

PARTNERING TOGETHER



Cover photo: Two sisters, one with her arm wrapped around the other, pose for a photo. Pictured above: Mom helps her little girl find her way.

PARTNERING IN SUPPORTED DECISION-MAKING

Supported decision-making is a model used to help people understand and make their own decisions as they move through life. All of us use supported decision-making to an extent on an everyday basis. We ask friends and family members for advice, we seek second opinions for medical decisions, we shop around and research major purchases. Informally, anyone can do this at any time.

When it comes to supporting people who have disabilities, it really doesn't have to be any different. Everyone has the right to seek advice or opinions from others and to ask for help when making decisions. We can also choose to have friends or family members accompany us to medical appointments, or

to help us with different types of paperwork like understanding a lease agreement or purchasing property. We even have the right to open joint bank accounts.

Family members and other supporters often worry about safety and security for people with disabilities. Supported decision-making is a strategy that can be used to help people stay safe and still allow them to make their own choices and decisions. It can simply be a statement expressing the desire to have someone lend a hand. It can be a notarized letter outlining who can help with what types of decisions. It can be an actual form defining the relationship between the supporter and

Continued on Page 2





Pictured: Two young women, hand in hand, make shaving cream cards together.

CONTINUED: PARTNERING IN SUPPORTED DECISION-MAKING

the decision maker. Ultimately, the decision still lies with the person, not a substitute. Supported decision-making is crucial for those who want to retain their right to make decisions when other people or systems feel that they are not capable of doing so. It is the next step in the process of transforming a culture where it has become acceptable to limit an individual's civil rights simply because they have a disability. Supported decision-making can be used by anyone, regardless of how they communicate or process/express their thoughts. It isn't about the ability to communicate, but rather the right to decide and be heard.

The key to effective supportive decision-making is to develop a team of family, friends and professionals who believe in the individual and are willing to help him or her understand and communicate his or her decisions. Developing strong self-determination and self-advocacy skills is also essential. Explore this issue to see how individuals with disabilities are supported in learning to make decisions early in life and in making their own decisions throughout the life span and dig even deeper at mofamilytofamily.org. ●



Access information and tools to help you explore
Safety and Security and more at
mofamilytofamily.org

CONTRIBUTORS

Partnering Together
is a publication of
Missouri Family to Family

Director

Michelle "Sheli" Reynolds, PhD

Creative & content support provided by

Rachel K. Hiles, M.P.A. and
Susan Bird, M.S.

Real Life Experts:

Tara Zahner
Kimmy Marshall
Sharon Colbert

Mary Warm
Rachel Hiles



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



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

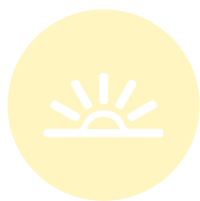
Having relationships and fun– hobbies, personal networks, faith communities



Citizenship & Advocacy

Making decisions and having choices in your life, standing up for yourself

View and download the guide
at mofamilytofamily.org



REAL LIFE **SUPPORTED DECISION-MAKING** STORIES



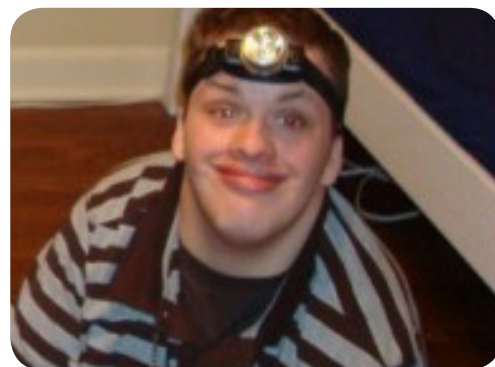
BEN

Ben lives with his family and graduated from a public high school where he was mostly included with his same age typical peers. Ben is very well-known in his community and has mainly been supported outside of school by family, but that changed when his twin brother went off to college. Guardianship became an issue on his 18th birthday when his parents received “the letter” from his school stating they should get guardianship or they wouldn’t have any input in educational decisions. They were also concerned about medical treatment and Ben’s finances. For Ben and his family, guardianship was too restrictive of an option. By simply asking for help from friends, family, and community members, Ben is being supported to learn new life-skills that help him to be more independent, and he is learning to use things like debit cards and limited bank accounts to help him better manage his money.



MRS. SIMMS

Mrs. Simms is an 84 year old widow whose physical health was beginning to fail. With the assistance of her daughter, Emma, they explored alternatives for her to prepare for the future while avoiding guardianship. They discovered that a Durable Power of Attorney (DPOA) for Health Care would allow Emma to carry out her mother’s treatment wishes should Mrs. Simms become unable to do so. After consulting with an attorney, Mrs. Simms decided to also establish a DPOA for Finances to enable her daughter to handle all financial matters should she become mentally or physically incapable of addressing her finances. The DPOA for Health Care and for Finances permitted Mrs. Simms to plan for her future care and avoid guardianship or conservatorship.



ERIC

The Special Needs Trust that Eric’s parents created for him when he was 18 years old did two things: it set up a fund that would give Eric the ability to purchase things that would enhance his life when they were gone, and it gave them the peace of mind to know that Eric’s financial support would not become a burden on his brothers and sister. These funds, once his parents have passed away, will give Eric the ability to continue doing the things he currently loves like visiting his siblings in another part of the state, going to stock car races or buying a new golf-cart to replace his old one. These funds would cover expenses for his home and to cover services that might not be covered with his current supports and benefits.

The stories above were excerpted from the MO Guardianship Resource Guide, a comprehensive look at the alternatives to guardianship and guardianship options in Missouri. To view or download the guide, visit moguardianship.com



**MO GUARDIANSHIP:
UNDERSTANDING YOUR
OPTIONS & ALTERNATIVES**



REAL LIFE EXPERTS ON...

SAFETY & SECURITY



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

Are you considering my safety and protection without making me overly dependent or taking away my right to be self-determined?



Pictured: Tara, with her husband and son.



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

My husband and I welcomed our beautiful baby boy, AJ, into the world in June of 2014. I had already made big plans for him, including who would provide child care and where he would attend preschool and elementary school. We were choosing for AJ to have a “normal” childhood when he was only about an hour old. It turned out that AJ had multiple illnesses in his first six months, including Myoclonic Seizures and symptoms of a genetic deletion syndrome. After receiving the genetic test results, the doctors told us AJ probably wouldn’t be able to walk, talk or function like a “typical child”.

From the time AJ was diagnosed with 5q14.3 Chromosome Deletion Syndrome, we became his number one caregivers and advocates. We chose what he ate, drank, and wore and how he sat, stood and slept. We worked diligently to find him every resource, service, therapy, and holistic approach available. We wanted him to WALK and to TALK. Instead of trying to teach independence and self-determination, I was trying to do everything the doctors said he wouldn’t do.

Recently, through completing Partners in Policymaking and learning about adaptive technology, assistive communication devices, and the vast number of resources available, I had a major epiphany: Why were we putting such specific demands like WALKING and TALKING on AJ when our real goal is for him to learn to COMMUNICATE and BECOME MOBILE and INDEPENDENT? We were teaching him that we wanted him to do things how everyone else does them and if he couldn’t, he wasn’t reaching his goals or living to his fullest potential. We weren’t seeing the bigger picture.

I will never forget one morning we built a square nest out of blankets and pillows on the floor. Instead of putting all the toys in his reach, I put one in each corner and just watched to see what he would do. What choice would he make? I sat and watched my little boy kick and roll and fling his body in one direction or the other to get to the toy he wanted. He chose which toy to play with, which sound he wanted to hear. He made conscious and self-directed choices. I learned something that day: AJ might not make choices the same way I make them, BUT AJ CAN MAKE CHOICES. We started presenting multiple food options. We began allowing AJ the power to make his own decisions.

Today, we let AJ play freely with his toys. We present different food options and the one that he stares at longer is the one he gets. We are learning his noises and mannerisms so we can clearly understand when he is rejecting an option. We are allowing our son the chance to communicate his choices to us and we are seeing incredible progress as his self-determination increases. ●

REAL LIFE EXPERTS ON...

SAFETY & SECURITY



School Age

Are you helping me learn how to say no or tell someone if I feel uncomfortable or am being abused?



Pictured: Kimmy's daughter helps her doll get a better view of the fish in the aquarium.

I am always learning about my daughter and how she feels about different things, but I never really thought to ask her specific questions. Or maybe I didn't ask too many questions because I felt I may plant ideas in my daughter's head about how she "should" feel. As a parent in general we question how our children feel or if they are uncomfortable, but with disability it can be more challenging because our children are constantly placed in uncomfortable situations due to their medical issues.

She was recently selected for the Botox medical trial for bladder incontinence, and I was given a survey about how she feels about certain situations regarding her bladder problems. I decided to ask her the questions and I was surprised by her answers. After the survey, I learned that she struggles with people knowing that she doesn't go to the bathroom like everyone else, that she feels sad a lot because she has to miss out on fun to go to the bathroom. She also said that she worries about being wet or smelling like urine or having an accident often and she feels very sad that she has to miss out on birthday parties and sleep overs because of her disability. I was naïve about my own daughter when I learned that she felt this way all the time.

We also discussed her fear of strangers helping her go to the bathroom. This hit home and it hit hard. She recently started a new school year, with that a brand new nurse who had challenges trying to cath her, and I now know exactly how she feels about this particular issue. I regret not asking her before now. I was already addressing these issues with the school district but I never knew she felt so strongly or so badly about the situation.

I do know that I have done some things right. I continue to reassure my daughter that its ok to be sad or to feel the way she feels. I want her to feel comfortable with herself and loved beyond measure. I really wish I could take away all the unnecessary stress and just let her be a 6-year-old girl with no problems in the world. ●



Kimmy,
Herculaneum, MO.
Kimmy is mom to Adrianna 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 in the future.

MISSOURI FAMILY TO FAMILY | UMRK 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...



Transition

Transitions from school to adult life..

Transition is a term to describe children moving from school to adulthood, but I have watched my son transition his whole life.

My son is a bright and creative sophomore in high school. Drayden's struggles with social interpretations, overstimulation, constant change and missed cues in school was a barrier. Drayden gravitates toward adults versus his peers as he feels like he fits in better and is understood. At seven years old, he was diagnosed with Aspergers and ADHD, starting our first transition into the world of IEPs and school meetings. I believe this is when he began filling his toolkit with skills to communicate who he is and how he communicates.

Drayden's transition plan began with equipping him with communication and coping skills to be his own person functioning with varying levels of protection from his parents. He learned to use his skills by continually having a seat at the table when discussing his transition plan. Every year he has used his skills enabling him to need less and less decision making support and protection. As he has gotten older and more confident in using his tools he has made some lasting friendships as he is now comfortable connecting with others. Drayden initiates, plans, and participates in social outings. Years ago, I'm not sure this was a possibility. Like most teenagers, my son is transitioning into independence. He is learning to drive, discussing employment opportunities, and college.

I began working on Drayden's transition plan when he was diagnosed. I believe every year and new grade level was a

Does my transition plan include learning how to "be my own person" so I won't need a guardian for decision-making support or protection? ★

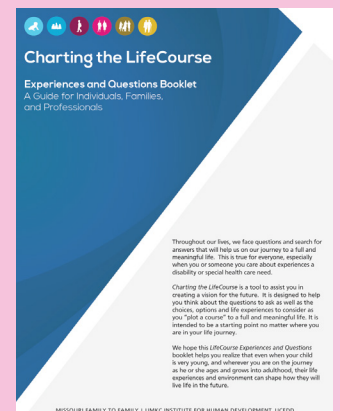
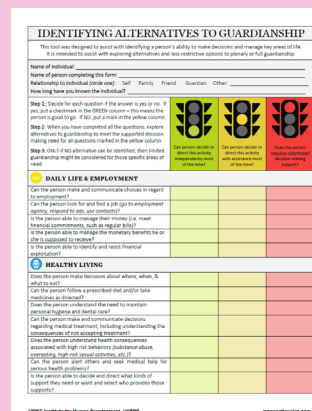
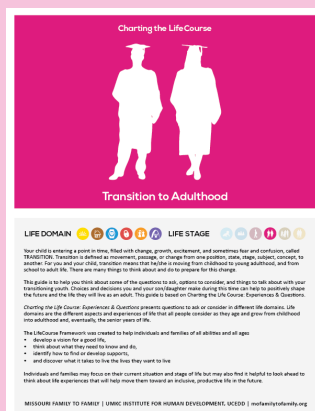
transition. He had to start over every year sometimes with new kids, definitely new teachers, a new environment and new communication processes. Over the years he has learned to advocate for himself, introduce himself and help others learn how best to communicate with him. It has been a joy and sometime scary to watch him venture out making his own decisions and dealing the consequences. In spite of it all, I am proud of my son and all he's accomplished. My son is a constant reminder of what happens when those around you demonstrate enduring faith, support, and love.

I have learned that although the question focuses on my son's transition plan, being his own person and not needing a guardian for decision-making support, he is not the only one transitioning. As a mom, I am also transitioning and learning to let him make his own decisions, use all of the skills he has learned over the years and deal with the consequences both good and bad. As parents, we want to shield our kids from all harm. I'm learning that the bumps and bruises along this road called life makes us who we are. It has been an amazing and wild ride watching my son grow and develop. The best is yet to come. ●

Sharon,
Kansas City, MO

Sharon is mom to a teenage son and a Missouri Family to Family stakeholder who lives in Kansas City, MO.

FREE MATERIALS TO HELP YOU NAVIGATE TRANSITION (AND BEYOND!)



To view or download materials, connect with a Family Information Specialist, and more visit mofamilytofamily.org.

REAL LIFE EXPERTS ON...

SAFETY & SECURITY



Adulthood

Living life as an adult

Who is partnering with me with in supported decision-making?



Pictured: Mary, a preschool graduate of the Edgar L. and Rheta A. Berkley Child and Family Development Center, has chosen early childhood education as her life work.

Hello everyone! Today is a great day because the sun is shining and the birds are singing. I hope you have a great day today! Today I am going to talk to you about myself and why decision making is important in my life.

My name is Mary Warm and I am 25 years old. I am a young lady who has Down syndrome. I was diagnosed Down syndrome when I was a little girl. As life goes on, I had a great life. I was happy that I had a great life then. I am still happy now that I have a great life. I love my life! I love my life because of all the people that is involved in my life. The people who are involved in my life are my family, friends, and teachers. Everyone means a lot to me! The reason is because they did a great job supporting and teaching me. This is my supporting team in my whole life. My family is involved by raising me, supporting me, and making sure I understand about life. My friends are involved by treating me as a person not just my disability. My teachers are involved by helping and making sure I understand about school life. Without my support team, I won't be where I am now.

Right now, I am living my adult life by having my own place, working part time at a daycare, and going to college for my

career as pre-school assistant teacher. I work at Berkeley at the UMKC campus. I went to University of Central Missouri in Warrensburg for the THRIVE program. This is a two year program where anyone with a disability who wants a college experience. I finished the program and now I am taking classes for my career at Penn Valley Community College. My supporting team supports me on my decision making. They help me when I need help and tell me about their opinions on my decision making. They will back off when I tell them I don't need help. I do respect their opinions because I know they are looking out for me and love me too.

I have the right to make my own decisions because I am no different from people who have disabilities. We all have the right to make choices about our own future. Thank you for reading and listening to my story ●



Mary,

Kansas City, MO

Mary is a graduate of the THRIVE program at UCM. She is studying early childhood.



REAL LIFE EXPERTS ON...



Aging

Getting older and preparing for end of life

SAFETY & SECURITY



Is Supported Decision-making or are other alternatives to guardianship in place to protect my rights as I age?



Pictured: Rachel's grandmother holding her as an infant by the ocean near Seattle (left); Rachel and her grandma recently.

My grandma has always been an instrumental part of my life. Growing up, she supported my physical needs by helping take care of our family, ensured my safety by providing child care for my mom while she worked, and supported my access to education by taking care of my school supplies and school-related expenses. Like many other grandmas, she also fulfilled my childhood whims and desires, funding summer art classes, filling my bookshelves, and taking me on little adventures.

I am my grandma's only living relative that she can trust. She doesn't have a very healthy relationship with my father. In the past, she has been the victim of financial and emotional abuse and has been easily taken advantage of by close relatives and others.

Over the past couple of years, my grandmother has had some health issues that resulted in a sharp decline in her mobility and a marked jump cognitive and memory problems (that I believe to be brought on by stress and trauma) in addition to the aging process. So now, instead of her taking care of me, our roles have reversed.

At the onset of her medical issues, my grandma sought a Durable Power of Attorney and Medical Power of Attorney. Even though she didn't need it at the time, she set it up to help protect her in the future. There have been times in the hospital and rehabilitation where it has been very helpful in making sure she received the care she needed. It also allowed me to handle her affairs while she was recuperating from her illness, paying bills and managing her finances.

Since I have become more involved in my grandma's daily life, I discovered that she was being exploited by scam magazine companies and rewards offers and had a significant amount of unnecessary debt. I created her "Financial Action Plan" and listed out several steps to eliminating these problems. One of the first things we did was move to a new bank and opened a joint account so that I could help her monitor her finances and make purchases on her behalf.

I convinced my grandma to get a smartphone and then we installed Mr. Number to block known spam numbers from reaching her by phone and we have been working to identify junk mail and scam offers by their appearance and small print.

It has been a long journey and we have had our disagreements along the way, but I think we both have peace of mind knowing we have these safeguards in place and she is still able to make her own decisions. Many people are convinced that seizing control of all of their assets and decisions by becoming their guardian will keep them healthy and safe. ●



Rachel,

Kansas City, MO

Rachel is part of the Missouri Family to Family team and the primary caregiver to her grandmother.



LifeCourse Integrated STAR: Supported Decision-making

When a person turns 18, they are presumed competent to make decisions about their life. Sometimes, a person might need help making decisions and staying safe. This Integrated Supports Star Bank shows some of the ways people can be supported to be safe and secure while living an inclusive community life.



View and download additional LifeCourse Stars and even more tools and materials at lifecoursetools.com



FREE TOOLS AND MATERIALS

TO HELP YOU THINK THROUGH SUPPORTED DECISION-MAKING

Thinking about guardianship? Did you know there are a number of resources at your disposal to help walk you through the process of determining what the most appropriate and least restrictive options and alternatives are to plenary or full guardianship for your unique circumstance?

IDENTIFYING ALTERNATIVES TO GUARDIANSHIP			
This tool was designed to assist with identifying a person's ability to make decisions and manage key areas of life. It is intended to assist with exploring alternatives and less restrictive options to plenary or full guardianship.			
Name of individual: _____			
Name of person completing this form: _____			
Relationship to individual (circle one): Self Family Friend Guardian Other: _____			
How long have you known the individual? _____			
Step 1: Decide for each question if the answer is yes or no. If yes, put a checkmark in the GREEN column – this means the person is good to go. If NO, put a mark in the yellow column.			
Step 2: When you have completed all the questions, explore alternatives to guardianship to meet the supported decision making need for all questions marked in the yellow column.			
Step 3: ONLY if NO alternative can be identified, then limited guardianship might be considered for those specific areas of need.			
<div style="display: flex; justify-content: space-around;"> <div> <p>Can person decide or direct this activity independently most of the time?</p> </div> <div> <p>Can person decide or direct this activity with assistance most of the time?</p> </div> <div> <p>Does the person require substituted decision-making support?</p> </div> </div>			
DAILY LIFE & EMPLOYMENT			
Can the person make and communicate choices in regard to employment?			
Can the person look for and find a job (go to employment agency, respond to ads, use contacts)?			
Is the person able to manage their money (i.e. meet financial commitments, such as regular bills)?			
Is the person able to manage the monetary benefits he or she is supposed to receive?			
Is the person able to identify and resist financial exploitation?			
HEALTHY LIVING			
Does the person make decisions about where, when, & what to eat?			
Can the person follow a prescribed diet and/or take medicines as directed?			
Does the person understand the need to maintain personal hygiene and dental care?			
Can the person make and communicate decisions regarding medical treatment, including understanding the consequences of not accepting treatment?			
Does the person understand health consequences associated with high risk behaviors (substance abuse, overeating, high-risk sexual activities, etc.)?			
Can the person alert others and seek medical help for serious health problems?			
Is the person able to decide and direct what kinds of support they need or want and select who provides those supports?			

Free tools and materials were created to help individuals and families understand guardianship laws in Missouri and guardianship options, as well as alternatives to guardianship that can be put in place that balance individuals' needs for support and protection with the right to self-determination and autonomy that we all enjoy.

These resources are specifically for individuals who might need decision-making support due to disability, mental health diagnosis, or aging, including:

- the *MO Guardianship: Understanding Your Options & Alternatives* webinar,
- *MO Guardianship Resource Guide*, a comprehensive guide which addresses common concerns, misperceptions, myths, and provides guidance for addressing the potential needs for support and/or protection of people with developmental disabilities, mental health, and age-related cognitive issues.
- *MO Guardianship Online Workbook*, an interactive online resource allowing you to flip through the pages to watch stories from real families about how they made decisions about support and protection for their loved one and answer questions to help you make the best choice for your family.

Visit moguardianship.com today to view or download these **FREE** resources!

THIS ISSUE FOCUSED ON:



SAFETY & SECURITY

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

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

NEXT ISSUE WILL FEATURE:



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.



HEALTHCARE UPDATE

From the Family Voices Blog: How The Affordable Care Act (ACA) is Helping Children with Special Needs and Their Families

The Urban Institute reports indicate that there has been a decrease of 36% in uninsured parents since enactment of the ACA, and noted that “the share of parents with health insurance increased 6.4 percentage points and the share of children with coverage increased 1.7 percentage points – a historic high for families.” Notably there were “large declines [in uninsurance rates] among low-income and Hispanic parents and a narrowing of the difference in uninsurance rates between parents and children through early 2015.”

Families with insurance reported better access to care than those without insurance, which means families didn’t go without care or struggle as much with medical expenses. Parents were more satisfied with the newer health plans and thought they could get care when their child needed it, which is especially important for children with special health care needs. One of the Urban Institute reports noted that these gains have been made even though “Children were not the primary target of the ACA’s coverage provisions given that they have had substantially lower uninsurance rates than parents and other adults.”

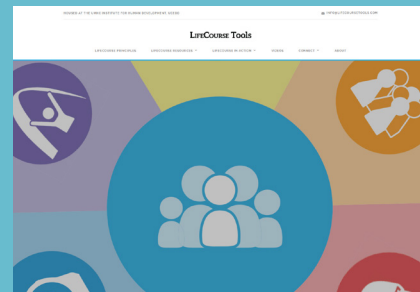


This information was excerpted from an ACA blog authored by Lauren Agoratus, M.A. To view the full tip sheet, more of Lauren’s tips, and additional resources to help you navigate the ACA can be found on the website of the Family Voices National Center for Family/Professional Partnerships at fv-ncfpp.org.

FEATURED RESOURCES

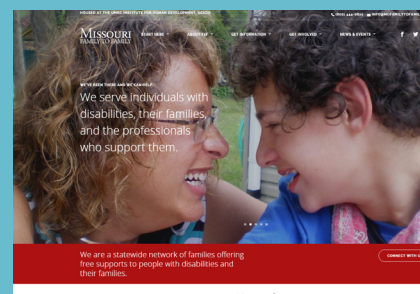
LifeCourseTools.com

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

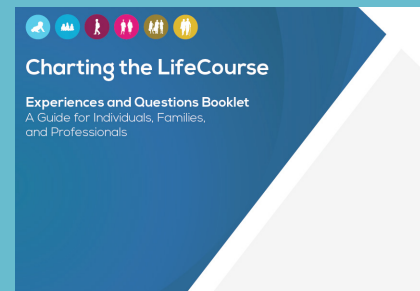
Connect with Missouri Family to Family online and access our products and information by age or topic. You can connect with us, sign up for our mailing list, and more. Check out our website today at mofamilytofamily.org!



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.



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!



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

VOL. 4, ISSUE 4 • 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



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).