The key to living a happy and successful adult life is learning how to develop relationships and interact with others in childhood. Getting to know peers in school (both in class and at extra-curricular activities), at community events, and in faith communities, creates a circle of people who begin to care about your children and will support and watch out for them.

Think back to your own life growing up.
- What activities, sports or clubs were you involved in at school?
- Did you have a favorite teacher or coach?
- Was your faith community a spiritual and a social haven?
- How did you take risks and push limits?
- What experiences helped shape who you are today?

Now, think about your child’s life experiences. Are you providing him or her with the same opportunities to develop his or her own identity? Explore likes and dislikes? Know and express wants and needs?

It is crucial to be creative and help your child get to know your community as well as the other way around. Have you considered purchasing a second-hand wheelchair to take to the playground so others can play like your Continued on Page 2
Family, Friends & Fun in the Community: Focusing on Social & Spiritual Life

Seek out the people who share the same interests as your child and purposely get to know them. It is important to develop relationships with intent and nurture them to ensure they become a two-way street. We all know how special our own children are to us, so it should not be a stretch to realize that others will enjoy their company and gifts as well.

Aside from the social and spiritual benefits, relationships also enhance a person’s safety in the community. There have been many stories of children with special health care needs or disabilities becoming lost and then recognized by someone in the community: a neighbor, a store clerk, school personnel or another family – someone who helped them get home safely. That assistance will not be available to your child if their community does not know them.

It is worth the extra effort it takes to involve your children in as many community activities as possible. To do this you have to give up some control. You have to be able to trust and rely on others to care for your loved one in your absence. Find ways to involve your children in activities that are of interest to them and encourage others involved in those activities to take the lead on including your child as they grow older together. No teenager or adult wants to hang around their parents 24 hours a day, seven days a week.

Continue exploring ways to enhance your child’s relationships and grow in their community throughout this issue of Partnering Together and online at mofamilytofamily.org.
Young children are constantly exploring their environments and developing their likes and dislikes. It is important for all families to foster and support this by exposing them to a variety of different places and experiences to help their children discover their interests. I started with activities and places that I enjoyed and went from there. I also found free family-friendly events in the community that we could participate in while Izaac was a baby. We have always taken Izaac to everything we do as a family in order to not “shelter” him from the world.

We have had to learn how to desensitize others about his differences. The first example of this is when we began taking Izaac to McAlister’s Family Night when he was still a baby. McAlister’s is a local restaurant that hosts a special evening every week dedicated just to families. When we first started going, he had a tracheostomy tube and a ventilator. We explained to the families who attended regularly about his special health care need and soon their perceptions of Izaac changed and he became just another one of the kids.

Since the children at Family Night have been growing up together, they don’t realize he is any different from them. If new children come and ask questions about him, his friends just reply, “That’s Izaac, isn’t he awesome?”

At the same time, we have taught Izaac how to respond to questions and reactions from other people about his differences. If anyone asks about his trach while we are out, we have taught him to say, “It helps me breathe” and move on. We have also worked hard to help him understand that people asking about him are not making fun of him, but they are just curious about why he looks different. A good offense makes the best defense for our family.

By taking Izaac out in the community when he was very young, we provided the best chance for successful inclusion as he grows older, which is an important key to his safety and self-determination.

SHEREE PURSLEY | SOUTHEAST FAMILY PARTNER
sheree@mofamilypartnership.org

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.”
Do you remember the friendships you had while growing up? You might remember giggling under a blanket at a sleepover or chasing each other through a yard with your “swords” drawn. You might remember that group of boys or girls you bonded with at weekend birthday parties or little league soccer. There aren’t many of us that go back to our childhood without at least a few of these fond memories.

Yet for children with special health care needs or disabilities, these early experiences may look quite different. Early years may be filled with doctor visits and surgeries. Cautious parents, with the best of intentions, may avoid places like daycares, playgrounds and even family or church functions altogether. As parents, we do what we think is best. We keep our children at home or only allow them in environments we feel are completely safe and supported. When we do this, we often don’t realize how much we are impacting our children and their ability to build lifelong, reciprocal relationships. We have to look further down the road to see how the life experiences and the environment we are setting up for our kids will impact their future.

Trying to envision any kind of future for your child may be difficult, but it must be done sooner rather than later. As parents we must be careful not to surround our children with so many supports and services that no other child even has a chance to form a friendship with them. Sometimes pulling back a little as parents and allowing our kids to just be kids can be more beneficial than completely enveloping them with services and supports.

These friendships with typical peers can often be a lifeline for your child later in their life. When they are in school and someone starts picking on them, who will stand up for them? If your child wants to go see a movie, will they be able to call up a friend and enjoy the movie as a “normal” teen would, or will they have to find out if his or her aide is available? The life experiences you expose your children to now matter.

Not sure where to start? Start small and start now. Keep your eyes and ears open for any opportunities to involve your children in community and school activities. Encourage them to get involved with activities or groups you took part in as a child. Places may not know how to be accepting at first. The first step is not asking if your child is welcome, but rather knowing that your child has a right to participate just like every other child. Offer the organization any additional support that may be needed but make it clear that your child wants to participate.

Fostering friendships can be a challenge, but when it is approached with a deliberate attitude and openness to try new things, the rewards can be lasting relationships and a great life.

CRystal bell | northwest family partner

crystal@mofamilypartnership.org

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.
Each of us have long lasting beliefs, standards for living, and
relationships we cherish, many of which may have started with
our involvement in a faith based community. As parents, are we
handing this legacy, this privilege and experience to our children?

When we parent a child with special health care needs, we can
get caught up in the day-to-day struggle of physical care. It is
easy to overlook the importance of their spiritual health. We
grapple with medical needs, work to make sure they get the
best education they can, and balance our family life. What we
usually think we don’t have time for is their spiritual lives.

Exploring faith can enhance every person’s life. It helps them in
their journey of self-discovery, builds their social connections,
and helps them form the social and moral standards by which
they choose to live.

Support your child to be a part of regular faith gatherings like
Sunday School, youth groups, prayer and study groups, worship
services and community service activities. They will grow in
strength and character and it will help them find acceptance
in their communities. Faith communities form connections
between people through their common beliefs. They care for
one another, share in their joys, and lift one another up in times
of sorrow. They work together for a common cause. Faith builds
personal relationships which can stand the test of time and trials
we all face.

Because we feel safe to discuss our needs and fears in our faith
communities we can often access resources we didn’t even know
were available. Connections, relationships, hope, inner strength
and peace are all benefits to having faith.

Let’s share our faith with each other and our children and find
our similarities today.

Faith communities are usually a central hub where people connect and meet. In addition, exploring beliefs and faith is a rite of
passage for all people as they grow up. Children and youth with special health care needs are no different.

Are you helping me explore spirituality and
find a welcoming faith community?★

Transition (14-22)

BETH DOODY | SOUTHWEST FAMILY PARTNER
beth@mofamilypartnership.org

Beth is the mom of three children, one of which lives in the home and has a
special health care need. She is knowledgable about Autism, Fetal Alcohol
Syndrome, Post Traumatic Stress and Sensory Disorders.
PAT FOX | NORTHEAST FAMILY PARTNER  
pat@mofamilypartnership.org

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.

Recently, I was reading an online discussion about the age it is appropriate to let a young girl wear makeup. Nearly everyone agreed that 13 was an acceptable age. This led into deeper discussion about when to let your children date, go to the mall alone, and many other common rites of passages. While everyone agreed on most milestones, some added cognitive skill as an additional factor.

People often question if we should let our children with special health care needs or disabilities do the same thing as others their age. Being overprotective of our children may come naturally, but we must give all of them space and the ability to explore the boundaries of life.

Parents must recognize and then build on the unique abilities and strengths of our teens in order for them to “fit in” with their peers. Are you guiding your child toward experiences that are age appropriate? Driving, school dances, shopping at the mall are all rites of passage for a teen. All of these activities are within your child’s reach. Sometimes all it takes is a little creativity and innovation.

For example, in order to make prom more memorable for a senior who used a wheelchair, her date and friends rented wheelchairs and others tried using them as well. The whole group danced while in the chairs. Everyone commented that it was the BEST prom ever.

With a little modification, our teens can experience the same things as their peers. It will help prepare them for adult life.
**HEALTH INSURANCE MARKETPLACE UPDATE**

Open Enrollment for 2015 coverage ended in February 2015. Open Enrollment for 2016 begins November 1, 2015 and continues until January 31, 2016, with the first date coverage can start for 2016 is January 1.

If you don’t enroll in a 2016 plan by January 31, 2016 and you do not have health insurance already provided by your employer, you can’t enroll in a health insurance plan for 2016 unless you qualify for a Special Enrollment Period. You can find out if you qualify at healthcare.gov.

There’s no limited enrollment period for Medicaid or the Children’s Health Insurance Program (CHIP). You can apply any time.

If you don’t have coverage in 2016, you may have to pay a fee. The fee is higher in 2016 than it was in 2015.

For the details on the Marketplace, like finding coverage that fits your needs and getting local help, connect with Cover Missouri. It has all the tools you need, including:

- 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, and
- Connections to in-person help in your area and a 24-hour hotline to answer your family’s questions about health coverage options.

Visit covermissouri.org today!

---

**FEATURED RESOURCES**

**What Are You Doing This Summer?**

Find out why typical summer experiences are important for children and youth with special health care needs and/or disabilities. Hear ways you can keep your children busy during the summer. Learn about resources available to help families plan for inclusive recreation and meaningful summer experiences. Watch the webinar at mofamilytofamily.org.

**Mofamilytofamily.org**

We updated our website with a new design and made all of our products available for you to view and download. You can also connect with us, sign up for our mailing list, and more. Check out our new website today at mofamilytofamily.org!

**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.

---

**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!

---

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!
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

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

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

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).