for well child examinations. This is a time for parents to ask questions and learn about their child's development as they grow up. For information about well child checks, see page 3.

Part of growing up is taking over responsibility for our own health matters. Medical transition happens when your child moves from pediatric to adult care. To read tips on easing the transition to adult medical care, flip to page 6.

Having the right tools to take care of your own and others' healthcare is essential to navigating the health care world. MOF2F has many tools available in print and online to help you take charge of your health. Visit us online or call us today. We are here to help. ●





M•O•F•2•F

MISSOURI FAMILY TO FAMILY

Many new things are happening with Missouri Family to Family! We recently released our newest version of the F2F Network folder. Last year, over 40,000 folders were handed out across the state to individuals with disabilities and special healthcare needs and their families by our partners and at special events.

So far this year, we have trained 33 new SOS mentors, who will be serving as a lifeline to other individuals and families. Although we have many new mentors, we still need more! If you are interested in serving as a lifeline for another parent or family member, contact us today!

The F2F network is a statewide collaboration of organizations that offer supports to individuals with disabilities and their families. Our network of organizations that support families in Missouri continues to grow. This time last year, we had seven affiliates; today, we have 95.

One thing that we are very excited about is the new Life Course framework we have been developing. We hope the

life course approach helps families realize that even when their child is very young and as he/she ages and grows into adulthood, their experiences and environment can shape how they will live their life in the future.

The cornerstone of this framework is a publication we recently published called *Charting the Life Course: A Guide for Individuals, Families and Professionals*. This guide was developed by MOF2F and our stakeholders to help individuals with disabilities or special healthcare needs and families at any age or stage of life 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.

Charting the Life Course is a tool to assist you in creating a vision for the future. It is designed to help you think about the questions to ask as well as the choices and options to consider as you "plot a course" to a full and meaningful life. It is intended to be a starting point no matter where you are in your life journey. You can see sample questions on page 6 or download it at mofamilytofamily.org ●

ACT EARLY: Checking more than fingers and toes



Did you know that Missouri law mandates that all newborns are screened for certain medical conditions? The screening includes a simple blood test, involving a few drops of blood from a baby's heel, and hearing check, but they are a huge step in detecting special healthcare needs in newborn babies. Many of the disorders babies are screened for are very rare, but they are also very serious and can result in serious medical issues if not identified and addressed early. Newborn screenings help identify if babies need treatment, such as a special diet or medication. Early identification is important for addressing special healthcare needs and improving the quality of life for children across the lifespan.

These tests are completed before your child leaves

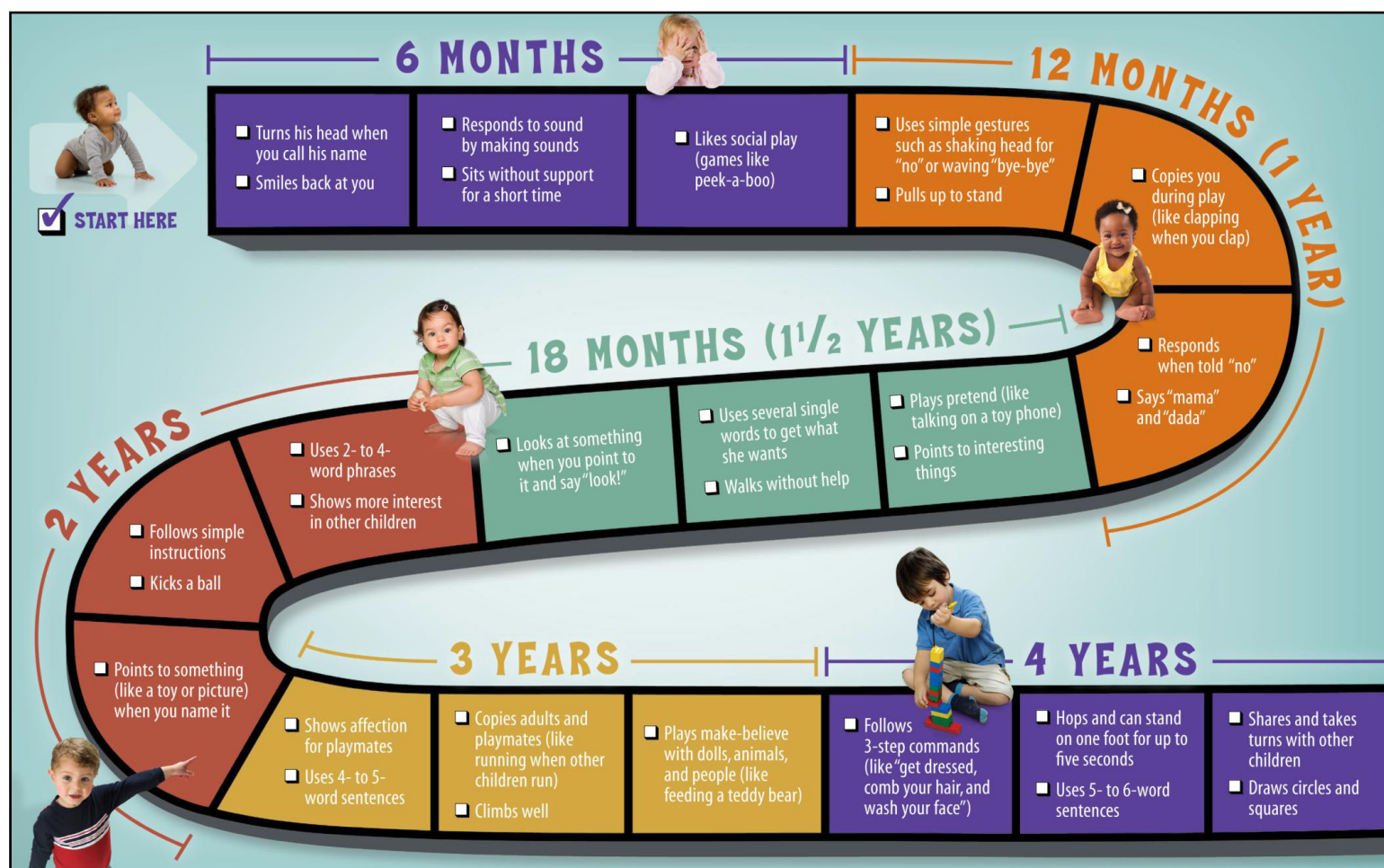
the hospital, usually 24-48 hours after birth. If your baby is born at home, you will need to make an appointment with your baby's doctor to have the screening test. These screenings will tell you and your doctor if your child is at risk for a condition. Sometimes, more than one newborn screening is needed. If an additional screening is needed you will be notified either by your baby's doctor, the hospital, or staff from the Department of Health & Senior Services.

After the newborn screening, it is important that you take your child to the doctor for well-baby and well-child checks. Well-child checks are covered under the Affordable Care Act as preventative healthcare, so your child has access to these visits regardless of whether you have insurance or not. Well checks include a physical exam as well as immunizations and screenings for vision, hearing, and teeth.

These visits give you a chance to ask questions and talk about any concerns you have about your child's development, behavior, and well being. Your doctor will also give education and guidance about your child's health and development.

Your child's well check-ups are important to his or her health and well-being. It is important that your child sees his or her doctor for regular well check-ups. You know your child best. If you are concerned about your child's health and development, talk to your child's doctor or nurse.

If you have recently received a diagnosis after a newborn or regular screening and need help figuring out what your family's next steps are, contact MOF2F. We can provide the information you need and connect you with another family who has been there. ●



Used with permission. From *Track Your Child's Developmental Milestones, MO First Steps and Parents as Teachers*.



FAMILY PARTNERSHIP

Toll-free: 1-800-779-8652 | On the web: mofamilypartnership.org

NORTHWEST REGION

FINDING THE RIGHT PEDIATRICIAN

Recently, someone told me “You are the CEO of your child’s life!” This spoke to me on many levels, specifically regarding my child’s healthcare needs. As I put on my CEO hat, I am empowered to make great selections and manage our healthcare providers. I am reminded that I am not only the parent, but part of the team that makes decisions regarding his care. It is important to determine, what is my approach to my child’s health? What characteristics in a pediatrician are important to me? For example, does he/she take a more proactive approach to treatment, or a more relaxed “wait and see” approach? Schedule a time to meet! A great CEO always conducts a detailed interview! Since the time with a doctor is typically limited, I encourage families to ask for an extended visit for a first appointment.

Regardless of a child’s needs, healthcare of children is often driven by one provider, the primary care physician or pediatrician. Before you start looking for your primary care physician, consider asking around—referrals are often a starting point. Then, decide what is important for your family. Are you only going to be visiting a couple times a year for sniffles and immunizations or are your child’s needs more complex and require frequent contact? Always come prepared with your top five questions to make the process quick and efficient. An organized binder with recent tests/labs/concerns can help explain your child’s past and current needs. Feel free to ask specific questions regarding your child’s condition. Such as, are you familiar with the needs of a child that requires G-tube feedings? During the interview, pay attention to the doctor’s manner. Do you have his/her undivided attention? Do you feel at ease asking questions? Also, pay attention to other aspects of the office. Was parking available and accessible? Was the staff friendly and helpful?

When our family’s insurance changed we were forced to pick a new pediatrician. Luckily, our old physician recommended one that would be a good fit for our needs. We needed a practice that was familiar with children with complex needs, would be willing to embrace our complicated case and answer our questions with patience and understanding. We have found our medical home. The right fit for our family means less stress navigating medical systems and a central place to get answers. I encourage every family, regardless of health need, to find a practice that embraces the values that your family finds important and listens to your concerns, because you are your child’s CEO! ●



SOUTHWEST REGION

PROMOTING AWARENESS ABOUT FETAL ALCOHOL SYNDROME

No parent is ever given a guarantee they will have perfect, healthy children. It makes no difference what race, religion, from urban or rural settings, what social background we have, we all take the same chance when we have our children. It is important to avoid activities that could be harmful to a developing baby when pregnant.

Fetal Alcohol Syndrome (FAS) is a condition that is caused when a baby is exposed to alcohol during pregnancy. Very early stages of development are especially vulnerable, often even before a woman realizes she is pregnant. Even a small amount of alcohol at crucial moments of development can impact a child’s health across the lifespan. FAS often goes undiagnosed because the symptoms are more behavioral or emotional and hard to “see.” When a family receives this diagnosis, it may be difficult to accept.

It is important to remember that all children are unique and have different ways of learning and interacting with others. For children with FAS, language development is often affected. Children with FAS may have difficulty learning from their mistakes or be impulsive. It is important to determine a child’s strengths so they can be encouraged about what they can do well. One-on-one attention and patience, (did I say patience?) as well as understanding the child’s needs will accomplish much. The importance of a calm and stable environment with consistent rules cannot be over stated. Taking away as much stress as possible can give your child the room needed to learn. Accommodations may include not timing tests, allowing them to stand when they read or do school work, chewing gum to let them work off anxious energy or focus, and providing frequent breaks. Any coping modification that helps them focus and learn is worth advocating for and including in their Individual Education Plan and communicating with their circle of support.

Our foster care system has a great number of children in their care who have FAS and are in desperate need of understanding and loving families to help them navigate through this frustrating disorder. It is very important to me to spread awareness about FAS, as our family has adopted a child with the condition. My hope is you will use this knowledge to equip women in your circle of influence to prevent FAS from affecting their children’s lives and help obliterate this preventable condition in the future. ●



FAMILY PARTNERSHIP
a collaboration between
MISSOURI FAMILY TO FAMILY | SPECIAL HEALTH CARE NEEDS

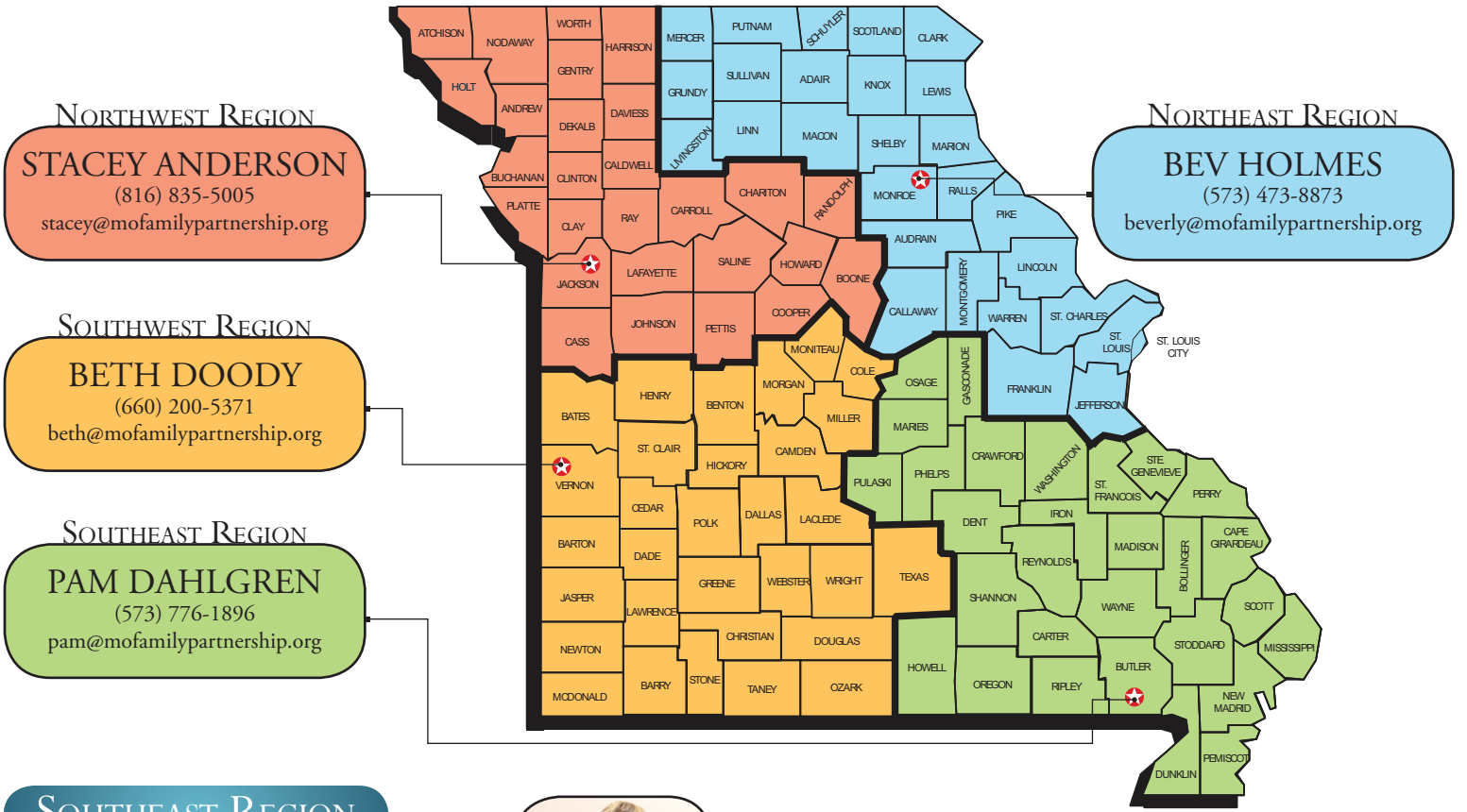
The Family Partnership is an initiative between:



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



which is funded by the Maternal and Child Health Bureau Title V Block Grant



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SOUTHEAST REGION

CARING FOR A CHILD WITH EPILEPSY

Being a parent of a child with epilepsy has many challenges. Being aware of what to look for and do during a seizure is vital to the health of your child. Seizures can be scary—each time my child has one I feel the rush of adrenaline!

During a seizure, a child may lose consciousness, have difficulty breathing or appear to stop breathing, or twitch or convulse. With milder seizures a child may be momentarily confused or unaware of his or her surroundings. Some seizures can only be detected by careful observation, because a child may blink or stare into space for a moment and then resume normal activities. Do your best to note the frequency, duration and symptoms of seizures so you can report this to your doctor.

After a seizure watch your child for signs of confusion, this is common and your child may be tired, disoriented, confused, or agitated for minutes to hours after the seizure. If your child wants to sleep allow it. Do not give extra medication without a prescription. Your child may be frightened or confused during and after a seizure, so be sure to offer plenty of comfort and reassure your child that everything is OK.

Parents caring for a child with epilepsy may benefit from seeking advice from professionals like psychologists, social workers, or specialized educators as well as other parents. For those whose kids have more severe epilepsy, this help is critical. Talking to others can help parents plan for the future by learning about options and identifying resources that will improve the child’s well-being. ●



NORTHEAST REGION

DOING YOUR HOMEWORK

Healthcare is a very important topic in the lives of families, especially those who have children with diverse medical needs. Your child’s health may bring daily challenges where no two days are the same, but we all share many of the same responsibilities, like finding the right doctors. As your child’s advocate, you know your child better than anyone else ever will and you are the one that makes the important decisions, so it is important to do your homework!

One of the greatest things about having internet is the ability to check out doctors, hospitals, and clinics. This can be a huge resource, especially if you are new to an area or need to transition from pediatrics to adult care doctors. Now you have the ability to find the providers you need and “interview them” prior to even getting your child in for a visit. It is very important that you not only are comfortable with the doctor, but that you are confident that your child will receive the best advice, treatment, etc. that can be offered. Many doctors vary in their skills, backgrounds, education and specialties.

Check out the providers in your area, and then call, email, ask questions or even set up an appointment to meet with them before scheduling to take your child in to make sure that it’s a good fit for everyone involved! It can be a great experience and make the transition to a new provider much smoother for everyone. ●



ASKING QUESTIONS ABOUT YOUR HEALTH

across the lifespan

Part of taking charge of your health means knowing what questions to ask. The questions below are to help you think through important health-related matters like managing and accessing healthcare and staying well. Your Family Partner and MOF2F are also there for you to answer any health-related questions!



Prenatal and Infants (0-3)

- Are you keeping me healthy with well-baby visits and taking me to the doctor when I am sick?
- Do your parental instincts tell you something isn't going quite right with my health, growth or development?
- Do you know if I am hitting my developmental milestones on time?
- Do you know what red flags to watch for?
- Are you expressing your concerns about my health or development to my pediatrician?
- Where are you taking me to find out about my health or development; what kind of testing do I need?
- Has anyone else mentioned concerns about my health or development to you?

★ = A practice that promotes self-determination



Early Childhood (3-5)

- Are you finding or accessing medical and health personnel experienced in caring for children with my diagnosis?
- Are you taking me to a pediatrician who understands and meets my needs?
- Does our pediatrician refer me to specialists when needed?
- Do you feel like you have to go along with everything the professionals tell you about me, even if your gut tells you otherwise?
- Do you know what to do if we don't like or if you disagree with my medical professionals?
- Will therapies help me to grow and develop?
- Am I part of a "medical home"?
- Have you invited local emergency personnel to our home to meet me and learn about my needs in case of an emergency?
- Are you teaching me about healthy, nutritious food and how my body works? ★



School Age (5-15)

- What do you need to tell the school nurse about my needs?
- What if I need to take medications or treatments at school?
- Do local emergency providers know our wishes if something happens to me at school?
- Are you keeping me up to date with regular childhood checkups and immunizations?
- Are you taking me to see specialists for specific issues?
- Are you teaching me to greet and interact with doctors and other medical professionals? ★
- Do I know how to ask for help or tell when I am sick or just don't feel well? ★
- Are you helping me understand my disability or healthcare needs and how they affect me as I grow and change? ★
- Do I know what is good (food, sleep, exercise) and bad (drugs, smoking) for my body? ★
- How are you helping me prepare for and understand puberty?



Transition (15-21)

- When should you help me start looking for practitioners who focus on adults?
- What health related tasks can I start to help with or do for myself? ★
- Are you helping me to know the symptoms, triggers, and side effects of my disability or healthcare need and how to get help or interventions? ★
- Are you helping me learn how to talk about my disability or healthcare needs with others? ★
- Can some of my therapies be replaced with regular physical activities?
- Are you helping me prepare for and understand puberty? ★
- Do I feel comfortable asking you or trusted adults about the changes in my body as I become an adult? ★
- Have you talked to me about birth control/reproductive health? ★



Adult Life (22-55)

- Who else understands my medical needs and information?
- Do I qualify for Medicaid or Medicare coverage?
- Can I get my own health insurance coverage? ★
- 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? ★
- Do I get regular physicals and routine exams, such as mammograms, prostate checks, and blood pressure monitoring?
- Am I being supported to eat healthy and be physically active? ★
- Is my reproductive health being looked after?
- Do I practice safe sex and/or should I use birth control? ★
- Do I understand the health risks of behaviors such as smoking, excessive alcohol use, or illegal drug use? ★



Aging (55+)

- Who else understands my medical needs and is available if I need help communicating those needs to others?
- Are my supporters aware of how some medications can affect an older person differently?
- Am I eating healthy meals and snacks?
- Am I staying as physically active as possible?
- Who will help me create a will and make my wishes known for medical directives? ★

You can find more questions in *Charting the Life Course: A Guide for Individuals, Families, and Professionals*. This guide helps families explore questions they might have while supporting a loved one with special healthcare needs to have quality of life across the lifespan. **View or download the guide today at mofamilytofamily.org!**



Affordable Care Act Turns Three!

The Affordable Care Act (ACA) turned three in March! Thanks to the ACA, many Americans are gaining access to health care that was never before afforded to them.

What changes have already taken place?

- **Preventative care is free for you and your family.** (2010)
- **Insurance companies are not able to cancel the policies of people who get sick.** If you or a loved one develop a serious illness, insurance companies can no longer say they can't insure you. (2011)
- **Young adults can stay on their family's insurance until age 26, unless they get coverage through their employers.** (2010)
- **Adults with high prescription drug costs on Medicare Part D are paying less for their medications.** People whose expenses are high enough to put them into the non-reimbursed "donut hole" are receiving discounts and rebates to deflect their own out-of-pocket expenses. (Effective in 2010 and lasting until 2020, when the donut hole will close entirely)
- **You now have the right to choose any available participating primary care provider for yourself or your family.** (2010)
- **Children with special healthcare needs or developmental disabilities (also called "pre-existing conditions") cannot be denied coverage.** (2010)

What changes are coming?

Later this year

- On October 1, 2013, open enrollment in the new Marketplaces starts. Different financial assistance programs will be directly linked into the Health Insurance Marketplace when enrollment starts. In the meantime, you or your child or teen may qualify NOW for no-cost or low-cost health insurance through Medicaid and the Children's Health Insurance Program (CHIP). Missouri has chosen to have an exchange developed by the Federal government.
- If you need assistance figuring out the exchanges and choosing a plan, there will be trained navigators available to assist you at no cost.

In 2014

- Beginning in 2014, neither children nor adults will be denied for a special healthcare need/disability.
- When key parts of the health care law take effect in 2014, more people than ever before will qualify for health insurance that fits their budget. You may be eligible for a free or low-cost plan, or a new kind of tax credit that lowers your monthly premiums right away.
- The Essential Health Benefits (EHB) package must be covered by health plans selling insurance through the Exchange and all Medicaid state plans. The EHB plan must cover services that families with children who have special health care needs access often, including: emergency services, hospitalization, mental health services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices and many others.

You can sign up for e-mail updates, prepare for the changes, and find what coverage fits your family's needs at healthcare.gov. Count on MOF2F to keep you up to date about health care changes. ●

RESOURCES

Healthcare.gov

At the Healthcare.gov portal, you can explore insurance coverage and options, get help decoding and understanding insurance information, find out details about the Affordable Care Act and how the Act's changes to the healthcare and insurance industries affect your family, and learn about how the ACA can help you stay healthy through preventative care.



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?

Charting the Life Course was developed to help individuals with disabilities or special health care needs and families at any age or stage of life 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 *Charting the Life Course* and many other resources at mofamilytofamily.org.



Friend us on Facebook and follow us on Twitter for news, contests, events and updates of interest!

Want a printed version of our resources? Need information in an accessible format or in Spanish? Call us at 800-444-0821 and we will connect you to the information you need!



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VOL. 2, ISSUE 5 • 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
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)
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
MDDC 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
moddcouncil.org



Missouri Family to Family
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
mofamilytofamily.org