• MISSOURI FAMILY TO FAMILY

PARTNERING GETHER





Cover photo: Shaylee leads her pony down a path on her family's farm. Pictured above: Isaac is dressed up in his best suit to go out with his family.

EMPLOYMENT

THROUGHOUT THE LIFECOURSE

While we live in an ever-changing world, the expectation that we all work or in some way contribute to society as adults remains the same.

In the past, many people with disabilities did not have many chances to find employment in their community alongside their non-disabled peers. They commonly worked in jobs that were created just for people with disabilities and segregated from the rest of the community.

Today, the way we think about employment for people with disabilities has changed. People with disabilities

are also valued employees in their communities. People with disabilities want to work and have their families and supporters see beyond old stereotypes and focus on the skills, abilities, and interests when thinking about employment. People with disabilities can, and do, hold real community jobs as productive and valued employees.

With the advances in technology our children can dream big and have access to a myriad of possibilities when it comes to daily living and employment. Educational opportunities, workplace structure, or *Continued on Page 2*



Pictured: Father and son take a test ride on a John Deere.

CONTINUED: EMPLOYMENT THROUGHOUT THE LIFECOURSE

environment and types of volunteerism can all be enhanced through the creative use of technology.

It is important for all children to have dreams for the future, but no one can achieve their dreams on their own. We all rely on our own personal strengths and assets, as well as the relationships we develop, the technology available to us, and the resources in our community to pursue our goals and dreams.

How did you find your first job? Did you mow lawns in your neighborhood? Babysit? Have a paper route? Volunteer? Most likely you relied on your parents, teachers, or friends of the family to help you get started. Establishing supportive relationships for our children and helping them explore heir community early on is crucial to having strong bonds in the community with people who know them and believe in them.

Explore ideas and resources to help your child dream big and attain their goals with the help of integrated supports in this issue of Partnering Together and online at mofamilytofamily.org.



Access information and tools to help you explore Daily Life & Employment and more at mofamilytofamily.org

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is a publication of Missouri Family to Family

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CHARTING THE LIFE COURSE

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



Community Living

Where and how you live - housing options, transportation, modifications



Healthy Living

Managing health care and staying well-



Safety & Security

Staying safe and secure – emergencies, guardianship options, legal issues



Social & Spirituality



Citizenship & Advocacy

View and download the guide at mofamilytofamily.org













REAL LIFE EMPLOYMENT STORIES







JENI

Jeni's first employment dream was to be a child care provider. She was disappointed when she was told she would not become certified for daycare work. Despite this setback, Jeni set a new goal to work in healthcare.

Today, Jeni works in the sterile processing department at a local hospital. In her department, the supplies are thoroughly cleaned and redistributed to hospital departments around the clock.

With the help of her job coach, Jeni was able to learn all the parts of her job. At first she was uncomfortable riding the elevator in the hospital to deliver supplies; however, after working with her job coach and coworkers, she was able to conquer her fear and continue learning the other tasks of her job. She particularly enjoys getting to talk with her coworkers every day.

MARY

Mary works as the receiptionist at North East Independent Living Services (NEILS). Whether clients call in or walk into the NEILS office, Mary is their first link to a caseworker, who finds suitable housing or other services for clients with disabilities. Mary originally worked at a workshop. but when she had to move to a different town, she enlisted the help of Learning Opportunities/Quality Works to help her find community employment. LOQW carried out a series of job assessments, helped her develop a resume and prepare for job interviews, and provided job coaching to help her get acclimated to her new job.

Her job as receptionist includes answering the phone and greeting visitors as well as distributing paperwork around the office. Mary says the job has provided her with income to meet her needs. "Whatever I need— as long as I save— I can afford to buy and not worry about my bills getting paid."

STEWART

Stewart was connected to his job in the MoDOT human resource department through his local career center and support from a grant from the Missouri Developmental Disabilities Council. Stewart keeps the department's personnel records up to date. He uses technology that was designed to help office staff carry out their responsibilities to keep records organized. "With the push of a button, an automated filing system rotates to the appropriate row of files, and Stewart finds the correct file and drops in the latest employment verification form, address change, or other document. The filing system adjust to table level, just right for working from a chair in Stewart's case, a wheelchair.

Stewart dreams of getting his license to drive and ultimately getting a van so he can drive himself to and from work. He has used the public transportation system where he lives to get back and forth from work.

The stories above were summarized from "Real Jobs Real Lives" published by the Missouri Developmental Disabilities Council.

To see all of the stories, visit:

http://moddcouncil.org/uploaded/Real%20Live%20Real%20Jobs.pdf





Prenatal & Infancy Early years, wondering if meeting developmental milestones

Do you have a vision or plan in mind for me when I get older that will support my growth and development now? ★

Pictured: Tara (middle), with her husband (left) and her son (right).

My family is pretty "typical." It consists of my husband, Andrew; our son, AJ; myself, and our pets. Andrew was born in June 2014. He is a happy, beautiful baby boy. His smile lights up a room. His adorable look pulls everyone in and his laugh is contagious. At first glance, you would never know that he was born with a rare genetic syndrome that only has 50 documented cases around the world. Due to his diagnosis of 5q14.3 Chromosome Deletion Syndrome, the first year of his life was a roller coaster of health concerns. After 19 months, we finally have a great grasp on his health and his syndrome. Although our future is unknown, we have great hope and vision for his future and our future as a family.

I have many dreams and hopes for the future for AJ. Some are day to day, while others are lifelong. I dream of a day when science and technology will catch up and provide answers and opportunities for rare genetic conditions. A day when people with disabilities are fully included and not segregated, excluded, or merely integrated. A day when it isn't an inconvenience or financial burden for the community to incorporate assistive technology and modified equipment in all public places.

My vision for AJ's good life is for him to be included. I want him to be accepted, just as he is. To us, he is perfect. I want others to see him as being perfect too. All I want for my son, is for him to always feel like 'part of the group.' We understand that he may have needs that are different from other kids his age. We understand that it might take more resources for him to do things. We understand that it might take more education for the community and more community support, but all we want is for him to be included.

Our family is hopeful that these requests will be met by the support of our community and not out of pity. Today, stores like Target and Hy-Vee are providing shopping carts for families of children with disabilities. Organizations like Variety KC are providing modified and adaptive equipment to children to give them the feeling of mobility and inclusion. Schools are learning that full inclusion is a better education model than integration. Children with Down syndrome are runway modeling and competing in the Olympics. With stories like this being shared across the nation, we have hope for AJ, and for other families, that possibilities are limitless.



Tara, Kansas City, MO Tara is a MOF2F Family Leader from the Springfield area. Her son, AJ, is almost two years old.

GOT QUESTIONS?

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CHARTING THE LIFECOURSE:

EXPERIENCES & QUESTIONS was created to help families and people of all ages focus on their current life stage, as well as look to the future and think about life experiences and questions to ask to make their vision of a good life a reality. To read or download, visit mofamilytofamily.org.





Early Childhood
Preschool age, getting a diagnosis

Do I have chores or responsibilities at home like cleaning my room or picking up my toys? ★

Pictured: Rachel holding her son as they walk down a path in nature.

Including toddlers and preschoolers in household chores is a great way to build self-confidence and teach them responsibility. Kids benefit from being given responsibilities because it helps them learn they can take ownership and know they are a valuable part of the family. By showing children the importance of responsibility from an early age, parents are teaching their kids valuable life lessons. It's important to set the stage for young children to embrace independence in the future and value their strengths.

You can start small by asking them to clean up their toys. Having play areas organized by putting toys into bins, containers, or baskets will make it easy for kids to know where things go when they clean. You can make it fun and engaging for kids to help by singing a "clean-up song" or making it a game, "Who can pick up the cars and put them in the green basket the fastest?"

Offering incentives also helps make household chores more fun. Sticker charts are a fun way to incorporate incentives. You can also try giving them a penny to put into a jar until they fill the jar and then you take them on a fun outing or do their favorite activity. This teaches children that they can still have fun while being helpful and independent, and at the same time, they will begin to learn the value of money. Let them pick which chores they want to do so they can make independent choices and take ownership over their jobs.

The lessons learned from having responsibilities from an early age will carry over into other aspects of their lives, such as getting along with others, working on a team, having confidence in their abilities, and, one day, getting a job and living an independent life.



Rachel, Springfield, MO Rachel is a MOF2F Family Leader from the Springfield area. Her son, Hudson, is four years old, and her daughter, Harper, is three.



LOG ON TO MOFAMILY TO FAMILY. ORG TO WATCH

SUPPORTING FAMILIES TO FOSTER SELF-DETERMINATION IN CHILDREN

Watch this webinar to hear Susan, a mom, share her personal experiences with fostering self-determination in her daughter. This presentation will help you explore the meaning of self-determination, hear about the importance of promoting self-determination, and listen to ideas and strategies across the life course.





School Age

Am I learning about lots of different jobs from my family, teachers and others? ★



Pictured: Caleb works on a gardening project through Youth Volunteer Corps of Greater Kansas City.



To find a Youth Volunteer Corps near you, visit www.yvc.org



Georgia, Kansas City, MO Georgia is a Family Information Specialist at Missouri Family to Family and long-time advocate for people with disabilities. Her son, Caleb, is 16 years old.

As our son, Caleb, started getting older, we realized there were fewer opportunities for him during the summer since he couldn't hang out independently with the other kids in the neighborhood. This was frustrating, but it provided a chance for our family to stretch our thinking as well. We began to think about what his daily life could look like when he got out of school. That's when we realized he needed to learn how to do things that would lead him toward being good at a variety of activities. This way, he could become employable in the things he loves.

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After inventorying his interests, we had a list of things he liked: animals, being outside, hiking, helping out, and anything related to computers. When we thought about the things he was already able to do that might be stepping stones toward work, we realized he's great at helping others when direction is given and his actions are reinforced. At that point, we felt that he would be a good candidate to try volunteering.

How do you find volunteer projects for 13-year-olds? I 'Googled it' and found Youth Volunteer Corps (YVC). YVC offers ongoing volunteer activities for youth ages 11-18, meeting all summer and during the school year for special projects. At \$40 a week, it is cost effective. They allow you to pick the activities so you can remove options that you know won't work for your child.

YVC gives Caleb a chance to explore a variety of activities and interests with his peers. Any child can participate, and if needed, they can take a peer role model, sibling, or personal care attendant with them. Social growth is as important as job skills development at YVC.

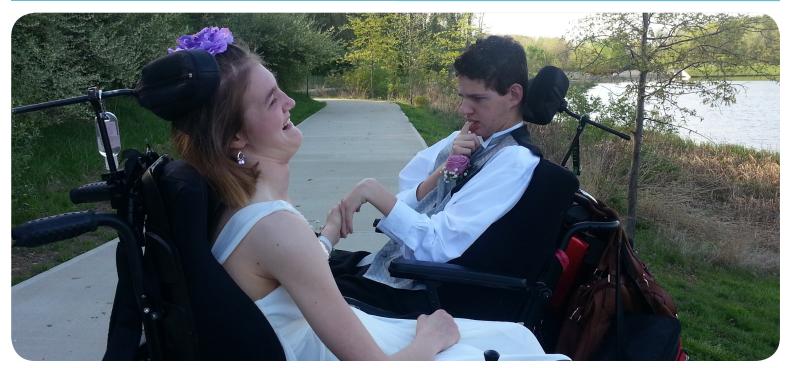
Overall, I think that Caleb has learned to look outside of his direct environment, be flexible and willing to learn new skills, spend time with a diverse group of people, and accept new expectations. These are skills every person needs to become a good employee. Volunteering has been a critical part of helping him work toward his goals. This will be his fourth summer serving with YVCKC.





TransitionTransitions from school to adult life...

Are you helping me understand that doing my best at school and being responsible will help me get a job I like someday?★



Pictured: Cheryl's son, Jacob, with his prom date.

From the time our children are born, we help them prepare for and explore who they want to be when they grow up. Typically they will either go to college or find gainful employment and be productive, contributing members of society. For those of us who have kiddos with significant cognitive and physical delays, that path may not be so clear.

As I read articles in this vast spectrum of special needs, I don't find many employment stories that fit our exact circumstances. There are those who can participate in gainful and competitive employment and those who will need job coaches and have tasks modified so that they can perform their job duties. Then there's the group, like our son, who doesn't fit into a category of competitive employment. While he has his own way to communicate, is happy 24/7, and spreads warmth and love wherever he goes, Jacob is non-verbal, non-ambulatory and needs maximum assistance for all of his activities of daily living. So we are blazing and creating new trails for him to be a "productive and contributing member of society"... by assisting him and advocating for him to build an adult life he loves based on what he learned and enjoyed throughout his education.

It's scary to think about life beyond the protective environment of the school system, but we've been helping him create meaningful experiences after school for years. Now we are building in even more experiences to fill up his day. For instance Jacob has a girlfriend he's been with for nearly 5 years. They get together for ice cream, to see a movie or go dancing as often as they can. He loves music and is in a rock band through a music therapy program that meets and performs on a regular basis. Jacob loves playing an instrument and expressing himself through music while building friendships and sharing common interests with an inclusive group.

Jacob and his peers also assists in a crafting program for elementary aged children. The purpose is to have these kids grow up in a world where being with people of all abilities is the norm! While we take advantage of both types of group environments, we feel it's vital to create more inclusive programming experiences, as these are the kids who grow up to become tomorrow's policy makers, leaders, teachers and neighbors, therapists, support staff etc. to children like mine.

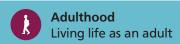


Cheryl, Chesterfield, MO Cheryl is a MOF2F Family Leader from the St. Louis area. Cheryl is an advocate for her son, Jacob, who is 20 years old.

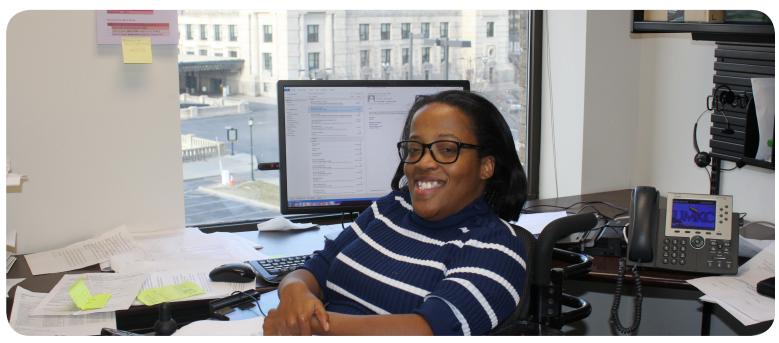
REAL LIFE EXPERTS ON...

GETTING TO DAILY LIFE & EMPLOYMENT





Can I find a job or volunteer opportunity that matches my passion or interests?



Pictured: Laura works at her desk overlooking Union Station.

I believe that young adults with disabilities can find a job or volunteer opportunity that matches their passions or interests. In my experiences volunteering for different organizations, serving on a local government committee, and working for the University Missouri–Kansas City Institute for Human Development (UMKC IHD), where I currently work, I have learned the importance of advocacy and networking skills.

I began volunteering at The Whole Person, the Center for Independent Living in Kansas City, during the summer before I started my bachelor's degree coursework at UMKC. I helped the staff with presenting about disability history to other organizations. My time at the organization was short but it ignited my passion for advocacy. From that experience, I learned that is important for me to understand the history of people with disabilities and from that point on I decide to devote myself to advocating and learning.

While I was in college, I also volunteered at Open Options (formerly United Cerebral Palsy of Greater-Kansas City). My time at that organization taught me not only the value of hard work, but also the value of my time. There, I supported program staff to research inclusive after-school programming options for children with disabilities and their siblings. The experience allowed me to hone my research skills. It also taught me that I can use my love of advocacy in a different way to help people with disabilities.

Another memorable experience for me was serving on the Mayors' Committee for People with Disabilities in Kansas City. My time on the committee taught me how to stand my ground and network with others with the same interest and passion in advocacy and disability rights.

All of my experiences have not only fueled my passion for advocacy and disability rights, they have also given me opportunities and experiences I would not have had otherwise and prepared me for success at my current job at the UMKC Institute for Human Development. Now I am working to help young people with disabilities learn networking, goal-setting, advocacy and self-determination skills.

In the end, I believe that all of these unique experiences combined have groomed me for my advocacy work. I will always advocate for the rights of people with disabilities and my work at UMKC Institute for Human Development has further increased my passion, interests, and knowledge of advocacy and disability rights.



Laura, Kansas City, MO Laura currently works at the UMKC IHD, Missouri's UCEDD. She graduated with her BA in Political Science with a minor in Sociology. She is a Diversity Graduate Fellow at UMKC.

REAL LIFE EXPERTS ON...

GETTING TO DAILY LIFE & EMPLOYMENT





AgingGetting older and preparing for end of life

What will I do to keep busy if I retire?



Pictured: Cindy, wearing a long, blue dress with white hawaiian flowers, spends her spare time hula dancing.

Disabilities come with one huge advantage: the ability to adapt. Our circumstances are ever-changing. Which is why we are perfectly suited to retirement. All change takes a moment to take in. Retirement is no different. But one morning you wake up realizing that no one manages your time but you. You can travel, volunteer, enjoy nature, write, paint, perform, foster animals or get a part-time job is you want.

Retirement does require some basic realities. Try to save money and pay off debts. Be prepared for a momentary sense of loss, i.e.: missing coworkers, routine, income and maybe a sense of purpose. But that adaptability gift will kick in soon enough. You will be surprised at the life you are about to receive.

As a young girl I only thought about the "nevers," experiences I'd miss out on because of my birth defects. At 62, I can't keep up with the possibilities!

As a young girl I only thought about the "nevers," experiences I'd miss out on because of my birth defects.
At 62, I can't keep up with the possibilities!





Cindy, Platte City, MO Cindy is a MOF2F Volunteer. She is retired federal law enforcement officers. Currently, Cindy is a hula dancer, Uke player, and songwriter.



THE GOLDEN YEARS: THINKING ABOUT AGING & RETIREMENT

Watch this webinar to hear Judy, a sibling, and Lisa, a mom, share their personal experiences with planning for the golden years. Learn why it's important to plan no matter your age or family situation, find out about a tool that will help you in planning for the future, and hear real life examples of how important your circle of support can be in planning for life transitions and aging.



FREE NEW PROGRAM PROVIDES TRANSITION ASSISTANCE FOR STUDENTS WITH DISABILITIES

The Pre-Employment Transition Services (PETS) program will offer work-related supports to public school students in Missouri who are not yet eligible for similar services through Vocational Rehabilitation. The program was made possible through legislative changes to the Workforce Innovation and Opportunities Act (WIOA).

PETS will focus on providing hands-on supports by working directly with students, families, and schools. These services include job shadowing, mock interviews, and counseling designed to help create a smooth transition into the workforce. Twenty-one PETS specialists from around the state have been selected and trained to help with the program, which will offer services in five areas: Job exploration, Work-based learning, Counseling for post-secondary education, Workplace readiness, and Self-advocacy and peer mentoring.

"Our job is to help students with disabilities make connections with various services," said PETS Project Director Robert Simpson. "We are working with these students in a hands-on fashion, getting them connected with the right services."

PETS is a collaborative partnership between several organizations around the state including the University of Missouri and the Department of Elementary and Secondary Education. All services are free to districts. Pre-Employment Transition Services has already made connections with over 300 schools.

For more information regarding PETS, please contact the University of Missouri's Hook Center for Educational Renewal at 573-882-0859 or hookcenter@missouri.edu.

From missouritransition.org

THIS ISSUE FOCUSED ON:



DAILY LIFE & EMPLOYMENT

What a person does as part of everyday life-school, employment, volunteering, communication, routines, life skills.

For even more resources on Daily Life & Employment, visit mofamilytofamily.org!

NEXT ISSUE WILL FEATURE:



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.



HEALTHCARE UPDATE

The Open Enrollment Period for 2016 health coverage ended January 31, 2016. However, if you didn't enroll in a health insurance plan by the deadline, 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 or foster
- Move from a different state or from a different county within Missouri.
- Become a U.S. citizen.
- Gain status as a member of a 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.

Open Enrollment for 2017 health coverage begins November 1, 2016 and ends January 31, 2017.

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

Charting the LifeCourse: Daily Life & Employment Guide This 20-page guide is meant to help transition age youth what daily life is going to look like after high school ends. It includes activities and resources



to begin to think about jobs, careers, or continuing education in adult life. Access the guide, as well as other materials, at lifecoursetools.com.

Mofamilytofamily.org Connect with Missouri Family to Family our products and information by age or topic. You can connect with us, sign up for our mailing list, 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

to know, identify how to find or develop supports, and and download the guide at mofamilytofamily.org.



Connect with us online for news, contests, events and even more resources!

Need info in an accessible format or in Spanish? Call us to get the information you need!

ARTNERING

VOL. 4, ISSUE 2 • MOFAMILYTOFAMILY.ORG

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

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

First Steps



Dept of Elementary & Secondary Education (DESE)

Oversees special education, vocational

Missouri **EDUCATION**

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

DMH Division of Developmental

disabilities such as intellectual

disabilities, cerebral palsy, head

Serves people with developmental

Disabilities



DIVISION OF

DEVELOPMENTAL DISABILITIES

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



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

disabilities. Services coordinated through 11 regional dmh.mo.gov | 1-800-364-9687

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

injuries, autism, epilepsy, and certain learning

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 disabilties.

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

