

PARTNERING TOGETHER



STAYING SAFE & SECURE IN THE COMMUNITY

We all face challenges and worries as our children grow and learn about the world around us. Older generations grieve that pick up baseball games are a thing of the past. Every aspect of our children's recreational activities are planned, programmed, supervised and controlled. Gone are the days where we learned about others and discovered ourselves through unsupervised outings with peers. Yet today we are even more worried about our children's safety. Even our smallest, most close knit communities are exposed to a world of dangers through media, internet and mobile devices. Bullying and hazing have gone to whole new levels. Exposure to violence, sex, drugs and alcohol happen earlier and earlier in a child's life. In response we have isolated our children from our communities, cut off

relations with our neighbors and controlled our kids' interactions with others to the point that we contribute to their vulnerability.

Where do we find safety and security? The "reality" show Survivor got it all wrong – you don't survive by defeating everyone else, but by working together, cooperating, sharing strengths and watching out for each other. It is vital that we raise our children to be self-determined, aware, cautious and confident so they are safe in the community. When they are young we are in complete control of them. We 'childproof' our homes. We use baby monitors and other methods to constantly know what they are up to. We bundle them up when it

Continued on Page 2



FROM THE COVER: STAYING SAFE & SECURE IN THE COMMUNITY

is cold and protect them from the sun in the heat of summer. As they grow, it is our duty to teach the skills they need to care for themselves and watch out for their peers.

It can be hard to foster independence when raising a child with special needs. We want to protect them – from bumps and bruises, from stares and inquiries, from negative connotations that can arise from being “different”. But if we isolate them from the community – from the grocery store, department store, library, church and playground, we are doing a disservice to everyone. Our children are a diverse part of the community, and their safety relies on them being in it. If your child wanders away from you at a store, isn’t it comforting to know that the employees recognize him and will help? If your child is the object of stares or questions – do you assert to her that her gift is one of educating others about special health care needs?

It is important to help our children have the same life-shaping experiences that we had. Sleepovers, outings, friendships and being involved in sports, the arts and volunteering are crucial. We need to develop these relationships with others who are naturally drawn to our children and who they respond and relate to. There is a big difference between the fear that your child will get hurt and the fear that your child won’t get to live a life filled with possibilities, hopes, dreams and desires. Explore this issue of *Partnering Together* to discover how to enhance your child’s safety and security by engaging in their community throughout their life course. ●

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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...

SAFETY & SECURITY



Early Childhood (3-5)

Have you talked to Emergency Medical Services (police, ambulance, and fire department) about our family?

Developing an emergency care plan is very important, and communication is the key to saving a life. Having a relationship with the local emergency medical providers can save a lot of time, pressure, and worry in case an emergency does take place.



I have not only contacted the local emergency response teams, but I also have a laminated sheet about Izaak with a brief bio of his health history, diagnoses, current medications, and medical equipment. This is with him at all times in his emergency bag. We also have a personal family emergency plan. If you live in a rural town allow extra time for emergency response team back-up in your planning. If something happens to me while I am watching Izaak, 911 has to be called for someone to take care of him and everything that needs to be done is written down. Also, since he has a trach and sleeps on a ventilator I have contacted our electricity provider and filled out a special needs form. If the power goes out, we are the first priority in our area. This is extremely important to do for families with life support equipment in the house.

Make sure if you have other children to include them in the family emergency plan so they know what to do, where to go

and how to help. To ensure my daughter's safety, my family has several neighbors on stand-by in case Izaak has an emergency. My daughter also feels more in control and a bigger part of the plan by helping. Her assigned role is to bring my son's emergency medical bag to our feet and call 911. This allows my husband and I to take care of Izaak until back-up arrives. Being prepared and organized is essential to saving a life!

Planning ahead is key. What are your family's activities? What could happen while participating? Ask yourself questions about your child. What is the worst possible situation and is everyone prepared for it? If you can ask and answer these questions before a situation becomes an emergency, your loved one is more likely to be safe and secure. ●



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Sheree has two children. Her son was diagnosed with Achondroplasia, a form of dwarfism, when he was born. She gives this advice to parents of children with special health care needs: "I encourage you to never lose hope as this is what saved my family. Also, reach out to others for help and understanding. You are not alone."



ASKING QUESTIONS ABOUT...

SAFETY & SECURITY



School Age (6-13)

Are you helping me learn who to trust and how to be safe? ★

This skill is essential to surviving the world well into adulthood, yet it is difficult even for many adults (with or without disabilities) so it's important to start teaching it early.

Safety is always on the minds of those with small children. From birth, we take measures to prevent injuries and harm. We buy outlet protectors, install baby gates and keep household cleaners and medications far from reach. As our children grow older, we focus on more complicated issues.

Sooner than we expect, our precious little ones venture into the world we know as adults. We like to think that we will always be there to protect them and help remind them what is right and wrong, appropriate and inappropriate, socially acceptable and not. Facing the fact that all too soon they will be independent adults is not easy. That's why it is critically important to take steps now to prepare your child to be safe in the future.

A child's level of functioning and personality must always be considered. Often children with special needs are very open and accepting of everyone they meet. They may be overly eager to please a new "friend." Teaching your child that it's okay for someone not to like them or what they are doing is an important step in helping protect them from potential mistreatment.

Helping your child develop good relationships with neighbors, community leaders, safety workers and medical staff can go a long way. Encourage your child to meet and talk to police officers, firefighters and EMTs to help identify trustworthy community members and ensure that someone will watch out for them when they are out and about on their own.

Helping your child make good friends early on can also help protect your child and offer more freedom while remaining safe. Very few kids want a parent or caregiver to follow them around wherever they go. Lifelong friendships can ensure they have someone looking out for their best interests because they care about them as an integral part of their lives.

The world can be a very scary place to send your child into, regardless of their needs. With advanced planning and careful



cultivation of healthy relationships, you can rest easy trusting your child is equipped with knowledge and solid relationships with people who have their safety and wellbeing in mind. ●



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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 connect families to each other and resources in their local area.



ASKING QUESTIONS ABOUT...

SAFETY & SECURITY



Transition (14-22)

Are you helping me learn when and how to call for help? ★

Adults with disabilities are often mistreated and even abused and neglected because they are afraid to report someone who is helping them or taking care of them because they are 1) dependent on that person and 2) lack other positive, healthy relationships.

We all want our children to be safe. Making safety a regular part of everyday conversation can ease most fears. If our child has special health care needs, these conversations become even more important.

Here are some questions my family has been thinking through and talking about as we prepare our daughter to be safe while she is out in the community:

- Do you model and enforce proper seat belt use/restraint in your car? If your child travels in a wheelchair, is it highway rated and properly secured in the vehicle?
- Is your child aware of personal safety? Does she understand there are bad, improper ways of being touched or controlled? Can he advocate for himself or tell you if he is mistreated, abused or neglected? Does she understand she has the right to say "no"? Many people with disabilities feel that since they need caregivers to help with everyday tasks, they must do as they are told and not complain. This need should never put a child or adult in a position of abuse or neglect.
- Have your children met local emergency personnel? Are they comfortable speaking to people in uniform?
- Do you practice a fire safety plan in your home with a safe place to meet? Do you stress that your child's personal safety is more important than toys, games or pets?
- Do you discuss who a stranger is, how they might act, or what they may try to do? Does your child know not to get into a car with a stranger? Is your family involved with Neighborhood Watch, and do your neighbors know your children?
- Can your child communicate who they are, where they live and who you are? Is this information on their person? How does your child get back to you if you are somehow separated from each other?
- Does your child wear ID information about medications, diagnosis or life threatening allergies? Can they identify their doctor or hospital? This could save your child's life and protect them from dangerous situations.



Emergencies can happen to anyone. Each small step we take now can help our children be more independent and safe in a world that doesn't always treat others as it should. Let's all be willing to have these important conversations with those we love and care for. ●



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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...

SAFETY & SECURITY



Adulthood (23+)

Does my transition plan include learning skills that will help me to 'be my own person' and not need a guardian for decision-making support or protection? ★

Letting go and letting children take risks is crucial to them learning how to stay safe in the community and make their own decisions. Being in control of every aspect of your child's life is not feasible as they grow up and assume increasing levels of responsibility over their choices and lives. Parents must foster self-determination.. and start early!

Venturing into adult life can be exciting as well as scary. When we are young, our parents do most of the planning and caring for us. As we move into adulthood, we take on the responsibility of making decisions and managing our daily lives. However, none of us make all of these decisions alone. We rely on parents, friends and mentors, professionals and personal research to form the best decisions we can in each part of our daily lives. From choosing a dentist to renting or purchasing a home to managing our finances, we all need support.

It is not uncommon for adults who need help with activities of daily living to have a guardian or caregivers who are thinking about becoming guardians. These activities could include paying bills, managing medications and appointments or shopping for and preparing meals. It is important to realize that people who have a guardian may not be allowed to decide where they live, who they live with, what they do during the day or how to spend their own money. The freedom to make these decisions plays an important part in defining all of us and shaping our quality of life. This freedom is one that everyone should be allowed to enjoy.

There are other ways to create decision-making supports for a loved one. To start, become part of a well-rounded community with access to activities like banking, leisure, faith, shopping, medical services, family and friends. Establishing yourself in the community is the first step to knowing who to trust when seeking advice. Making a transition plan that relies on being active in the community can help.

Another thing to consider in long-term supports for loved ones is the roles others play in their lives. Those who care about them, including close family members and loving friends, provide a natural lifetime commitment, affection and self-esteem. They are also likely to know the most about their



personal needs, wants and desires. Those who care for them may include friends, professionals, service coordinators or paid staff. They can help in the areas of day to day care, finances, inclusion and advocacy. Planning who provides support in the various roles may remove the need for formal guardianship.

There is not a one-size-fits-all answer for support and protection. Deciding what will work best in your unique circumstance can be complex. To get more information and tools or to talk to another family about how they made decisions about guardianship and transition, go to mofamilytofamily.org. ●



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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

2015 Open Enrollment in the Health Insurance Marketplace opened November 15, 2014. If your family still needs coverage for 2015, there is still time to enroll in a plan that meets your needs and budget. Your coverage can start on February 1 or March 1, depending on when you enroll. The Open Enrollment period ends February 15, 2015.

Does your family already have a plan through the Marketplace? Many families have been automatically enrolled in their current plan or a similar plan so can count on coverage into the new year. Even if your family has been automatically enrolled, you can still change to a different plan and find out if you are eligible for help with costs until February 15, 2015.

Need help figuring it out? Cover Missouri has all the tools to help you navigate the Health Insurance Marketplace, including:

- Videos to help you understand health insurance and the Marketplace,
- Calculators to help you find out if you can get help paying for health insurance and how much your family can save,
- Materials and information about in-person events where you can learn more and get assistance if you need it,
- Connections to in-person help in your area and a 24-hour hotline to answer your family's questions about health coverage options.



COVER MISSOURI

Visit covermissouri.org today! ●

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

MO Guardianship: Understanding Your Options & Alternatives

Do you have questions about guardianship?

Guardianship is not a quick fix. Get connected to tools and information you need to make an informed decision, including an archived webinar, resource guide, online workbook, and more at moguardianship.com



MO GUARDIANSHIP: UNDERSTANDING YOUR OPTIONS & ALTERNATIVES

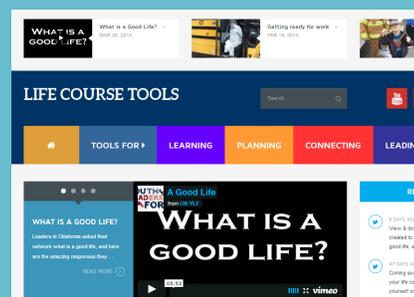
Why are you thinking about Guardianship?

Someone may be telling you that you or someone you love needs to have a guardian. It might be school staff (school routinely send out a letter about guardianship when a child who has an IEP turns 17), a medical professional, a service coordinator, or even another parent.

There is often a general assumption that just because someone has a disability, mental health diagnosis, or is aging, he or she will need a guardian. In reality, everyone is presumed competent to make choices about their own lives when they become an adult, unless a court says otherwise. With the right supports, many people with disabilities or special healthcare needs are able to remain "their own person," making their own decisions and being in charge of their own lives. The trick is to find a balance: giving the person enough support and protection so they can live a safe and healthy life without taking away their rights and freedom to make choices and decisions for themselves.

There are a lot of reasons why individuals with developmental disabilities, their families, and key supporters might be

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!



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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



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).