

PARTNERING TOGETHER



WHAT WILL I DO DURING THE DAY NOW THAT I'M AN ADULT?

People do many different types of things during the day as an adult that make their life meaningful. One of the things we do as an adult to fill our day is work.

Why do people work? The simple answer is to make money to support themselves financially and afford the things they want. Work is also an opportunity to make friends, learn new things, and achieve a sense of accomplishment! Work is an important part of adult identity that gives people something to do with their time, adds structure to their day, and helps them achieve a sense of purpose. This is as true for people with disabilities as it is for anyone.

Getting ready for work begins early and

continues throughout the life course. Beginning in childhood, families, schools, and other supporters can encourage children to develop a vision for their future, including what kind of job they would like to have. All children dream of what they want to be when they grow up, and children who have disabilities or special health care needs are no different! As children prepare to leave school, they begin to focus even more on jobs and careers. As an adult, sometimes we change jobs or careers, and eventually begin to think about retirement.

This issue includes ideas and resources to help make thinking about employment easier no matter which stage you may find yourself focusing on for your family. ●





A lot has been happening with Missouri Family to Family (MOF2F) as we reflect on another year and the beginning of a new volume in our history (and the newsletter!).

Over the past year, MOF2F completed 1,555 requests from individuals with developmental disabilities/special healthcare needs, their families and professionals. They received information and referral from our Family Specialists, were matched to another family with a similar background, or both. 74% of those who requested help found the support received from MOF2F was useful in helping them feel more confident about getting what is needed to handle their current situations.

We are celebrating the fact that our network continues to grow. We have 80 new peer mentors, which increases our Family & Volunteer Network to over 550 members. We still need help from families like you, so please let us know if you would like to join! In addition, the MOF2F affiliate network grew from 48 to 123 affiliate organizations. Also, MOF2F now oversees the Family Partnership initiative in partnership with the Department of Health & Senior Services Special Health Care Needs, which makes our network of supporting families even stronger!

Missouri has the unique opportunity to participate in a national project called the Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities. This summer, the kickoff for the entire project took place in Kansas City, Mo., and brought people from Connecticut, District of Columbia, Oklahoma, Tennessee, and Washington to begin a dialogue about supporting families. We will keep you updated on any development with the project.

Charting the Life Course framework continues to grow. We are now working on a new product with the Show Me Careers Consortium to help families zero in on specific questions they should be asking and the steps they should be taking to prepare for the future. The first packet will focus on employment. Thus, our first issue of this new volume of *Partnering Together* is talking about getting ready for employment. We hope it will help you think about what you steps you might need to take to support your family member to get ready for work! ●

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CHARTING THE LIFE COURSE

This and future issues will include articles and resources to help you think through topics from our guide, *Charting the Life Course*.



Daily Life & Employment
What you do everyday– school, employment, volunteering, routines



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



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



Safety & Security
Staying safe and secure– emergencies, guardianship options, legal issues



Social & Spirituality
Having relationships and fun– hobbies, personal networks, faith communities



Self-Determination & Advocacy
Making decisions and having choices in your life, standing up for yourself

View and download the guide at
mofamilytofamily.org

Asking questions about...

Daily Life



Early Childhood (3-5)

Are you asking me what I want to be when I grow up?

Preparing for employment starts early. Observing and talking about different jobs and life roles when young will help your child be able to express preferences and choices about the kind of job they would like to have and what they like about that job. It will also help determine what kind of training, education or skills they will need in order to be successful. Creating a vision for a future that includes work helps point your family in the direction the child wants to go!

"Big! Red!," exclaimed my excited 3 year old, as he tugged on my leg. I glanced at his teacher with a confused look on my face. "Today we had the local Fire Department come to the school. He loved the big, red truck," she explained. As we drove home that day, I realized he was ready to talk about firemen and what they do, and I was just as ready to engage his curiosity about careers and explore his interests a little bit more.

It is never too early (or too late) to encourage a closer look at the world around us and tap into your child's hobbies and possible career paths. Ask the question, "What do you want to be when you grow up?" Every child will describe a different journey, and that is okay.

As you embark in this conversation, realize that regardless of your child's needs, they deserve a path, a goal, and experiences that will bring fulfillment and joy into their world. Start within your own environment and the careers that you see on a regular basis. Begin with your own family and look at the jobs that parents, grandparents or other relatives may do. Explore the jobs of teachers, doctors, mail carriers, trash truck drivers, church staff, and even the dog groomer. These are great opportunities to ask questions and discover that there are many options in each field.

For a person with special health care needs, these encounters should be no less, and nothing should be discouraged. Provide options to experience these careers by developing a hobby or volunteering with organizations that pique their interests. My child loves cooking, so instead of locking up our kitchen cabinets, we embrace his eagerness. He has cooking utensils within his reach and wears his apron and chef hat with pride as he watches Saturday morning cooking shows. We discuss becoming a chef and let him assist in mealtime preparation.

It is important to remember that all careers will require different amounts of education and training and include different duties, like interaction with the public. There is also a wide array of



options for working at home or day options that fill the soul, but don't get a paycheck. What the future holds for your child is up to you!

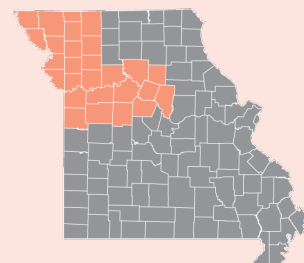
Encourage, educate and motivate your child to have a place in this world that provides inclusion, purpose and happiness.●



STACEY ANDERSON

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Stacey is the mom of two boys. Her expertise is in navigating systems, providing guidance for parents with a new diagnosis, and arming parents with tools to advocate for their child's medical and educational well being.



Asking questions about...

Daily Life



School Age (6-13)

Do you make sure I have responsibilities at home, like other family members, such as daily chores?

Responsibilities, such as chores, helps a person understand the satisfaction of having a valued role and the same expectations to work and contribute as everyone else. We all benefit when given the chance to learn and make good choices for our futures.

Having a child with special needs always brings unique challenges to the family. None of us want our child to feel isolated, left out, feeling they have nothing in common or to contribute to others. Our job as parents is to help them overcome their challenges, grow into happy, strong, independent, contributing members of our families and communities.

Sometimes we don't teach simple things to our children because their challenges overwhelm us, and it's easier and quicker to do the task ourselves. We must remember our goal of independence for them, even if that means taking extra time, making modifications, having a helper sharing part of the task, or offering frequent reminders to stay on task.

We use visual charts at our house. They show tasks to be done, what part of the day to accomplish them, and an "atta girl" when they are completed. Our child moves each item over to the "completed" column as she does her daily chores. Since she is easily overwhelmed, we broke our charts into smaller ones and placed them in different areas of the house.

Here are things we expect our child to do on a regular basis:

- dress herself
- make her bed
- place dirty clothing in hamper and put away clean clothes
- pick up toys and towels after bath
- set the table
- get some of her own drinks and snacks
- help with simple cooking tasks (like stirring ingredients)
- help put grocery items away
- hand Dad tools when he maintains the mower or car
- turn lights and TV on or off
- vacuum (which she just started recently and loves doing!)

We also have seasonal chores in our family. In the spring, she helps plant the garden, pick berries, and care for baby animals. In the summer, she helps pick produce and prepare it for canning or freezing, gathers sticks for our wiener roasts, and



keeps her rabbits cool. The fall is time to gather pecans and walnuts and winterize the farm.

One of her favorite chores is cleaning up after her horses and brushing them. We expect her to help feed and water all the animals, gather eggs and clean cages. The animals are her pets and therefore (mostly) her responsibility. What better way to learn to care for yourself than to care for others!

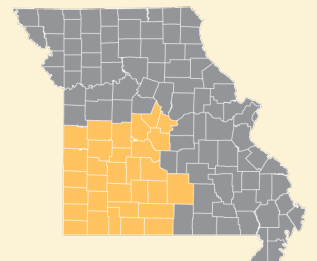
Chores teach important life skills that children carry throughout a their lifetimes. The more we encourage them to do on their own, the less help they will need in the future. ●



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Beth is the mom of three children, one of which lives in the home and has a special health care need. She is knowledgeable about Autism, Fetal Alcohol Syndrome, Post Traumatic Stress and Sensory Disorders.



Asking questions about...

Daily Life



Transition (14-22)

Are you giving me opportunities to go new places and try new things so I can figure out what I like to do?

The rich and vast experiences we have in the community help us understand all the possibilities that are available to us. Having new experiences and exploring the community can help youth envision what is possible for their own future. When youth know more about what is available to them and what they might like to try, they are better equipped to plan their path toward future goals.

When children try new things, it helps them become better people and encourages them to look at their futures. I try to give my children many opportunities to have different experiences. Some of them have been disastrous, but I keep encouraging my kids to continue embarking on new paths to become more well-rounded individuals.

My children do not handle loud crowds well and get scared easily, but I still took them to the zoo. In the end, they had a great time. Our kids love football Fridays in the fall, so we try preparing them before we go. Sometimes they have meltdowns, other times they love it. Our friends and community have welcomed us and help us during our outings, which makes attending games and supporting our team easier.

Your community may not always seem like the most welcoming place for your child, but helping others get to know them and introducing them to the world beyond your family are worthwhile pursuits.

There are many places that can be a great start in your community:

- Checking out churches to find out which programs and activities fit your family's interests
- Taking your child to local parks, museums and other places to see what the community has to offer
- Taking mini vacations or daytrips to nearby towns to shop and visit new and interesting places
- Dining out to try new foods and discover different flavors
- Enrolling in sports and summer camp to make friends and learn new hobbies
- Volunteering in the community with your child to teach important life lessons and help build a connection with the community

The sky is the limit on what you can do to help your children try new things and see different places. Participating in new experiences helps guide them in making choices about what



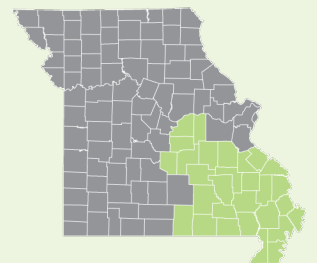
they like to do. Be creative, read books, talk to other families about what they have done. Some introductions to new things might be challenging or even scary at first, but don't give up. Reintroduce them again later, and keep trying to find new things to do together! ●



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Pam lives in southeast Missouri with her family. She has five children (two biological and three adopted) and has fostered 23 children. She is experienced in foster and adoptive care.



Asking questions about...

Daily Life



Adulthood (23+)

What will I do during the day, now that I am an adult?

Youth and families must begin to see beyond disability and begin to focus on what the person **can** do – what they are good at, what they like, and what they can give back to others through work or volunteering. Learning skills and gaining experience through work, volunteering and community exploration can lay a foundation for successful employment in the future.

The importance of planning ahead sometimes escapes one's mind, because daily challenges can be overwhelming and make it difficult to see beyond today. Planning ahead for individuals that need additional support to be successful whether in the workplace, volunteering at a local business or nonprofit, or just doing something they love like a favorite hobby takes time, patience, resources and a lot of planning. Transitioning into adulthood means that resources and programs offered through school or other programs may not be available as an adult. Therefore planning ahead gives time to search out what's available and also gives time to research local options or search outside their own community.

Planning ahead is very important in ensuring that all of our life transitions are well thought out, we are preparing for challenges along the way, and we are able to accommodate new situations.

When I was a child, I wanted to grow up and be a mom to lots of kids. Years and five kids later, I realized that what I want now for my life has changed. Now I want my kids to be whatever they want to be. Whatever they choose, I will support as long as it is going to make them happy and of course, help them be independent!

For my oldest son, planning for the future wasn't always easy. Lots of challenges arose, but the focus of planning ahead never changed. We always talked about what he wanted to do when he grew up. As a kid, one of his hopes was to fly an airplane. He also wanted to play professional baseball. Physical challenges didn't allow him to do many things that other kids his age were doing.

Then, as a young teen, we talked about what kind of work he wanted to do. We considered work using a communication device to independently input data into a computer program. The type of setting he would work in and the accessibility of the work place would be important. We also had to think about transportation and the things he might need support



with while at work, such as eating, taking his medicine or using the bathroom.

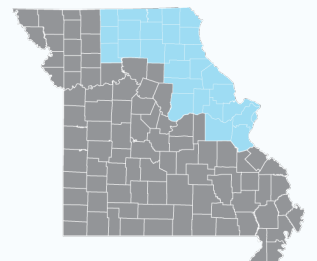
It's important that each person have as much independence in choosing what they do with their adult life as possible. Also, preplanning with guidance is imperative rather than waiting until they turn 18 and wondering what they will do until a plan comes together. That makes for a lot of, "What am I going to do now?" and "How many days of thumb twiddling will take place before their opportunity is here?!" ●



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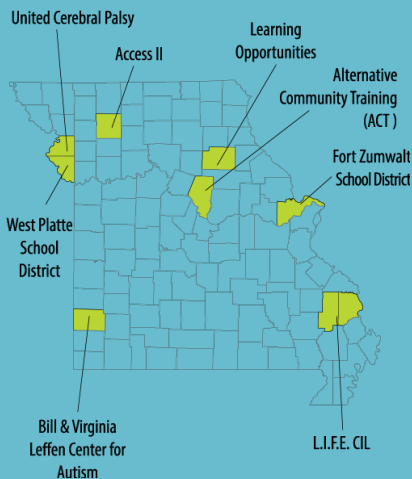
Beverly is the mom of five children and lives with her husband and kids in northeastern Missouri. She is knowledgeable in the areas of advocating for your family in different arenas and developing good communication skills.



FEATURED RESOURCES

Show-Me-Careers

The goal of the Show-Me-Careers project is to scale up effective practices that support the seamless transition from school to employment for youth and young adults with intellectual and developmental disabilities (I/DD). Eight communities were chosen to test ideas for real and lasting change in the area of school-to-work transition. Each community receives funding and technical assistance through the Show-Me-Careers Consortium to improve employment outcomes for youth with I/DD. Learn more at showmecareers.org



Charting the Life Course: A Guide for Individuals, Families and Professionals

Do you know what you need to know?
Do you know what questions to ask?



Charting the Life Course 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.

Charting the Life Course Webinar: Focusing on Employment

Learn about employment options, find out about Missouri initiatives around employment, and discover resources dedicated to employment in your community. Watch the archive 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!



Health care exchange open for business

The federal health law was created to:

- Make it easier and more affordable for Americans to get quality health insurance.
- Improve the quality of health insurance and health care.
- Increase the focus on preventive care.

While some parts of the law have already started, major parts of the law will take effect in January 2014, like the provision that prevents individuals with pre-existing conditions from being denied health coverage.

Under the law, most Americans will be required to have health insurance starting January 1, 2014. There are some exceptions. The Missouri Health Insurance Marketplace is a website where you can compare and buy the insurance plan that fits your needs. You can use the Missouri Marketplace to buy insurance for yourself or your family if you are uninsured or don't have access to affordable insurance through your job.

The Missouri Marketplace opened on October 1, 2013, and health insurance coverage starts January 1, 2014.

The Missouri Health Insurance Marketplace

The Missouri Health Insurance Marketplace and SHOP Marketplace are a lot like travel websites where you can compare prices and buy hotel or airline tickets.

People will be available to assist you with understanding and buying health insurance policies. Individuals and families can talk to navigators or certified application counselors, by phone at 1-800-318-2596 (TTY: 1-855-889-4325), or in person. You can get help at various locations across Missouri. They can answer your questions about the Missouri Health Insurance Marketplace.

On the Missouri Health Insurance Marketplace website you can:

- Compare health insurance plans.
- Calculate the cost of health insurance plans.
- Find out if you qualify for a premium tax credit or cost-sharing reduction.
- Find out if your business qualifies for a tax credit.
- Learn if you qualify for Medicaid.
- Buy a health insurance plan for you, your family, or your small business.

To visit the Missouri Health Insurance Marketplace, visit <http://healthcare.gov> and select Missouri as your state.

You can find in-person help to navigate the marketplace, along many other tools, by going to the **Cover Missouri** website at covermissouri.org/find/find.php

From the Cover Missouri coalition website: covermissouri.org



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OUR PARTNERS

TIPS



For Kids

TIPS for Kids

Training in Interdisciplinary Partnerships and Services (TIPS) for Kids is the Leadership Education in Neurodevelopmental and Related Disabilities (LEND)

training program in Missouri. The LEND program provides intensive training for advanced graduate students and post-doctoral fellows in the field of neurodevelopmental and related disabilities.

573-882-0757 | tips4kids.org



Department of Health & Senior Services, Special Health Services

Provides statewide health care support services, including service coordination, for children and adults with special health care needs who meet eligibility requirements. Programs include: Children and Youth with Special Health Care Needs, Healthy Children and Youth, Medically Fragile Adult Waiver, and Adult Brain Injury.

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



Family Partnership

The Family Partnership was formed by Special Health Care Needs (SHCN), of the Missouri Department of Health and Senior Services, to enhance the relationship between SHCN and the families they serve. The Family Partnership also serves as a means to provide support and information to families of individuals with special health care needs and identifies ways for families to connect with each other.

800-779-8652 | mofamilypartnership.org

UMKC - IHD



INSTITUTE FOR HUMAN DEVELOPMENT
A University Center for Excellence in Developmental Disabilities (UCEDD)

The Institute for Human Development, located within the University of Missouri - Kansas City, is an applied research and training center for human services. It exemplifies the University's goals of academic excellence and a campus without borders by helping people, agencies, and the community reach their fullest potential.

800-444-0821 | www.ihd.umkc.edu

Missouri Developmental Disabilities Council



Federally-funded, 23-member, consumer-driven council appointed by the Governor. Its mandate under P.L. 106-402, the Developmental Disabilities Assistance and Bill of Rights Act, is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration in all aspects of community life.

800-500-7878 | moddcouncil.org

DMH Division of Developmental Disabilities



The Division of Developmental Disabilities (DD) serves individuals with developmental disabilities such as intellectual disabilities, cerebral palsy, head injuries, autism, epilepsy, and certain learning disabilities. Such conditions must have occurred before age 22. Services are coordinated through 11 regional offices.

dmh.mo.gov | 1-800-364-9687

Missouri Family to Family is housed within Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) at the University of Missouri - Kansas City Institute for Human Development. It is the state's HRSA Family to Family Health Information Center, and is a Parent to Parent USA Alliance Member. This newsletter was developed in partnership 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 (#H84MC08005 and D70MC09834).