

# PARTNERING TOGETHER



## MY HOME SWEET HOME

In the *Wizard of Oz*, Dorothy said, "There is no place like home." This is true for all of us, even though we choose many different settings and have varying preferences about where we live. Some people like to live alone, others enjoy living with family members, friends, or roommates. Some people want to live in a house in a quiet neighborhood and others prefer staying in an apartment in the bustling city.

In the past and sometimes still today, many people with disabilities haven't been involved in the decisions regarding where they live. Living options are often based on the person's disability or diagnosis instead of who they are as a person and what matters to them. Many people often aren't aware of all the available living options. Without supportive people helping and encouraging them, it is difficult to

explore possibilities and develop a vision for a good life.

In childhood, families, schools, friends, community members, support coordinators and others can encourage the child to think about their future, including where and with whom they want to live. All children dream about what life will be like when they grow up, and children who have a disability or special health care need are no different! As youth prepare to leave school, they begin to focus even more on adult life. Adults often move several times until they finally find one spot to settle in, and some never do!

This newsletter will focus on questions to ask, things to do, and resources to access to develop a vision of where your loved one might like to live in the future. ●



Missouri Family to Family (MoF2F) continues to stay busy providing information, referral and peer support to individuals and families who experience special health care needs or developmental disabilities. The volunteer peer mentor network is easier to join than ever with online live webinar orientations. All you need to participate is the ability to watch the webinar on a computer and call into a conference line. Check out the training calendar at [mofamilytofamily.org](http://mofamilytofamily.org) for upcoming webinars, or email [mofamilytofamily@gmail.com](mailto:mofamilytofamily@gmail.com) to schedule an orientation at your convenience.

We have been working on a new project, [Lifecoursetools.com](http://Lifecoursetools.com). [Lifecoursetools.com](http://Lifecoursetools.com) is a new, one-stop resource for individuals and their families, the professionals who serve them, and organizations that support them. Our goal is to provide a place to share information and provide tools to help families get the facts, explore their options, create a vision for the future, and connect with resources they need to make their visions possible. We cannot do it without the help of families! Visit the site to learn how you can help as a reviewer, blogger, curator, camera crew or host/hostess of focus groups to gather feedback and keep the site fresh and new.

Missouri has the unique opportunity to participate in the a national project focused on supporting families, The Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities, which is now in its second year. The Supporting Families project involves working with six states to develop systems of support for families throughout the lifespan of their family member with intellectual and developmental disabilities. For more information about the project and how Missouri is involved visit [supportstofamilies.org](http://supportstofamilies.org).

The Strengthening Families, Navigating Life Family Enrichment conference was a great success. It was attended by parents and support providers who experienced a great weekend getaway of entertainment, speakers, workshops and networking opportunities. Stay in the loop for next year's event by registering for email updates at [mofamilypartnerhip.org](http://mofamilypartnerhip.org). Now that the annual conference is over, the Family Partnership program is focusing on hosting regional events this summer and would like your input/ideas about what you want to do. Contact your Family Partner to provide feedback and sign up for email updates. ●

## CONTRIBUTORS

**Partnering Together**  
is a publication of  
Missouri Family to Family

**Director**  
Michelle "Sheli" Reynolds, PhD

**Family Partners**  
Michelle Dover, NW Family Partner  
Beth Doody, SW Family Partner  
Crystal Bell, SE Family Partner  
Pat Fox, NE Family Partner

**Creative & content support provided by**  
Rachel K. Hiles, B.A.  
Susan Bird, M.S.



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

# Asking questions about...

# Community Living



## Early Childhood (3-5)

Am I able to get out and about to explore and learn about my community? ★

Learning how to be respectful, participating citizens in our communities starts early. Getting out in the community and exploring all the diverse kinds of people and places that exist will help your child learn about all the rich experiences the community has to offer as they build their world view.

At the center of every life is the concept of home. Structurally, they come in all different sizes, colors and floor plans. Some have dining rooms than can host a feast. Others have decks perfect for a lazy summer afternoon spent reading and day dreaming. The physical options are many, guided by our individual tastes, preferences, resources and imagination. We can and do spend a great deal of time planning and designing the three dimensional structures that hold our belongings. Entire industries are built and exist around the construction of the house itself. However, beyond the beams and paint, our homes are personal sanctuaries. They represent the center of our lives, the base where we share meals, love, pray, laugh, plan and dream about all the concepts that we believe define a good life.

Where we choose to live, the community that we choose to call home, depends on how we see our lives unfolding. It is an incredibly personal choice that should be available to all. Do I like the hustle and bustle of an urban lifestyle? Do I need to be able to attend the theatre every Friday night to feel whole and complete? Or do I prefer the peace and comfort of a quiet rural setting on an acre of land? Do I love the beach? Do I need the sound of the waves to feed my soul? Quite simply, choosing where we live defines how we live and the opportunity to make that choice belongs to each one of us.

More important than the structure and the setting, is the concept of community. What we need and the ease of access to those needs is an essential component in deciding where we make our homes. Our needs are as individual as we are, however, one thing we all need to survive as human beings is a connection with other people. The option of being able to live in a community that provides the freedom to discover all the possibilities for living a good life is embodied in the concept of home. Access to public transportation, modifications to common areas, organizations that provide direction and



support are all necessary to ensure that we all are able to participate in our communities regardless of physical or developmental disabilities.

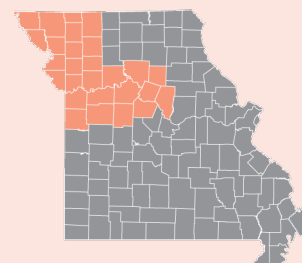
Our homes are more than a container where our bodies physically come to rest at night. They are the base from which we launch ourselves into the world to see, taste, touch and experience all it has to offer. Each of us has a floor plan for our lives. That plan, that dream is the real definition of a home. ●



### MICHELLE DOVER | NORTHWEST FAMILY PARTNER

michelle@mofamilypartnership.org

Michelle is the mother of two boys. Her younger son was diagnosed before birth with a rare neurological disorder. Michelle says that parenting her children is her primary job; but she also practices law part time in Kansas City with an emphasis on estate planning for clients with special needs.



# Asking questions about...

# Community Living



School Age (6-13)

Am I starting to learn to do things to maintain and upkeep a household? ★

Responsibilities, such as chores, help a person understand the satisfaction of having a valued role and the expectation to maintain a household just like everyone else. We all benefit when given the chance to learn and make good choices for our futures.



Have you started teaching your child to help with upkeep in your home? If not, the earlier you start, the more self-determined they will become. Understanding your child's abilities and challenges are important as they learn to maintain their home. Maybe a few accommodations will be needed, but don't allow their disability to become an excuse for being left out of family responsibilities.

For our child, being self-determined doesn't come naturally. She needs prompts and simple instructions to keep her on track. Especially if the process is something she doesn't particularly enjoy or takes more than a few minutes to complete. After asking our child what she liked about her home, I was able to help her connect the dots as to why management of our home is so important. Her answer about her home was basic: she likes hanging out, doing things she enjoys, being warm, comfortable and safe. I was able to give examples of why our home is comfortable, because it is clean and orderly. Since one of

her strengths is organizing, I allow her to help me put things away in an orderly fashion. She likes that she can find things when she wants them and can take pride in doing a big job. I take time to praise her for being so grown up and helping me out. Each job she accomplishes helps her realize she is becoming more independent.

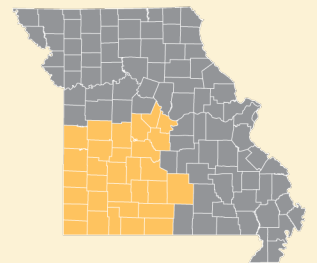
Dusting, running the vacuum, matching socks, folding laundry, feeding a pet and putting toys or clothing away are just a few examples. Many simple tasks can be done by almost everyone. Helping with dishes, wiping down the dinner table or setting it before a meal, each task gives your child a chance to feel useful and independent.

Will our children be capable of taking care of their homes completely on their own as adults? Maybe not, but let them do all they are capable of and feel self-reliance. This will help them learn they are an important part of their families and communities. ●



**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 knowledgeable about Autism, Fetal Alcohol Syndrome, Post Traumatic Stress and Sensory Disorders.



# Asking questions about...

# Community Living



Transition (14-22)

Have you talked with me about where I might want to live in the future (after school ends/when I am an adult)? ★

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.

When my oldest son, Peyton was born and I received the diagnoses of Down Syndrome and congenital heart defects, so many things went through my head, "What medical issues will I have to deal with?" and "What schools will he go to?" All the questions that run through a parent's mind when they find out they have a child with a disability. Unfortunately, a lot of the materials I uncovered on the internet painted a bleak future for children diagnosed with Down Syndrome. I began to focus on what I needed to make sure happened for Peyton in his life. I thought about what my idea of a good home for him was and what my idea of a productive lifestyle is.

However, as time goes on and I begin to look toward the future, the types of questions running through my head begin to shift to things like wondering what Peyton wants as his life progresses. I think, as parents, we often learn from the beginning to take control of the environment that our children are in, trying to shape it the best way we know how to fit our idea of what a fulfilling life is for them without ever really considering asking them what they feel is right for them.

In the beginning of planning a future for my son, I am ashamed to say I put limits on him, often telling family members that we planned on building a little house for him at the edge of our property. As Peyton gets older and asserts his independence more and more every day, I chuckle at how small I thought for him, how my inability to see the possibilities for his future could have held him back from ever being able to have a dream and a vision of his own.

Maybe some of it was the area that I am from, maybe some of it from my own upbringing. Whatever the reason, I am so very thankful that my thinking has changed early enough in my child's life that I am able to look towards transition and know that I can explore many different



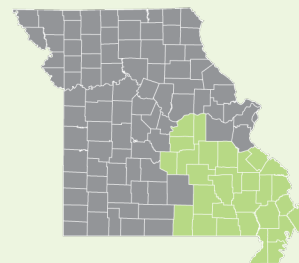
options to offer my son. He will be the one to choose to live in his own home with family or friends, in a group home, or even on his own.

I now approach life with a new resolve, however, to start now to help make all the choices a possibility for him through advanced planning, research, education and training. I am thankful that his future is bright. ●



**CRYSTAL BELL | SOUTHEAST 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 connecting families to each other and resources in their local area.



# Asking questions about...

# Community Living



## Adulthood (23+)

Have you helped me figure out what kind of supports I will need to either continue living at home or move into my own place after I graduate? ★

In the past, the service system provided everything for people with disabilities, including where they lived. People didn't have to think about transportation, grocery shopping, and taking care of their basic needs. Now, supporting individuals with disabilities in the community means providing services and supports to people in the home of their choice how they want to receive them. Understanding the options for supports is the key to a living arrangement work!

It is important to start planning early for life after high school. The time you spend together helping your child create or build a vision for the future is crucial for their success as an adult.

Since becoming a self-determined adult starts early and continues to build as we mature, it is essential for parents to set their children on the path toward independence while they are young.

Does your child have access to social clubs and friends that make sense for her?  
Is he able to get around the community with public or private transportation?  
Is she responsible for household chores?  
What are you doing to prepare your child to meet his goals?

As adults living in the community, we have to think about where we will live, how we will get around, and how to access community resources. Some questions to consider as you are thinking about community living for the future:

Does your child have a clear vision of what he wants to do after graduating from high school?  
Are you developing the supports necessary to help your child live in their chosen environment?  
Do you need to make any adaptations to your home to accommodate your child in a more independent space for him? Or is there an opportunity for her to live in a nearby apartment with a roommate or on a college campus?  
Is remote monitoring an option to help your child be both independent and safe?  
If staffing is necessary, does your child have a voice in who works for him?

These are just a few of the important life lessons that you need to help your child prepare for life after graduation. Think about what you do day to day to keep your household going and ensure that your child will be able to do them in their chosen living environment as an adult. ●



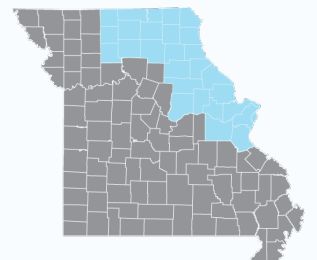
Need help navigating the next step? Your Family Partner is here to help! Check out our website at [mofamilypartnership.org](http://mofamilypartnership.org) or call your local parent partner today.



## PAT FOX | NORTHEAST FAMILY PARTNER

[pat@mofamilypartnership.org](mailto: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.





## Health Insurance Marketplace Update

As of May 1, 152,335 Missourians are now enrolled for plans in the Health Insurance Marketplace.

This number surpassed federal predictions by 29% and ranks Missouri fourteenth in total number of enrollees. It is great news that so many people in Missouri now have quality health insurance.

Open enrollment for 2014 coverage is over. But you may still have options to get health coverage. Go to [healthcare.gov](http://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.

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](http://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. ●



From [Healthcare.gov](http://Healthcare.gov) and Cover Missouri [covermissouri.org](http://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](http://mofamilytofamily.org) today to sign up!

## FEATURED RESOURCES

### Focusing on Housing: An Array of Options

This free, archived webinar is available to help you

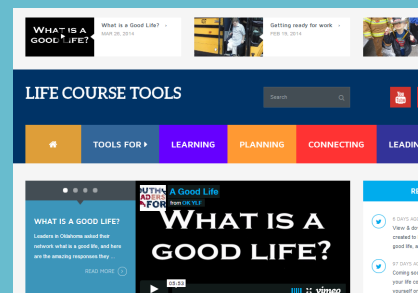
- hear about the many options for living in the community
- learn about supports people can access at home to be independent and
- find tools that will help you decide the living option that fits your family's situation



View or download the webinar at [mofamilytofamily.org](http://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](http://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](http://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!



MISSOURI FAMILY TO FAMILY •

# PARTNERING TOGETHER

VOL. 3, ISSUE 3 • 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)

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



#### 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 (#D70MC09834).