

PARTNERING TOGETHER



Cover photo: Erika smiles as she sits in a model of the DeLorean, a car featured in the 1980s film *Back to the Future*.

Pictured above: A red van, with doors open, showing how it has been adapted to include a wheelchair lift.

GETTING AROUND IN THE COMMUNITY

The way we travel from place to place has been completely transformed over recent years. Even just 100 years ago, families were traveling from place to place by horse drawn carriages.

Today, we are constantly hearing about innovations and new ideas for transportation and travel. With advances in science, technology, engineering, and mathematics, people are going places they never dreamed of in ways they could never imagine.

Despite all of these advances, many people with disabilities still encounter

barriers to getting around and often have limited access to opportunities to get around in their communities, as well as enjoy the freedom to travel and explore for recreation and leisure. Barriers include limited options for transportation, lack of safe and accessible rights-of-way, and policies that are not inclusive of people with disabilities. These barriers often result in social isolation, poor health, unemployment, and even homelessness.

With the help of technology, great strides are being made in the way people with disabilities access their communities and ***Continued on Page 2***





Pictured: A young man tries out a driving simulator at a summer transportation camp.

CONTINUED: GETTING AROUND IN THE COMMUNITY

the world. People with physical disabilities are driving with assistance of adapted vehicles. Individuals are building their own transportation support systems using their family members, friends and other types of supports. Through Uber and ridesharing apps, a ride is available in minutes with a touch of a button. Communities are working to enhance transportation options for all of their citizens. Formal transportation programs and systems are reviewing and changing their policies to be more inclusive and accessible to everyone.

This issue of *Partnering Together* includes real stories from individuals from across the state who used technology to overcome barriers to getting around and to explore the world around them. In addition, our Real Life Experts share their perspectives across the LifeCourse on accessing a wide variety of supports to help them get around. Review this issue for ideas to help you get around and explore your community with the help of integrated supports and check our website for even more resources at mofamilytofamily.org.



Access information and tools to help you explore
Community Living and more at
mofamilytofamily.org

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CHARTING THE LIFECOURSE

This and future issues will include articles and resources to help you think through topics from *Charting the Life Course: Experiences & Questions*.



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



REAL LIFE **TRANSPORTATION** STORIES



ALEX

Alex is a sixteen year old who lives in a suburban community outside of St. Louis.

Alex was having trouble reading street signs and bus routes due to low vision. He discovered that use of an iPad would allow him to instantly enlarge maps, web pages, maps and text information with a pinch of a finger. After getting an iPad for a trial period through Missouri Assistive Technology's device loan/borrowing program, his teacher put in a request through the Assistive Technology Request (ATR) program to get an iPad that Alex could use long term.

Now, Alex is able to get out and go independently, because he is able to see the information as well as navigate via GPS.



RAVEN

Raven is a teenager who lives with her family in Missouri.

Complications from two years of Leukemia treatments resulted in her experiencing the deterioration and collapse of her shoulder, hip, knee and ankle joints, leaving her unable to walk. She was using an office chair with rollers to move around her house, until her mother came in contact with Missouri Assistive Technology's Missouri's Recycle and Re-Use Program. Through this program, she was able to obtain a light-weight wheelchair, bathroom safety equipment and an electric scooter.

Now, Raven is looking forward to the freedom and mobility these needed items provide her. "Without the equipment...I would be stuck in bed every day. Now I can be the teenager I was meant to be."



RYLEY

Ryley is a young girl who lives with her family in a community in Randolph County in Northeast Missouri. Ryley uses a wheelchair for mobility.

As she grew, it was becoming more and more difficult for her parents to lift her and her wheelchair while coming in and leaving the house. The construction of the entryway in their home made a wheelchair ramp impractical.

Ryley's support coordinator connected her family with Missouri Assistive Technology and helped them apply for a Kids Assistive Technology program (KAT) grant to help them fund the installation of a vertical platform lift.

Now Ryley's parents can help her in and out of her home safely and easily.

The success stories above were shared with us by Missouri Assistive Technology, Missouri's Statewide Assistive Technology Program and connects individuals with disabilities of all ages to needed technology to help them with all areas of life- education, employment, daily activities, staying safe, socializing, and more.

[Visit them online at at.mo.gov](http://at.mo.gov)



REAL LIFE EXPERTS ON...

COMMUNITY LIVING



Prenatal & Infancy

Early years, wondering if meeting developmental milestones

Do I need assistive technology for myself or our vehicle so I can get out in the community and places I need to go?



Pictured: Dale (left), and Elizabeth (right), fish together. Elizabeth is using her stander.

**Dale,**

Kansas City, MO

Dale lives with his wife in Kansas City and is the father of three children. He is a Partners in Policymaking Graduate.

Our daughter was diagnosed with a spinal cord tumor at six months. It wasn't long before we had to start exploring different transportation options for her. When she grew out of her first car seat, we invested in a convertible car seat that should have lasted many years. At first, the car seat was great. It had side impact protection and it kept her in a supported upright position so she wouldn't tip over. Eventually, we went to an armless booster seat, not because she outgrew her car seat but because we could no longer lift her over the armrests. Our current vehicle has a captain's chair with armrests to help her keep her balance.

We have always found ways to help Elizabeth be more independent in every environment. At 15 months she used a mobile stander (standing frame wheelchair) which fit in the trunk of our sedan. Her first wheelchair also fit in the trunk, without the wheels. Following a trip my wife and Elizabeth took, with the stander in the trunk, the luggage in the back seat next to Elizabeth, and the wheelchair in the front passenger seat, we realized that we needed a different vehicle. We tested out a minivan for a week on vacation and that sealed the deal— we could fit the chair, the stander, and other equipment in the van, and lifting and transferring became much easier when we no longer had to stoop to get her in the car.

Our family is very active and enjoys getting out in nature. For bicycling, we started out with a trailer we found on Craigslist to an Elite ride-behind seat that lasted two years. Now, Elizabeth has outgrown these and we are now looking into a hand cycle for her. She had an adaptive trike that was given to her by an acquaintance who grew out of it. We passed it on to another family when she grew beyond its therapeutic capabilities. For hiking, we used an internal frame carrier rated to 50 pounds, another Craigslist find. We also invested in a Freewheel for her wheelchair—a wheel on an axle that clamps to her foot rest, lifting the front casters off the ground and making her chair more like a jogging stroller. It is great for grass, gravel, and snow. Elizabeth also uses a powered, homemade all-terrain cart (Craigslist again) for independence in most outdoor environments.

As she gets older, we continue adapting to Elizabeth's transportation needs. We have learned a lot through our experiences in our local community and our travels that have helped us learn the best strategies for supporting her. One thing we have learned is that most people are willing to help us gain access when it is difficult by moving obstacles or helping lift her in her chair. It is important we all work together to give our children as much independence through mobility as possible and make the investment in new, second-hand, or donated equipment as available. ●

REAL LIFE EXPERTS ON...

COMMUNITY LIVING



Early Childhood Preschool age, getting a diagnosis

My daughter, Adrianna, is six years old and has Spina Bifida. In her unique situation, she has mobility both in and out of her wheelchair. Despite this, getting around has always been a challenge and I constantly have a backup plan.

Day-to-day life for us is a series of questions. When and where are always on my mind. How far will she have to walk? Should she use her wheelchair? Where will we do her bathroom business? Adrianna uses an intermittent catheter and needs help to go to the bathroom, so we need to have solid plans in place before we go anywhere. Thankfully, there are resources available to find a suitable bathroom, but sometimes we are squeezed in a small stall with little light trying to make it work.

Recently, we attended an event in our community. Even though it was advertised to be "accessible," getting around felt like a nightmare. I wasn't prepared for all of the grass and gravel. The accessible bathrooms (Porta Potties) were located in the middle of a grassy, hilly field surrounded by swampy land. We did the best we could, but both Adrianna and I were exhausted at the end of the event.

One very important lesson I have learned is to go with the flow. It's hard for us as parents to anticipate every possible scenario. It can get very stressful, and, at times, I feel it would be much easier to stay home. Then reality sets in. I want Adrianna to live a full life. This includes going to places in the community, like the grocery store, zoo, and park.

School can also be very challenging, especially during events and field trips. This has been a very frustrating kindergarten year. The annual kindergarten field trip was to a local petting zoo, which was not accessible and had no accessible bathrooms, even though I requested they consider other options and even provided suggestions of alternative activities. I have worked hard to advocate for Adrianna and teach the district to consider ALL students ALL of the time. In my eyes they don't have a choice, because my daughter did not choose to have Spina Bifida. In addition, she is not the only student who uses a wheelchair in her grade. I feel things definitely need to change, and I will do what I can to make that happen. I want Adrianna to have the same opportunities as everyone else, and I think most parents would agree.

I don't think I will ever get over strangers staring and approaching me, asking "What happened to her?" or "What is wrong with her?" Or, someone yelling from across the store, "That's the cutest little girl in a wheelchair I have ever seen!" I think to myself, "Yeah. She IS cute, but not because of the

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



Pictured: Adrianna checks out the scenery at the zoo.

wheelchair." One never knows what to say in these situations. I just wonder what goes through Adrianna's head, because I wouldn't want to tell her what's going through mine. She doesn't seem to be bothered by it, at least at this point.

All I can do is try my best to help her have a happy life and try to make everything a possibility and not an inconvenience. ●



Kimmy,
Herculaneum, MO.
Kimmy is mom to Adrianna and a Missouri Family to Family Volunteer.



REAL LIFE EXPERTS ON...

COMMUNITY LIVING



School Age

How am I getting back and forth from school and to school-related activities (field trips, extra curricular activities)?



Pictured: Abby rides in wheelchair-accessible van that was donated to her family.



Terri,
Kansas City, MO
*Terri is the mom of two children,
an advocate for children with Rhett
syndrome, and a MOF2F Volunteer.*

My daughter is semi-mobile. Walking came late and has come and gone over the years. My daughter was four years old in Early Childhood when transportation first became an issue. We always carried her on and off the bus, as she was an itty bitty girl, and although she could walk, she did not have the strength or ability to climb up and down the steps or in and out of the seat on her own.

At four, she got her G-Tube. It took one comment from me, asking them to be careful when lifting her around the waist, and suddenly, she was required to be transported on the bus in a wheelchair. While I understood it is hard to always help her walk and keep her upright, I knew from the beginning that the school district putting her in that wheelchair would become her norm. This was soon proven to be true, as every time I went to the school, she was in her wheelchair, being pushed from class to class instead of being assisted with a hand or gait belt.

As we both got older, transporting Abby became more difficult. As she grew, my back would give out on something as little as a sneeze. We realized we needed a van to have more room lifting her in and out, as she never did gain that ability.

Riding with friends was almost never an option as Abby needed a 5-point harness adaptive car seat, which can take up most of the back seat of any vehicle. Lifting her and asking them to carry a adaptive stroller or wheelchair was out of the question.

When Abby was nine, I all but broke my neck while lifting Abby and fell down a flight of stairs. After major surgery was necessary for me, I could no longer lift her on my own in any way. We knew our only options for transportation were to utilize Special Needs, Medicaid or Share-a-Fare services, or get a wheelchair lift van.

The energy and funds that went into getting a lift van were an emotional and financial strain on our family. The vans are expensive to purchase. Once we did get a van after a year of phone calls, fundraising, contest entering and advocating, we were shocked to go from 30 miles per gallon to 10 mpg. Purchasing our lift van for Abby was the best decision we ever made for our family regarding transportation. Abby absolutely loves it and the relief I have gotten for my back and neck is priceless.

While I know there are many transportation services we could have used, often one must arrive super early or wait hours after an appointment. Like most families, we are constantly on the go and this didn't make sense for us. Our own accessible transportation was the best choice for our family. ●

REAL LIFE EXPERTS ON...

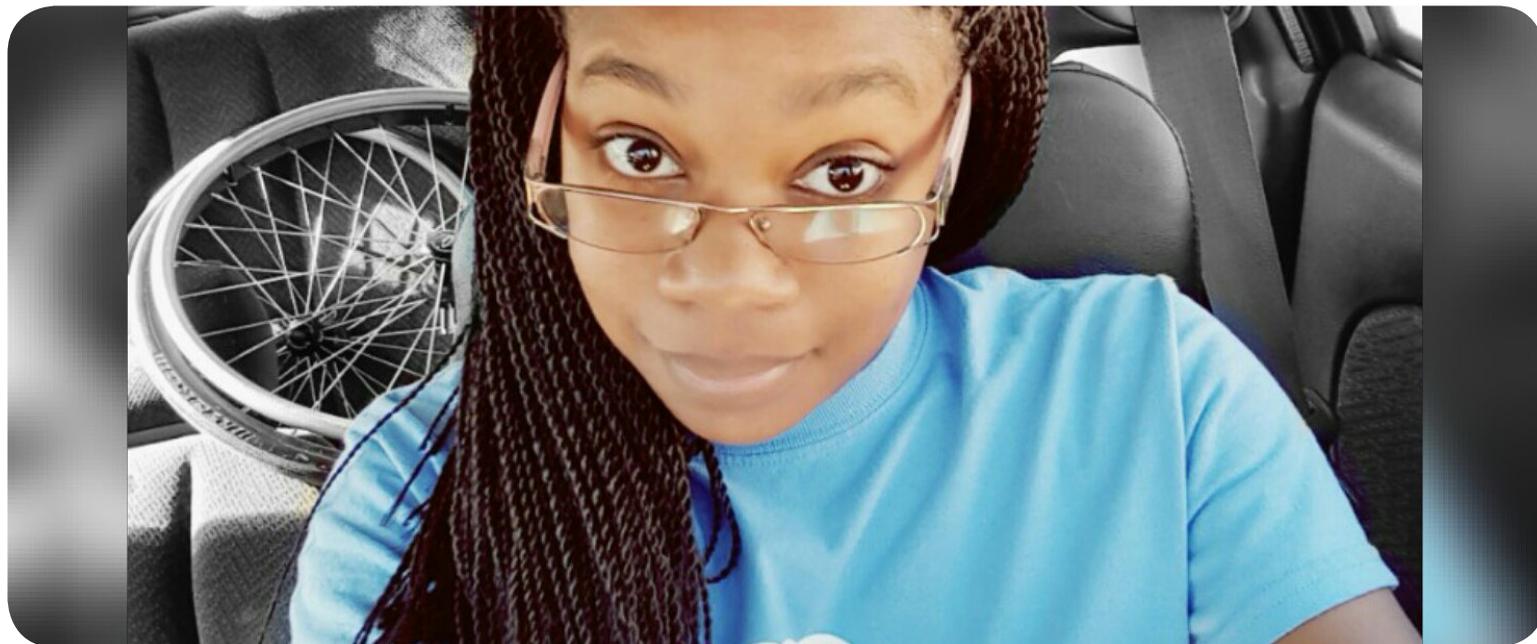
COMMUNITY LIVING



Transition

Transitions from school to adult life..

Am I learning how to get around in my community (learning to drive, ride the bus, take a cab, etc.)? ★



Pictured: Shunta is driving in her car, with her wheelchair in the back seat behind her.

I have used a wheelchair all my life and had many different experiences with transportation. In middle school, I used van services to get to and from school. I was old enough to stay home alone so the driver would push me to my house and lock me in, then go out the front door. I was the only student who used the van.

In high school, I rode a full-size school bus with wheelchair lift. I was the only one on the bus and was not part of the regular route. It got lonely with no one to talk to, but it wasn't too long of a ride. I had to leave school before the other kids. I got to pick friends to ride with me, but I missed all of the after school chatting at the lockers and in the hallways. As a kid you want that interaction. You already feel segregated enough not being able to run around like everyone else.

“ It was hard to see everyone else driving. I didn't know I could learn to drive, because I was the only person at my school with a disability. After high school, I wasn't sure how I would get around. So many of my friends we're driving, but how could I? ”

When my friends could drive, they gave me rides to things like ball games. My mom took me to my choir and orchestra concerts. It was hard to see everyone else driving. I didn't know I could learn to drive, because I was the only one at my school with a disability. After high school, I wasn't sure how I would get around. So many of my friends were driving, but how could I?

Public transportation would be difficult because of where I lived, so I connected with vocational rehabilitation and they set me up with driving lessons. Twice a week an instructor taught me how to use hand controls. I now drive myself and have the opportunity to live independently thanks to the support of vocational rehabilitation and others.

Growing up is never easy. No one has the same experiences or support systems. Some have it tougher than others, but it's truly in the way you look at life. Transportation is just another transition that must take place in order to grow as adults. No one said the transition would be easy, but the outcome is a beautiful thing. ●



Shunta,
Kansas City, MO
Shunta is a Missouri Family to Family peer mentor who lives in Kansas City, MO.



REAL LIFE EXPERTS ON...

COMMUNITY LIVING



Adulthood
Living life as an adult

How do I get around to places I need or want to go?



Public transportation in Kansas City has been extremely limiting to me as a blind person for the past 11 years. It has created barriers such that I am now moving to a city that offers many more options for transportation. It has been difficult to safely and reliably access a workplace to be a productive member of the workforce. Getting to and from a wide variety of other essential places, like grocery stores, banks, shopping centers, doctor offices, and veterinary clinics has also been challenging. Share-a-Fare, the paratransit system, has been my main mode of transit. Without this service, there would be no feasible way of getting around the city, especially when having to travel long distances.

There is little to no bus access where I live. Often my fallback transportation is Uber. Uber is an independent transportation service that allows one to set up and schedule rides through a smart phone application, which has proven to be invaluable to me. Uber rides are more timely and affordable than taking regular city cabs. Fare estimates are given so that one can know what he or she can expect to pay. All payments are made through the app, making it much easier to travel without having to worry about any type of money exchange and safer for all riders. Uber has become so popular that a lot of business people are also relying on it. For me, Uber has been a true lifesaver in times of great need, where I haven't had any other supportive services to use as a back-up.

Besides the iPhone, which allows me to schedule transportation through the Uber app, I also use free GPS navigational apps,

Pictured: Erika waits to board a Kansas City Metro Max bus.

such as Blind Square or Google Maps. Never before have I had any of this type of technology at my fingertips. Over time, Apple products have become more sophisticated. A blind person can acquire so much more information about his or her surroundings through a feature known as "Voiceover," allowing one to be much more confident while travelling.

For the past 20 years I have been fortunate to have a guide dog as my mobility aid, leading me in and out of places where I need to go once I've reached my destination. My guide dog, Chandra, a black Labrador retriever, has travelled many miles with me throughout the time we have been together. She is my third guide, and takes quickly to learning new routes, due to her impeccable training received at Guide Dogs for the Blind. The guide dog school houses two top-notch training facilities for breeding and training guide dogs and matching them up with a blind person to forge lifelong partnerships. With the use of my guide dog, various smart phone apps, and public and private transportation systems I have learned to navigate most any environment. ●



Erika,
St. Louis, MO
Erika recently moved to St. Louis with her boyfriend and is an advocate for people with disabilities.

REAL LIFE EXPERTS ON...

COMMUNITY LIVING



Aging

Getting older and preparing for end of life

Is it safe for me (and others) to drive?



Pictured: Jack poses, in the middle, with his sons.

Driving has always been very important to me. After retiring from owning my own photography processing business, I drove for Meals on Wheels. I also drove people to doctor and dental appointments for a hospice service. In August of 2014, at 85 years old, I had my left knee replaced. Three days later, I went to rehab and had a heart attack. During that timeframe my children and loved ones decided I should sell my car and put the money aside for taxi service, essentially turning in my keys. That led to a pretty big argument. I felt locked in, having driven since I was 16. I have had freedom with my car, but this situation left me feeling a little challenged.

“ I felt locked in, having driven since I was 16. I have had freedom with my car, but this situation left me feeling a little challenged. ”

My daughter-in-law had connections to the Rehab Institute of Kansas City (RIKC) driving program. We agreed I would take the course and see if I could pass the exam. I worked with RIKC for about 6 months. In the end, my instructor couldn't find a reason to take away my right to drive. I got the green light to drive in my neighborhood and to places like church, the grocery store and my relatives' homes. If I wanted to drive on the interstate, I needed doctor's approval.

The RIKC program is very comprehensive. My instructor assessed my peripheral vision and went over doctor reports for my hearing. She had me tell her everything that was on my mind while I was driving— a man walking his dog on the left, a school sign on the right, approaching a stop sign, making sure to stop before the white line and recognizing the correct stopping distance between cars— to name a few. The program made me much more aware while driving.

If you or an aging loved one are faced with the decision to have to turn in your keys I recommend taking a driving course like I did. It helped me to be more aware and attentive of my own driving and of other's driving habits. I even correct my family members' driving sometimes, much to their chagrin! ●



Jack Denzer,
Overland Park, KS
Jack is a retired professional photographer of over 60 years and a self-proclaimed musicophile.

To connect with the Rehab Institute of Kansas City's driving program, visit rehabkc.org



FREE NEW PROGRAM CONNECTS PEOPLE WITH TRANSPORTATION OPTIONS IN THEIR OWN COMMUNITY

MO Rides referral service works with local transportation providers to coordinate affordable rides for people with transportation challenges. MO RIDES referral service connects riders to transportation providers whether they are in a rural area or “in town.”

MO RIDES referral service coordinates efforts with transportation providers to find affordable transportation for people who need a ride to work, medical appointments, shopping, church, to visit family, friends and more. MO RIDES staff provide an individualized referral based on the conversation they have with each caller and where they need to go. The MO RIDES service is free, but the rider must pay the transportation company they choose for their ride. Riders may also visit morides.org to search for transportation companies in the Missouri counties where they need a ride.

MO RIDES began as a pilot project of the Boonslick Regional Planning Commission (RPC) that originally served the five counties in their area. Now it is a statewide service. MO RIDES is funded mostly by the Boonslick Regional Planning Commission, the Missouri Department of Transportation, and the Missouri Developmental Disabilities Council. Recognizing that transportation is a major barrier for people with disabilities in Missouri, the Missouri Developmental Disabilities Council has been investing in projects to promote Human Service Transportation Coordination. In addition to partnering with the Boonslick RPC, they are also partnering with the Mid-Missouri and Meramec RPCs in hopes that the RPCs will develop workable coordination strategies with sufficient details so that they could be used by other communities.

To get connected to a ride or learn about transportation providers available in Missouri, call MO RIDE’s toll-free number at (844) 836-RIDE (7433) or visit morides.org.

THIS ISSUE FOCUSED ON:



COMMUNITY LIVING

Where and how someone lives— housing and living options, community access, transportation, home adaptations and modifications.

Visit mofamilytofamily.org
to explore resources related to
Community Living.

NEXT ISSUE WILL FEATURE:



SAFETY & SECURITY

Staying safe and secure—
emergencies, guardianship options,
legal issues.

Visit mofamilytofamily.org
to explore resources related to
Safety & Security.



HEALTHCARE UPDATE

Do you need health coverage? Open Enrollment for 2017 runs from November 1, 2016, to January 31, 2017.

You may qualify for a Special Enrollment Period to enroll in Marketplace coverage. A Special Enrollment Period is a limited window of time outside of the normal open enrollment period when you can apply for a Marketplace plan.

If you have any of these life changing events, you could qualify:

- Get married or divorced.
- Have a baby.
- Adopt a child or put a child up for adoption/foster care.
- Move from a different state or from a different county within Missouri.
- Become a U.S. citizen.
- Gain status as a member of an American Indian tribe.
- Leave jail or prison.
- Lose your health plan for any of these reasons:
- Lose coverage through your job (does not usually include if you chose to end it).
- You get divorced.
- Your individual plan ends in 2015.
- Your COBRA expired.
- You turn 26 and can no longer be on your parent's plan.
- You lose Medicaid or CHIP coverage.

You generally have 60 days from the life changing event to apply and enroll in a Marketplace plan.

To access more health coverage materials and get connected with in-person assistance to navigate the healthcare exchange, visit Cover Missouri's website at covermissouri.org

From covermissouri.org

- Sign up for the MOF2F mailing list to get the latest updates about new resources, upcoming events, partner announcements, and other information related to supporting families with developmental disabilities and special health care needs in Missouri.
- Visit mofamilytofamily.org today to sign up!



FEATURED RESOURCES

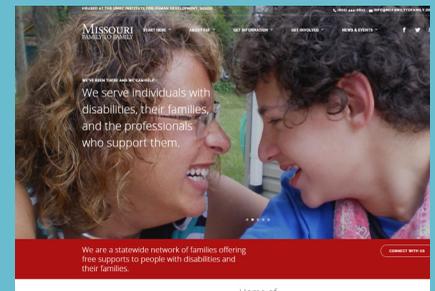
LifeCourseTools.com

Log on to LifeCourseTools.com for free tools and materials to help you plan your vision for a good life, explore the possibilities for your current life stage or focus area, and figure out what steps you need to make your vision possible!



Mofamilytofamily.org

Connect with Missouri Family to Family online and access our products and information by age or topic. You can connect with us, sign up for our mailing list, and more. Check out our website today at mofamilytofamily.org!



Charting the Life Course: Experience & Question Booklet

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 at (800) 444-0821 to get the information you need!



PARTNERING TOGETHER

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“ Staying informed, connecting with others and strengthening your skills can assist you in your life journey... ”

KEY RESOURCES

MO Family to Family
Connects families and individuals to information and support as well as opportunities to lead and make a difference.
mofamilytofamily.org | 800-444-0821



First Steps
Offers coordinated services and assistances to young children (0-3) with special needs and their families.
dese.mo.gov/se/fs/ | 866-583-2392



Dept of Elementary & Secondary Education (DESE)
Oversees special education, vocational rehabilitation, independent living programs.
dese.mo.gov | 573-751-4212



MO Parents Act (MPACT)
Provides parent training, information, and peer support to help parents advocate for their child's educational services.
ptimpact.org | 800-743-7634



Centers for Independent Living (CILs)
22 CILs provide information, advocacy, and access to supports and services to people with disabilities in Missouri.
mosilc.org | 888-667-2117



MO Assistive Technology
Works to increase access to assistive technology for people with disabilities of all ages to help them live more independently.
at.mo.gov | 816-655-6700



MO Association of County DD Services
Network of local Senate Bill 40 Boards in Missouri that connect families of individuals with developmental disabilities to community supports and needed services.
macdds.org | 573-442-5599



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.
health.mo.gov/living/families/ | 800-451-0669



DMH Division of Developmental Disabilities
Serves people with developmental disabilities such as intellectual disabilities, cerebral palsy, head injuries, autism, epilepsy, and certain learning disabilities. Services coordinated through 11 regional offices.
dmh.mo.gov | 1-800-364-9687



UMKC IHD, UCEDD
Provides pre-service preparation and community services and training, and conducts research, evaluation and information dissemination to improve quality of life for people with disabilities.
800-444-0821 | www.ihd.umkc.edu



MO Developmental Disabilities Council
Federally-funded, 23-member council appointed by the governor that assists the community to include all people with developmental disabilities in every aspect of life
800-500-7878 | moddcouncil.org



MO Protection & Advocacy Services
Provides legal advocacy and services for children and adults with all types of disabilities and their families on a broad range of issues, including education, employment, guardianship, benefits, and more.
800-392-8667 | moadvocacy.org