



Limitless Opportunity



The Missouri Developmental Disabilities Council helps create a world we all want to live in.



Council Highlights

The MO Supported Decision-Making Consortium, which began a coordinated effort to increase knowledge and use of Supported Decision-Making (SDM) in Missouri.

MO Victimization Task Force (VTF), which has meetings to explore challenges and solutions around victimization of individuals with disabilities.

2019 MO Transportation Summit and MO Transportation Task Force, which founded a task force to create a more affordable, efficient and coordinated transportation system in Missouri.

First Responder Disability Awareness Training (FRDAT), which was developed by Niagara University and consists of three comprehensive curricula being implemented in Missouri for law enforcement, fire/EMS and 9-1-1 telecommunications to improve the safety of individuals with disabilities.

For more information on the above programs and on MODDC's 5-Year Plan, please visit www.moddcouncil.org and click on "What We Are Doing."

Words from our Governor

“Awareness must be raised that segregated institutions, services and processes are not only more financially costly to our society, but they are also costly to those with disabilities who desire to live independent, productive lives. It is further costly to our communities, as society misses out on the rich talents and experiences those with disabilities have to offer their communities.”

Systemic Change

The Missouri Developmental Disabilities Council advocates for independence and inclusion in every community

BY MATT JOCKS

There is limitless opportunity for people with disabilities and the places in which they live. That's a core message of the Missouri Developmental Disabilities Council.

It's also a big part of the Council's own history. When the Council emerged in 1971, advocacy for people with developmental disabilities reflected the accepted approach of the time. Primarily, that meant securing resources for sheltered facilities, which met basic needs but kept people apart from the community at large.

"The Council has basically done a 180 [-degree change] from that," said Sherrie Hanks, a retired staff member of the MODDC. "Now they fund support methods to get people into the community, to do away as much as possible with group homes as the answer."

It is part of the concept of "system change," which reorients the support and advocacy system to one that promotes independence and integration into the community. It also means getting people with disabilities more involved in their own advocacy efforts.

"My affiliation with the Council is one of the really important aspects of my advocacy efforts," said Cathy Enfield, current Council chair, whose self-advocacy accomplishments were recognized by the Missouri House



The Missouri Developmental Disabilities Council
PHOTO COURTESY OF MODDC

of Representatives in House Resolution 2836. "I continue to be encouraged by the MODDC's efforts to help us, as people with disabilities, to not only have our voices heard, but to help increase the willingness of others to really listen to our voices. In reality, the efforts are of importance not just for people with disabilities, but for everyone, if we can ever hope to achieve a society that is truly accepting and inclusive."

And without a doubt, the most powerful voices are those who are directly involved. This change in approach has made the community more effective at the political level.

"It used to be that the legislature would not really work on these issues," said former Executive Director Kay Conklin, who added partnering with other organizations has also been effective. "I love People First. It's made up of people with disabilities all over the state. One of the things they do is have members make a presentation to the journalism students at the University of Missouri, to teach them how to write about these issues."

This has improved access and attention to inclusive education, employment and community living, all of which means more independence and self-direction.

"For me," said Hanks, "the biggest thing is giving individuals their own voice. Pushing the idea that you don't have to just take what you've got."

In reality, the [Council's] efforts are of importance not just for people with disabilities, but for everyone, if we can ever hope to achieve a society that is truly accepting and inclusive.

**Cathy Enfield, Chair
Missouri Developmental
Disabilities Council**

Work Ethic

BY
MATT
JOCKS

A Jefferson City man is a valuable, contributing member of his community

When Elijah Mayfield is behind the wheel of a car, he is not alone. But he is definitely making his own way in the world.

Mayfield is 23 and employed at the state capitol, delivering mail and documents, and was recently appointed to the Governor's Council on Disability, both of which have garnered him some attention, including media coverage. But he best proves what those with Down syndrome are capable of when the cameras are off.

"I was probably a little more protective of him," said his father, Todd Mayfield, who works in the lieutenant governor's office. "My wife pushed him a little more. But he just took that and ran with it."

Any discussion about Elijah quickly leads to his work ethic. Whether it's his job at the capitol, his second job as head manager of the Lincoln University men's basketball team or his volunteer work at SSM Health-St. Mary's Hospital, Mayfield has attacked his duties with gusto.

"I love being able to help people," he said. "At the capitol, I get to deliver important documents and to other state agencies like the Missouri Highway Patrol. I like it because I get to see and talk to a lot of different people."

For Todd and his wife, who received information and resources from MODDC from the time Elijah was a preschooler, watching Elijah grow has been a constant process of measuring Elijah's capabilities and supporting him to reach his goals.

Elijah is still driving with a learner's permit, meaning Todd is at his side. There's no driving on the interstate but, around town, Todd said, "He's a better driver than at least 80 percent of the drivers I see."

Mastering this skill is also self-liberating. "When I drive, I feel like I can do anything in the world," Elijah said.

Then there are those St. Louis Cardinals, Elijah's favorite team. His connection to the team is enhanced by his relationship with ex-Cardinal great Albert Pujols, who has a daughter with Down syndrome and started his own foundation. Through Pujols, Elijah has been able to meet players and coaches.

The next step for the Mayfields is preparing Elijah to live independently.

"I like the thought of being able to have friends and family come see my place," he said.

"That would make me feel very proud."

He wouldn't be the only one.

"When we were young parents, we had a lot of images in our minds about how this would turn out," said Todd.

"It has far surpassed any of the wildest expectations we had."

When I drive, I feel like I can do anything in the world.

Elijah Mayfield



PHOTO COURTESY OF THE MAYFIELD FAMILY

Housing Help

Missouri Inclusive Housing Development Corporation, known as MoHousing, is a non-profit organization that receives grant funding from MODDC and helps people with developmental disabilities find safe, affordable, universal design quality housing.

At the basic level, MoHousing connects individuals with housing, but it has also adopted more specific goals, including:

Promotion of universal design in housing

A concept in design that creates housing more accessible to all, including features like ease of entry from room to room, accessible locations of electrical outlets, and location of storage spaces.



Monitoring and inputting local housing ordinances and state laws

MoHousing seeks to change laws that either discriminate or might have unintended adverse consequences for those with disabilities.



Development of housing teams

Seeking to be responsive to issues particular to each community or area.



Promoting the use of assistive technologies

An emerging aspect of improving life, with great potential.



Count Me In

Inclusive learning environments empowered a Kansas City woman to go after her goals

BY MELANIE ANDERSON

Many college students count down the days to summer vacation, but Mary Warm can't wait to begin summer session at University of Missouri-Kansas City, where she's pursuing her bachelor's degree.

"I really want to [show] that people with disabilities can go through their education and be more educated," said Mary, who graduated from Metropolitan Community College-Penn Valley in Kansas City in May. "I want to get my master's degree in early childhood [education], so I can be an inspiration to others."

Throughout her education, Mary, who has Down syndrome, has learned alongside students with and without disabilities. "We didn't want Mary, nor did Mary want, to live in a segregated environment," said her mother, Julie Warm, Ph.D. "[We wanted her] to have quality of life at every step of the journey."

Mary's K-12 schools offered an inclusive education program called FIRE, which provides support to students with disabilities and — as Mary points out — also benefits students without disabilities. "We help them see people who are different and how they learn different," she said.

After high school, Mary completed the two-year THRIVE Program at the University of Central Missouri. She lived on campus and learned skills for living independently and pursuing employment and higher education.

It was a formative experience for both Mary and her parents. "We fully expected Mary to come out of there with independence," said Julie. "The biggest shock to



Mary Warm (center) with her parents on campus.
PHOTO BY CRAIG SANDS

her dad and I was how it changed us, how it forced us to reconsider the daily supports that we were giving her."

When Mary began her first semester at community college, her mother joined her at a meeting with Disability Support Services, which worked with Mary to provide educational accommodations. "Once I got her introduced to the right people, that was it," said Julie. "She was off and running."

While Mary was in charge of her education, she appreciated her family's support, which included rides to campus with her grandfather, heart-to-heart chats with her sister Anna and advice from her parents.

"Having that support really, really is important to me," said Mary, who balanced her studies with a part-time job at her former preschool.

When she graduated, family, friends and teachers celebrated with her. "It is our biggest hope that Mary would have been embraced and included in her community, and she has been at every level," said Julie. "Just like everybody else, education is foundational to that inclusion."

Mary looks forward to continuing her education and becoming a teacher. "Teaching is very important in life, but also very important to me and who I am," she said.

I really want to [show] that people with disabilities can go through their education and be more educated.

Mary Warm
Undergraduate, University of Missouri-Kansas City

Inclusive Education 101

In an inclusive learning environment, everyone wins. "[Research shows] that students with disabilities who are included have far better outcomes in terms of their adult life — obtaining a job, independent living, social networks," says April Regester, Ph.D, associate professor of Special Education and director of Faculty Support and Engagement in the College of Education at University of Missouri-St. Louis. "We also see great benefits for students without disabilities, since teachers reach more students by using strategies like Universal Design for Learning and Multi-Tiered Systems of Support."

When planning for your child's inclusive education, Regester recommends:

Taking advantage of **peer-support programs** at your child's school. Regester established the **Missouri Peer Supports Project**, with a grant provided by MODDC, and it encourages high school students with and without disabilities to support and learn from one another.



Referring to **TASH** (tash.org) for K-12 planning resources and **Think College** (thinkcollege.net) for college planning resources.



Brandon Waters graduated from college and now has a full-time job with Trip Mate, Inc. in Kansas City.
PHOTO COURTESY OF BRANDON WATERS

An Artist in Residence

BY
MATT
JOCKS

A Nixa man lives a life of his own creation

There is the world Allen Nelson lives in. And there is the world he creates for himself on a blank sheet.

Slowly but surely, those worlds have come together.

Nelson's road, living with a developmental disability and shuffled from one foster placement to another, has not been easy. However, his art has always been his outlet, and now it is becoming his path to steady work.

It began selling pieces here and there, and has grown to a more organized effort, participating in art walks and promoting his work through his LeeDragon Facebook page. Even better, with the assistance of the Missouri Developmental Disabilities Council, Nelson is working toward a steady gig as an art instructor.

That would bring together his two passions: art and helping.

"I really love people," he said. "I want to be a teacher so bad. I want to show that everyone can do art. If you get your mind focused, then you can see what you can create."

Maintaining a positive outlook has sometimes been a challenge for Nelson: He was in 13 placements. As he started to list them, he realized he couldn't remember them all. But he knows that many did not go well.

"I got beat up a lot," he said. "But there was nowhere else for me to go. I have a lot of scars."

Now in a supported living arrangement, Nelson works on his art and helps the staff. In return, he gets something that has often been in short supply in his life.

"They respect me for who I am," he said. "They are always there for me. It's like a family."

Meanwhile, there is that world he creates for himself. It can be bat wings or a comic book story or familiar superheroes.

"There was one kid who looked at one I had done of Superman — Christopher Reeve," Nelson said. "He asked how much it was and I said usually 6 [dollars]. But the kid had a dollar, so I said I'd make a deal for \$1. It made that kid's day. And that made my day."

For all that he has endured, Nelson would like to see a

future with more days like that, through his art and teaching.

"My thing is that there is always a better day ahead," he said. "People want to fight now, I just walk away. I say I'm too old to fight. I've been through a lot but I've maintained who I am. I just try to be nice, to be kind."

They respect me for who I am. They are always there for me. It's like a family.

Allen Nelson
Artist and self-advocate



Allen Nelson is a working artist.
PHOTO COURTESY OF ALLEN NELSON

Job Help

Integrated Competitive Employment for individuals with developmental disabilities means employment in a business that employs workers with and without disabilities, pays everyone a prevailing wage and promotes inclusion in the workplace.

Once a career choice is clear, being an active job seeker is a huge responsibility. It's important to be actively looking, using all the tools and resources available. **Here are a few tools:**

My Next Move (mynextmove.org)

Search by industry to find requirements, average salary and take an online assessment.

Career One Stop (careeronestop.org)

General job site that includes a section for workers with disabilities. Includes more than 250 videos that detail job requirements.

Snag A Job (snagajob.com/resources)

Includes tips and videos to assist in a search. Visitors can search by community.

Disability: IN GKC and Our Ability Connect (disabilityin-gkc.org)

For those in the Kansas City, Missouri and Kansas City, Kansas areas, the site connects candidates with employers who are seeking to hire people with disabilities. Candidates can build their profiles and seek employers who have made a commitment to disability inclusion in their workplace.

Missouri Vocational Rehabilitation (dese.mo.gov/adult-learning-rehabilitation-services/vocational-rehabilitation/vr-offices)

State agency with local offices to assist people with disabilities in finding employment.



Making Connections

Getting from Point A to B in St. Louis takes patience, ingenuity and determination

BY MELANIE ANDERSON

At home in St. Louis, if Andrew Lackey can't reach his destination on the bus or MetroLink, he asks family or friends to drive him in his accessible van — but only on occasion. “I want to be as independent as I can be,” he said.

Transportation can be complicated for the wheelchair user and frequent business traveler, but Lackey succeeds in getting to where he needs to go by planning ahead. “St. Louis is one of the better cities in the state [for public transit], but when I would get out of St. Louis it was always a challenge,” said Lackey, who traveled throughout the state as a former public policy analyst for

the Missouri Developmental Disabilities Council.

Lackey discovered Amtrak as a convenient mode of travel to Jefferson City and Kansas City, but meetings in Springfield and Kirksville were more difficult to access. “I was able to convince someone who was also going on the trip to park his car in my garage and then drive me in my

I want to be as independent as I can be.

Andrew Lackey
Deputy Commissioner,
City of St. Louis Office
on the Disabled

accessible van all the way to Kirksville,” said Lackey. “I could have taken the Greyhound bus but ... once you get off the bus, then how do you get to your final destination?”

At times, Lackey has used the airport as a transfer station — taking one service to the airport and another to his destination. “It feels a little surreal when you're setting that up,” he said. “... When [places are] not connected ... I think that can discourage some people and that's a shame.”

Lackey would like to see accessible ridesharing, which is offered in other parts of the nation including New York City and Chicago, and accessible taxis become more widely available.

He also supports streamlining the ride-scheduling process. “There are transportation services where if you need an accessible vehicle, you go on the website and you just click a box — that's it,” he said. “You don't have to call a special number. It's convenient but more importantly, it's spontaneity.”

Now that Lackey serves as deputy commissioner for the City of St. Louis Office on the Disabled, he is traveling less. His 20-minute commute involves rolling to work, where his duties include ensuring new buildings and sidewalks meet accessibility standards.

“Sidewalks are an important part of transportation,” said Lackey. “In order for transportation to be effective it has to connect to all these different things. We're trying to make sure that in the City of St. Louis, everyone with a disability has more and more options in terms of transportation.”

Rides for All

Coordinating transportation can be especially challenging for people with developmental disabilities living in rural Missouri.

A place to start is **MO RIDES**, a statewide referral service created by the Boonslick Regional Planning Commission (BRPC) that connects riders with local transportation services.

“MO RIDES collects your information, ... does a little research, [and] calls you back [with] transportation options,” said Deana Dothage, a former mobility manager who helped develop MO RIDES. “... [MO RIDES]

figures out the best possible solution, even [if] it isn't the perfect solution.”

Mobility management also plays a crucial role in identifying transportation needs in specific areas. After BRPC and other stakeholders recognized the need for a multi-county service in the areas around Lake of the Ozarks, a task force determined that contracting with an existing transportation service to create a new route would be more efficient and cost-effective than creating a new agency. “During my time involved, that was one of our biggest successes,” Dothage said.



Visit morides.org or email findaride@morides.org for more info

Supported Decision Making



With the passage of S.B. 806 in 2018, Missouri joined a nationwide movement away from traditional guardianship alternatives for people with developmental disabilities. The bill mandated that courts consider less restrictive arrangements, under the principal of supported decision making.

Elizabeth Moran, deputy director of the Missouri Developmental Disabilities Council, has a professional and personal stake in the issue. She is the sister of a person with a developmental disability.

"I think many people consider guardianship much like the phrase, 'guardian angel,' she said. "In some cases, that might be a reasonable parallel to draw. In many cases, however, it is not. Too often, we hear of individuals under guardianship who are living in horrific conditions, isolated from family and friends, abused, neglected or exploited. More often than not, guardianships are unnecessary and take away an individual's right to make choices."

Moran said research has shown that the loss of control over one's own life can have negative impacts on mental, emotional and physical health.

"Supported decision making and other alternatives to guardianship ensure personal liberty and freedom, promote community inclusion, and most often provide the most appropriate means of long-term supports necessary for individuals to live a truly integrated life," she said.

An Independent Life

BY
MATT
JOCKS

One Bevier man learned to be a self-advocate and now lives a life he's chosen

It can be something as simple as being able to wake up in your own bed.

Everyday decisions come without a second thought for most people. For people with developmental disabilities, however, those choices have often been taken out of their control.

For example, under the terms of a parental custody agreement, Bradley Wilson (who goes by B Chunk) was to spend some nights with his father, away from his primary home with his mother.

Though Wilson enjoyed spending time with his father, he wanted to sleep in familiar surroundings.

Courts and legal guardians used to have control of those decisions, but under the principle of supported decision making, that has changed. People with disabilities have more power to speak for themselves and to choose who advocates for them.

In Wilson's case, he found powerful advocates in the Missouri Developmental Disabilities Council, County Connections and the Missouri Protection and Advocacy Services.

For people with disabilities, one of the many challenges is simply being heard. Asked about the many times his wishes have been dismissed or ignored, Wilson said, "Yes. That was harsh."

Although Corrigan Lewis, a lawyer with Protection and Advocacy, won the decision that granted Wilson the decision he wanted, Wilson was involved throughout. He laid out his case to County Connections Case Manager Nicole Donaubauer and sat through mock court sessions, preparing to address a judge.

"B Chunk was very nervous, but he knew that in order for his voice to be heard, this is what needed to be done," Donaubauer said. "He was able to demonstrate supported decision making in his life on a regular basis, but needed a judge to help make that known to others."

For Wilson, the results are simple: the chance to spend his nights at home, cooking some macaroni and cheese or maybe a pizza. He spends his days volunteering at a nursing home, as well as running and walking at the YMCA.

Asked if the experience of fighting for and winning what he wanted was an important step, he answered with an enthusiastic "Right!"

He wasn't the only one who learned from the process.

"Witnessing B Chunk go through this transitional period has opened up my eyes to just how strong he really is," Donaubauer said. "He is now a confident self-advocate and continues to overcome his fear of new things and new people."

He is now a confident self-advocate and continues to overcome his fear of new things and new people.

Nicole Donaubauer
Case Manager,
County Connections



Bradley Wilson at home making dinner.
PHOTO COURTESY OF THE WILSON FAMILY

Be a Part of an Inclusive World



Get Involved!

Please visit www.moddcouncil.org and click on the link to our Position Statements to learn more about the following:

- ✓ Diversity
- ✓ Education
- ✓ Employment
- ✓ Guardianship
- ✓ Outreach
- ✓ Personal Safety
- ✓ Restraint
- ✓ Transition
- ✓ Transportation

For a list of additional resources, please visit www.moddcouncil.org and click on our "Resources" page.

MODDC is actively looking for new voices!



Apply to Join the Council...

Assist MODDC with creating a Council and programming that promotes diversity, inclusion, and progressive ideas. This will assure that individuals with developmental disabilities and their families can 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.



...Or become our Partner in Policymaking

MODDC's Partners in Policymaking program teaches leadership skills and techniques to develop positive partnerships with elected officials, school personnel and other individuals who make policy decisions about services that you and/or your family use. Next year's class is forming now!



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Both applications to become a MODDC Council member and to participate in the upcoming 2020 Partners in Policymaking class can be found at moddcouncil.org.



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