

PARTNERING TOGETHER



Cover photo: Girl breaks through the finishing line

Pictured above: a young man swings at a ball with the help of a supporter

FITNESS & NUTRITION HEALTHY LIVING ACROSS THE LIFE COURSE

Often, when we think about healthy living, we think of healthcare and medical services like getting an annual physical or going to the hospital for a serious health problem.

Even though healthcare is extremely important, there is more to managing our health than the professionals and the physical structures of the medical system we come into contact with. Factors like where you live, work, and play can also seriously impact your health. At the forefront of healthy living is physical activity and a balanced diet.

Fitness and nutrition are key to experiencing health and quality of life in the here and now, as well as avoiding illness, injury, and serious health complications into adulthood. Fitness

goes way beyond exercising a few times a week. Fitness also includes getting adequate sleep and avoiding behaviors like smoking and using alcohol and drugs excessively.

Research shows significant benefits to eating a balanced diet and participating in regular exercise even as we venture into adulthood and as we enter the golden years.

Fortunately, no matter where you might find yourself in your personal health journey, you can move your health trajectory in a positive direction by using integrated supports to make better food choices, adopt healthier behaviors, and get more physically active.

Continued on Page 2





CONTINUED: FITNESS & NUTRITION

As our culture remembers the importance of nutrition and fitness, communities everywhere are offering resources to help people eat healthier and be more physically active, even at the grocery store. New technology emerges everyday with the ability to monitor our diets, exercise or activity, sleep patterns, and other health-related issues.

Explore this issue to see how individuals with disabilities and their families are focusing on healthy habits, fitness and nutrition for a healthy lifestyle using integrated supports and dig even deeper at mofamilytofamily.org. •

Pictured: A young man watches a basketball as it nears the basketball hoop.



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

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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 LifeCourse: Experiences & Questions*.



Daily Life & Employment

What you do everyday– school, employment, volunteering, routines



Community Living

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



Safety & Security

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



Healthy Living

Managing health care and staying well– medical, dental, behavioral, prevention



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 EXPERTS ON...



Prenatal & Infancy and Early Childhood
Early years, getting a diagnosis



Pictured: Above, Sarah's husband and their two children playing; below: Sarah's daughter with another child at playtime.



HEALTHY LIVING



Are you taking me to activities such as baby yoga, Mommy and Me classes, etc?

After our daughter, Mollie, was diagnosed with autism, my husband, Tony, and I went on the pursuit to help her in any way we could. We enrolled her in First Steps services (occupational, physical, and speech therapy) once a week. We were also able to add Easter Seals services with Applied Behavior Analysis (ABA). She made great strides with consistent therapy.

Tony and I, along with her First Steps providers, agreed that this kind of attention to her needs would need to continue after she transitioned out of First Steps. After First Steps, Mollie attended preschool in the school district and received occupational and speech therapy.

As Mollie has gotten older, her needs and behaviors have changed. She has progressed in many aspects, while becoming more sensitive in others. Over the course of her journey through preschool, we discovered that Mollie absolutely loved school and responded really well to the structure of her week. My husband and I discussed the importance of her being involved in activities to ensure she was continuing to build on her newly acquired skills, as well as learn new skills. Mollie needed opportunities to socialize (in a non-academic atmosphere), work on fine and gross motor skills, and stay active while having fun, and not just in the form of traditional therapies.

After exploring our community, we discovered that there are many community resources and activities widely available in lieu of formal therapy. For example, the YMCA offers toddler yoga, tumble time, gymnastics, sports, and more. There are also many free ways to get your child active, like going to the park.

We chose to participate in a Mommy and Me group. We found that if we (as her parents) stay active and involved, she is more apt to join in on the fun and interact during the activity. We learned this early on as we saw how both of our children would watch us and quickly join in activities we were doing. Our family has had so much fun interacting with each other, and at the same time, the kids take away valuable skills and experiences on which they can build. ●



Sarah,
Lake Ozark, MO
Sara is a wife and mother of two from the Ozarks area. She owns and operates My Playhouse Indoor Play Café in Osage Beach.



REAL LIFE EXPERTS ON...

HEALTHY LIVING



School Age

Do I know what is good (food, sleep, exercise) and bad (drugs, smoking) for my body? ★



Pictured: Susan's daughter, Elizabeth, on her adapted bicycle.

Overall, our family enjoys a very active and social lifestyle. We regularly participate in peer groups, advocacy organizations and church. We work hard to develop social networks and encourage each other, our friends, and family.. We're involved in many community activities and take advantage of walking trails, bike trails, and neighborhood swimming pools. Despite all of this, our family has always struggled with fitness and nutrition. With our two older sons, it seemed a lot easier. They consumed the same portions and types of foods that our seven-year-old daughter does today, but they were more physically active and maintained a healthier weight throughout their childhood.

Our daughter, Elizabeth, uses a wheelchair. She engages in many healthy activities like dance, drama, basketball, tennis, therapeutic riding, and handcycling, but it is much harder for her to burn the calories needed to offset her diet. We have discussed many strategies to reach a healthy weight with nutritionists at her doctor visits and recently asked for a referral to the nutrition clinic. We have also tried a lot of different things at home. The most successful thing we did was omitting certain items, like bread and juice, from our shopping list.

Elizabeth knows a lot about healthy foods and which foods to enjoy occasionally or avoid altogether. She helps cook meals at home and prepare her school lunches. She chooses one hot lunch each week. Her drink choices are usually milk or water. She doesn't drink any soft drinks and very little juice. We don't use tobacco and don't drink to excess— she has learned about the consequences of those behaviors at school and through conversations at home.

As for fitness, even though each of us has activities we enjoy, we don't have consistent fitness routines. We deal with opposite work schedules and rarely get a chance to walk or bike as a family. Transferring Elizabeth to and from her wheelchair is becoming increasingly difficult with her age and size, and public locker rooms often present challenges. Excuses aside, we just don't make the time or commitment it takes to become physically fit. We are aware that our choices and habits affect each of us individually and as a family— yet, like many other families, we still struggle to work together to change our fitness and nutrition choices and lifestyle. ●



Susan,
Kansas City, MO.
Susan is mom to Elizabeth and a Missouri Family to Family Volunteer.

GOT QUESTIONS?

Charting the LifeCourse

Experiences and Questions Booklet
A Guide for Individuals, Families,
and Professionals

Throughout our lives, we face questions and search for answers that will help us on our journey to a full and meaningful life. This is true for everyone, especially when you or someone you care about experiences a disability or special health care need.

Charting the LifeCourse is a tool to assist you in creating a vision for the future. It is designed to help you think about the questions to ask as well as the choices, options and the experiences to consider as you "plot a course" to a full and meaningful life. It is intended to be a starting point to realize where you are in your life journey.

We hope the LifeCourse Experiences and Questions Booklet helps you realize that even when your child is very young, and whenever you are on the journey as for the ages and grows into adulthood, their life experiences and environment can shape how they will live the life in the future.

MISSOURI FAMILY TO FAMILY | URBAN INSTITUTE FOR HUMAN DEVELOPMENT, UCCSD

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.

REAL LIFE EXPERTS ON...

HEALTHY LIVING



Adulthood

Living life as an adult

Since I was a child, my parents always emphasized the importance of exercise and proper nutrition. You see, I was born with Spina Bifida, so I have leg muscles that are not as strong as those of an individual without a physical disability. Because of this, the importance of keeping my leg muscles as strong as possible and my weight at a healthy amount was always a strong focus growing up. My mom did leg exercises with me, and before I was self-motivated, she rewarded me with balloons and toys. Eventually I internalized the importance of fitness of nutrition and made working out and healthy eating a part of my daily routine.

Fast forward to a year ago, when my mom became very ill. I lost track of taking care of myself, because I was so focused on taking care of her. Add to that that I was now in my 40's, so my body's physical capabilities and metabolism had also changed. I had gotten to a point where I was not exercising at all and, therefore, was having A LOT of difficulties walking. I had chronic back and hip pain. My weight was at the highest it had ever been, so my blood pressure was high. I had heartburn all the time.

I felt ashamed of the choices I was making and who I was becoming... until it finally dawned on me that I needed to STOP this downward spiral! My mom had instilled in me the importance of taking care of myself. I needed to take care of myself, so I could take care of her. I also needed to take care of myself because I'M WORTH IT!

I found a fitness and nutrition program that included components of healthy living that were important to me:

- portion control with portion control containers,
- making healthy eating choices with a sensible food plan approved by my dietician,
- video workouts that I could do in the comfort of my home,
- accountability from a coach and support group, and
- personal development.

To date, I have lost a significant amount of weight. I am feeling confident, empowered, happy, and healthy again. I believe this program is one I can realistically stick with for the rest of my life, as I have made it a natural part of my lifestyle, as fitness and nutrition were in my youth.

Yes, I go through periods where I get stressed and want to stop, but I am focusing on my personal development through my fitness program, so I'm encouraged to get back on track exercising and eating right.

To help keep me accountable, I use social media. I LOVE Facebook. I am encouraged through social media to remain

Am I eating healthy meals and snacks and staying physically active?



Pictured: Malinda pauses for a selfie while getting fit lifting weights at home.

accountable to my friends and family. I also rely on my wellness support group through Facebook. I also consistently use Fitbit to monitor my physical activity throughout the day and share my accomplishments with my supporters.

I am in a happy place again, thanks to the informed choices I have made with my long-term goals in mind and maximizing the supports available to me through my fitness program. ●



Malinda,

Kansas City, MO

Malinda is a MOF2F Volunteer. She works at an organization that serves people with developmental disabilities. She is married and has three dogs.



**Aging**

Getting older and preparing for end of life

Am I staying as physically active as possible?

WE HATE TO DIET AND EXERCISE.

The Debt: It's like a credit card. You love the flexibility it gives but hate having to discipline yourself to pay it off each month. After 30 years of marriage we found ourselves reminiscing over yesterday, when we used to be slim, active and healthy. Now, perusing old pictures while we balanced the picture album on our protruding bellies we wondered how we got into such a mess.

The Myth: It's easy to buy into the myth that, because we're older it would be near impossible to get back into shape. Yearly physicals brought information that required us to take action or pay the consequences. We had "overdrawn" on our wellness account you might say. We have now learned that saying you are too old to make changes is a myth.

Technology: Sparkpeople.com has a free service where you can log in your health concerns. You can monitor health concerns there and keep track of your weight loss progress. It counts your nutrition intake. You add all the meals you plan to eat for the day and can even print them out to keep yourself on track for the day.

Not having to obsess over what we were going to eat that day has really helped. We just cook it or packed it along with us for the day. This takes a lot of stress out of eating. We eat something every three hours and are losing weight right out of the gate. We learned that our taste buds began to change and we actually enjoy many healthy foods. We make sure to include three fruits and veggies a day. For us this seemed to be the key to our weight loss. Without those we didn't have as much success.

The Gym: As the title says, exercise is not something we love to do, but we knew if we began to eat healthy we would have to shape up or deal with the unsightly flab that inevitably appears when you lose weight. We tried watching the news at the gym or putting on headphones and listening to music. We even set up movies on our iPad that paired with a headset. Before we knew it we were putting in 45 minutes to an hour in exercise. We hardly noticed, but others did and that motivated us to keep going.

Encourage yourself: One thing to do when you are getting discouraged about your progress is to get together with friends who haven't seen you since you began your journey to better health. They are sure to notice your progress and this can give you a shot in the arm to move forward.

Eat what you like: Just not all the time. Find recipes that are healthy and delicious. There are tons of them on the internet or at the library. One of our favorite foods is Mexican food. We visit our favorite Mexican food restaurant once or twice a month and still lose weight. We feel it is best to enjoy this now and then so we don't feel like we never get to have our favorites. Eating very healthy meals the other 28-29 days each month, we find that we still lose weight.

One of us is diabetic and so when they are being begged to take a bite of the yummy sweet dessert, that's when they discipline themselves to do, "Just one bite!" When begged

to take another they say "I will if you want to deal with me going into insulin reaction." That stops the begging cold. Friends know when there is diabetes involved so they really shouldn't be shaming us into eating sugar. They should be ashamed.

Don't weigh yourself constantly: I see people go to the scales about every time they come to the gym. They walk away looking stressed. Since stress has been shown to work against your ability to lose weight, we only weigh about once every month or two. Then, we are satisfied we are making progress and not getting into a funk over our weight. So far we have both lost approximately 30 pounds in five months. We are wearing clothes two and three sizes smaller. We used to hate going shopping for clothes, but we enjoy it more nowadays.

Never say, "Never:" For too long we did. Now that we are having wonderful results in our golden years, may we encourage you to take the first step? It's always the hardest, but it can lead to a path of feeling good each day and having the energy to do more of the things you enjoy. We used to get worn out on vacations because we were so out of shape. We're going to take two this year! ●



Clayton and Melissa,
Kansas City, MO

Clayton and Melissa are a married couple in Kansas City.

FREE TOOLS AND MATERIALS TO HELP YOU PLAN FOR A HEALTHY LIFESTYLE

No matter which life stage you may find yourself or your loved one, you can hit the restart button your health! Missouri Family to Family created free tools and materials to help individuals and families think through their vision for a healthy life that are available at lifecoursetools.com.

The My LifeCourse Healthy Living Portfolio was developed in partnership with a developmental disability services organization to meet the needs of Community Health Workers who were working with individuals to navigate the healthcare system and improve their health, but anyone can use it to help them make an action plan to maintain or achieve good health.

The first page of the portfolio features a questionnaire to help people reflect on what is going on in their life around their health. The inside features a worksheet that can be used to reflect on their past experiences with health, both good and bad, and outline steps to take to accomplish their vision for a healthy life. The back of the portfolio includes a worksheet to map the supports needed to be healthy.

Even more resources are available to help you complete the My LifeCourse Healthy Living Portfolio or explore health generally. Get the *Charting the LifeCourse: Experiences & Questions* booklet, which can help individuals and their family members think about the questions they may need to ask in order to get them in the right direction for current and future life stages. Download the Integrated Support Options grid, which lists ideas to get people started thinking about integrated supports in all of the life domains. Visit lifecoursetools.com today to view or download these **FREE** resources!

THIS ISSUE FOCUSED ON:



HEALTHY LIVING

Managing and accessing health care and staying well— medical, mental health, behavior, developmental, wellness, and nutrition.

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

NEXT ISSUE WILL FEATURE:



SOCIAL & SPIRITUALITY

Having relationships and fun— hobbies, personal networks, and faith communities.

Visit mofamilytofamily.org
to explore resources related to
Social & Spirituality.





HEALTHCARE UPDATE

IMPORTANT! CHANGES TO MO HealthNet coverage in Missouri!

MO HealthNet officially transitioned to managed care this year, starting May 1, 2017. Coverage is now offered through three different managed care plans (MissouriCare, Home State Health, and United Healthcare).

Open enrollment for MO HealthNet Managed Care was from to January 1 to April 3, 2017. Plans were automatically selected for those who did not enroll. Participants already enrolled in a managed care plan (except for Aetna Better Health, which ended), had the option of staying in it or switching to another plan.

The following people were required to select a managed care plan:

- People enrolled in MO HealthNet for Families, Kids, Pregnant Women and Newborns, or Uninsured Women
- People enrolled in Transitional MO HealthNet Children's Health Insurance Program (CHIP)
- Children who are in state care, receiving Refugee Assistance or an Adoption Subsidy are also required to enroll.

EXCEPTION: individuals enrolled in MO HealthNet for seniors or those who are blind or disabled did not need to select a managed care plan.

Need help navigating Mo HealthNet Managed Care?

TALK TO SOMEONE IN PERSON:

Assisters are trained people who can answer questions and help you compare managed care plans in person, at no cost. Find help near you at covermissouri.org or call 1-800-466-3213 or 1-855-284-3236 (Spanish line) to make

an appointment.

MO HEALTHNET RESOURCES:

Online: <http://dss.mo.gov/mhd/participants/mc/>
Phone: Call the Enrollment Helpline at 1-800-348-6627
Managed Care Enrollment Guide: <http://on.mo.gov/2k7gN7q>



COVER MISSOURI

This Healthcare Update was adapted from a resource developed by Cover Missouri.

Learn more at covermissouri.org



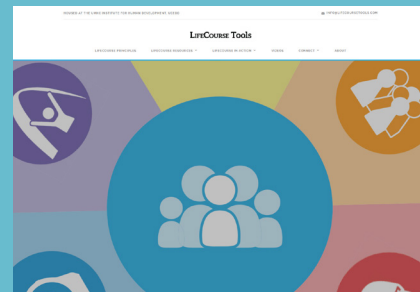
Sign up for the MOF2F mailing list to get the latest updates about new resources, upcoming events, partner announcements, and other information related to supporting families with developmental disabilities and special health care needs in Missouri.

Visit mofamilytofamily.org today to sign up!

FEATURED RESOURCES

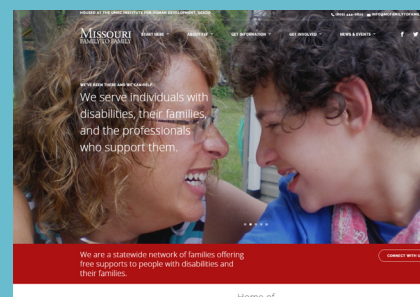
LifeCourseTools.com

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

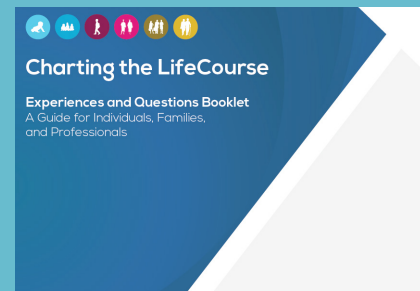
Connect with Missouri Family to Family online and access our products and information by age or topic. You can connect with us, sign up for our mailing list, and more. Check out our website today at mofamilytofamily.org!



Charting the LifeCourse: 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 Care Needs
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

Missouri Family to Family is housed within Missouri's University Center for Excellence in Developmental Disabilities (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 product 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).