

# PARTNERING TOGETHER



## CITIZENSHIP & ADVOCACY

*FOCUSING ON BEING PART OF THE COMMUNITY & STANDING UP FOR YOURSELF*

Being known and valued in the community gives a person a sense of worth and citizenship. Learning to make choices, set goals and speak up for needs and wants leads to becoming more self-determined and is essential to advocating for self and others.

Advocacy for your child with special health care needs starts early, at the first sign that something may be different. Following your parental instincts and seeking a second or even third opinion, researching all possibilities, and seeking advice from those who have been there before are all steps toward speaking for your child. As your child grows, your opportunities to advocate on their behalf increase. From early childhood through the school years and into adulthood you will be both your child's greatest advocate and greatest cheerleader as you

help him or her become an active, confident, and contributing citizen in the community.

As early as possible it is important to help your child become a self-advocate. A great way to get started is by encouraging him or her to order food in restaurants and check in at doctor appointments. It seems simple, but you will build confidence in asking for something needed or wanted and your child will get used to providing information, such as his or her name and birthday, and eventually address. Another crucial step is redirecting questions about your child to your child. For instance, if someone asks: "How old is she?" turn to her and ask: "How old are you?" Not only are you giving your child power and permission to speak for herself, you are teaching the other person to address

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### **BEING PART OF THE COMMUNITY & STANDING UP FOR YOURSELF**

her directly. If your child doesn't communicate verbally or is difficult for others to understand, it is still important to "give him the floor." Allow him to answer questions in his own way, and then translate if necessary.

While we tend to want to protect and isolate our children we must do just the opposite and pointedly become active in the community. If your child is interested in dance – enroll him in dance. If she wants to play T-ball – go for it. Even if you face struggles in adapting or accommodating activities for your child it is worth it for him or her, your family, and the community at large to be included. Everyone has the right to live, love, work, play and pursue life aspirations in their community. Pursuing this right to the fullest will develop your child's community. Along the way caring relationships will form and independence will develop.

Continue to explore ways to increase your child's advocacy skills and citizenship in this issue of *Partnering Together* and online at [mofamilytofamily.org](http://mofamilytofamily.org). ●



Access information and tools to help you explore **Citizenship & Advocacy** and more at [LIFECOURSETOOLS.com!](http://LIFECOURSETOOLS.com)

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is a publication of  
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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



### Citizenship & Advocacy

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

View and download the guide at [mofamilytofamily.org](http://mofamilytofamily.org)

## ASKING QUESTIONS ABOUT...

## CITIZENSHIP & ADVOCACY



### Prenatal & Infancy (0-3)

Do you present yourself as an expert regarding me, and are you helping me to learn to be the expert on myself and my needs? ★

In order to get past the question, “What’s wrong with my child?” and move toward planning the best life possible for your child, you must move beyond labels and thinking inside the disability bubble so you can be the best advocate; they will need you. You are the expert on your family and your child. In this stage, advocacy starts with working with the health care professionals.



I consider myself an expert when it comes to my child’s health, not because I have all of the answers, but because no one cares for him more than I do. The doctors have many patients, but I only have one Izaac. I have been with him in the hospital and working with health care professionals from the beginning. I know which treatments were successful and which interventions haven’t worked as well.

Izaac uses a tracheostomy (trach) tube to breath. Having a trach is hard enough, but it is even harder when others ask about it. He needed to have a response, so I taught him to say, “It’s my trach, it helps me breathe.”

Our family has worked hard to educate him about his special health care needs while at the same time teaching him that he has the potential to do anything he dreams. Our work to instill these beliefs in him allows him to thrive. I believe if we were to start our journey at this point—we would have a lot of catching up to do and it would take years to overcome.

One of our primary roles as parents is teaching our children to be as independent as possible and stand up for themselves. Since I have taught him about his circumstances, Izaac has become more independent and changes his own trach and trach ties. One of his challenges is putting on shoes, socks, and shorts. We are working as a family to adapt to his capabilities. ●



**SHEREE PURSLEY | SOUTHEAST FAMILY PARTNER**  
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Sheree has two children. Her son was diagnosed with Achondroplasia, a form of dwarfism at birth. 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...

## CITIZENSHIP & ADVOCACY



### Early Childhood (3-5)

Do you present yourself as an expert regarding me, and are you helping me to learn to be the expert on myself and my needs? ★

Your children are watching you interact with others on their behalf and learning how to interact with people themselves. They will model your behaviors and your value base. In this stage, you will have to advocate for your child with early childhood professionals to ensure that the trajectory toward your vision for the future is supported.

Parenting during early childhood can be an exciting time of wonder and, yes, even some stress. If your child has been given a diagnosis you might feel anger, fear or frustration, or even grief. Things you have heard and understood about disabilities may cause you to feel concern for how others will view your child.

Arm yourself with knowledge about your child's diagnosis, but do not let that define your child. Allow them to be who they want and challenge them to participate in activities with other children their age. If modifications are needed, find ways to make them. Showing your child you believe anything is possible for their future will give them a great advantage and positive self-esteem.

Your child watches how you engage in conversation and activities with their peers, other parents, teachers, and professionals. How you treat and talk to your child will influence how others react to them and their challenges. Helping others see your child as a person and understanding his or her vision of the future will go far in building a successful life for your child. Every person should be treated equally. Giving respect, allowing their thoughts to be shared, and finding out their interests will help everyone who interacts with your child.

Look to the future even though your child may be very young. How do you want it to look? There is an amazing tool called the **Life Trajectory Worksheet** that will help you plan the direction of your child's life. You can find it at [LifeCourseTools.com](http://LifeCourseTools.com). You can also find other great information and resources to get you thinking about what you can do now to make the best future for your child. Print out a copy of the Life Trajectory sheet and do a little brainstorming. Think of it as building blocks—one on top of the other until the goal of a good life is achieved. We all want the same thing for our children: to be happy, independent, self-sufficient, and successful adults.



In closing, I have been truly honored and am grateful for being able to reach out to many families in Missouri with children with special health care needs. I have been blessed to be touched by your lives and the stories about your journeys with your children. I will be stepping away from Family Partnership as of October 1, 2015. I wish the new Southwest Family Partner the very best. ●



### BETH DOODY | SOUTHWEST FAMILY PARTNER

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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...

## CITIZENSHIP & ADVOCACY



School Age (6-13)

Do you present yourself as an expert regarding me, and are you helping me to learn to be the expert on myself and my needs? ★

You are the expert on your family and your child. In this stage, you will have to advocate for your child in the school system and the community to foster inclusion and citizenship to ensure that the trajectory toward your vision for the future is supported. In this stage, children should start taking over advocating for themselves.

IEP, FERPA, HIPPA, CCA, inclusion, self-contained, adaptive, 504. The list of terms that a parent must understand when their child with special health care needs enters school is mind boggling. You may just be entering this often scary, new world or you may be a seasoned veteran with years of experience. Whatever your situation, ensuring success for your child often means the difference between days filled with friendships and fun or days filled with loneliness and isolation.

The first step is developing a plan, or trajectory, for your child's education. Thinking about the steps that need to be taken now for your child to have a good life is important. There are many tools that you can use to start this journey at [LifeCourseTools.com](http://LifeCourseTools.com). After developing a plan, it is great to get your child's team on board. Take the tools to the next IEP meeting, share and explain them, and emphasize a team approach.

IEP meetings can be emotionally charged events, attitude is huge. Your own mindset greatly affects the tone. Take ownership of the meeting, planning it as you would any other. Work with the school on a good time of day to meet; show up with a smile and good attitude. Providing snacks can also help the tone. Be sure to have copies of your tools for everyone. It is easy to feel outnumbered and intimidated at your IEP meeting, but allowing these feelings gives your power away. Acknowledge that everyone is an "expert" in something and respect their expertise. Recognize your expertise as the one who knows your child best. Having this attitude gives you more confidence and helps you see the value in other's opinions. Encourage your child's participation and voice in creating a vision for the school year and future. Taking a support person can be helpful to share your goals and have someone "on your side." My support person helped me stay strong and built accountability.

Developing a good team for your child is more than a good meeting. Volunteering in the classroom, returning paperwork in a timely manner, and keeping open lines of communication



are just a few things that foster these important relationships. Encouraging e-mails and sending extra supplies are small steps that show your commitment to partnership.

Remember the social element of school. All too often we get caught up in worrying about the adults in our child's life and we forget that developing friendships can be hard. We need to look for ways to build friendships, such as providing access to inclusive opportunities. When we make sure that our child is included in social opportunities, he or she gets to know other children.

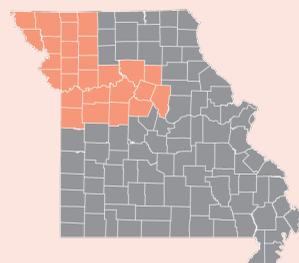
Remember to start early, start now. The steps you are taking impact your child's future. Navigating life can be tricky but proper planning helps your child have a successful, good life. ●



### CRYSTAL BELL | NORTHWEST 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 connect families to each other and resources in their local area.



## ASKING QUESTIONS ABOUT...

CITIZENSHIP & ADVOCACY 

## Transition (14-22)

Do you present yourself as an expert regarding me, and are you helping me to learn to be the expert on myself and my needs? ★

In this stage, families should be thinking about what lies ahead for adulthood and handing off the reins. Be prepared for many different transitions – school to work, adult medical care, relationships. Being a good self-advocate and self-determined starts early and continues throughout the lifecycle.



Each of us spends our teenage years dreaming about and preparing for life as an adult. As we grow up, our values, social connections, interests, passions, and life experiences all come together to shape our worldview and paint a picture of what our lives will be like when we finally make it on our own.

We all look forward to making our own choices and decisions; however, if your ability to make choices for yourself are limited the likelihood of being able to control your destiny is small. Even though we believe that all people have the right to live, love, work, play and pursue their life aspirations in the community, sometimes, there is still the idea that just because a person has a disability or special health care need, he or she will need a guardian. In reality, everyone can 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 health care 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. You can learn about all of the alternatives to guardianship as well as access tools for figuring out what is right for your family at [moguardianship.com](http://moguardianship.com).

We must allow our youth the ability to make choices and enjoy the dignity of risk, as well as the consequences of making choices and taking risks, that we all learn from as we grow into adulthood. School staff, medical professionals, and even legal counsel cannot tell you what is best for your family. Only your family can decide what is right for your unique situation. To find resources to help you learn more or connect with another family who’s been there, visit [mofamilytofamily.org](http://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.





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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](http://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/](http://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](http://mofamilypartnership.org)



#### 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](http://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](http://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](http://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).