

# Direct Connection

MISSOURI DIVISION OF  
DEVELOPMENTAL  
DISABILITIES



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**CONNECTING WITH THE  
DIVISION OF  
DEVELOPMENTAL  
DISABILITIES**

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Health

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Disabilities

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## Education, Advocacy, and Leadership Opportunities for Self-Advocates and Family Members

Missouri's Developmental Disability Council (MODDC) strives to ensure that the voices of individuals and family members across Missouri are strongly heard and taken into account. The Council works to obtain perspectives from self-advocates and family members across the state on various issues, programs, supports, and services that impact them on a regular basis or will have an influence on their lives in some manner. The Council's mission is "to assist individuals, families, and the community to include all people with developmental disabilities in every aspect of life."

The Council helps individuals and family members remain aware of current trends affecting the field of developmental disabilities. Additionally, the Council provides opportunities for individuals and family members to become involved with public policy decisions and to acquire strong advocacy and leadership skills.

One program administered through the MODDC is called Partners in Policymaking, commonly referred to as "Partners." The Partners program is based on an innovative national model of leadership development geared toward adults with developmental disabilities and parents of young children with developmental disabilities. The leadership skills acquired through the Partners program provide a foundation for working positively with elected officials, school personnel, and policy makers. Partners' graduates are encouraged to continue their involvement in the field of developmental disabilities through providing testimonies to elected officials, attending public forums, and working to educate community stakeholders about the vital issues that impact people with developmental disabilities and their families.

For additional information about the Missouri DD Council, visit:  
[http://moddcouncil.org/?page\\_id=1](http://moddcouncil.org/?page_id=1)



# New Family Resource and Autism Specialist (FRAS) Position Housed in Regional Offices

The Division of Developmental Disabilities (DD) recently underwent a restructure following the budget reduction of 66 staff from the regional office structure. One activity related to the restructure involved looking at each technical assistance position housed within each primary office. Two of those positions were the Family Support Coordinator and the Autism Navigator. As a result of the restructure, these two positions were combined to form a Family Resource and Autism Specialist (FRAS) position. A FRAS is located at each of the following six regional offices: Kansas City (Albany), Springfield (Joplin), Central Missouri (Rolla, Kirksville), Sikeston (Poplar Bluff), St. Louis County (Hannibal), and St. Louis Tri-County.

FRASs are responsible for assisting with activities that facilitate the overall goal of supporting families across Missouri. FRASs work to provide training, technical assistance, collaboration, and outreach that advances the principles of best practice and supporting families within the regions. They collaborate with regional SB 40/TCM entities and other family oriented agencies/organizations to advance best practices which support families across the lifespan. In addition, the FRASs have a basic knowledge of current resources that are specific to autism and the support and/or caregiving role of families. FRASs work in conjunction with Missouri's Family-to-Family (MOF2F) Resource and Health Information Center to help connect families across the state to important peer-to-peer support, leadership opportunities, and a variety of information related to developmental disabilities or special health care needs.

FRASs are additionally responsible for working closely with the Parent Advisory Committees (PACs) across the state to better serve families and individuals who have a diagnosis of autism in Missouri.

For additional information about the FRAS, visit the Division of DD's website at: <http://dmh.mo.gov/dd/fsc.html>  
For additional information regarding autism services in Missouri, visit: <http://dmh.mo.gov/dd/autism/>

## Autism Awareness Month

April 2<sup>nd</sup> was World Autism Awareness Day, and April marked Autism Awareness Month, dedicated to the recognition of Autism and Autism Spectrum Disorder (ASD), a developmental disorder which affects as many as 1 out of 68 children in the United States today. During Autism Awareness Month, organizations promote unique educational and fundraising events to increase awareness and understanding about autism and individuals who are affected with autism in communities worldwide.

Some Missourians recognized Autism Awareness Month during Autism Legislative Day on April 7<sup>th</sup> at the State Capitol Building in Jefferson City. This event was cosponsored by the Missouri Parent Advisory Committee on Autism and the Missouri Autism Report (MAR). Families and providers from across the state shared information and cupcakes with state legislators to help raise awareness about autism and to thank Missouri lawmakers for their support of the autism community.

By increasing awareness through activities that occur during Autism Awareness Month, there is hope for better understanding of individuals with autism.





# Quality of Life

## ERIC'S STORY

Eric is a 41-year-old gentleman who lives with his aging father in a quaint home in rural Missouri. He is a friendly person who enjoys having visitors, joking around, listening to music, and watching sports with his father, who has been Eric's primary caregiver for many years. Born with a developmental disability, Eric is non-ambulatory and requires supports in all areas of daily living.

Through the years, as needs have arisen, Eric's family has been linked to community resources including agencies that provide additional personal care supports for him. As time passed, it became necessary to use a Hoyer lift to safely transfer Eric in and out of his wheelchair. Due to the size of his bathroom, the Hoyer lift could not be used, so Eric was still being transferred by his father or caregivers whenever he needed to be bathed. Over time, this transferring was starting to develop into a safety concern for Eric as well as for those lifting him.

In May 2014, Eric was approved for funding through the Comprehensive Waiver for Environmental Accessibility Adaptations to have his bathroom remodeled so he could bathe without any safety risks. A provider was chosen to do the remodeling. The contractors, with this company, were able to remodel the bathroom in about two weeks which was wonderful for Eric. However, it gets even better for Eric. Eric's family and caregivers reported that the employees went above and beyond while completing their job. Eric enjoyed interacting with the contractors during the project.

The contractors replaced the tub with a walk-in shower and opened up the area in the bathroom so the Hoyer lift could be used to safely transfer Eric into his bathroom. Eric is now able to bathe without risking his own safety or feeling like he is putting a strain on his caregivers.

Eric gained more than an environmental adaptation that helped keep him safe and improved the quality of his life; he was able to enjoy the opportunity to connect with the workmen who treated him and his family with kindness and respect. Additionally, Eric was able to remain in his natural home and avoid any unwanted moves. Eric's family can now continue to provide him the supports he needs, and Eric can continue living the life he is accustomed to in his home with his family.



*“Logic will get you from A to Z; imagination will get you everywhere.”  
-Albert Einstein*



## Front Door

Supporting Families is one of the Division of DD's top five priority areas. Efforts are made across many platforms to address how families are supported in Missouri across the lifespan and through the supports and services they receive. The Division of DD is committed to working with families and individuals on various levels and listening to concerns, needs, suggestions, and opinions. The Division works to solicit the voice of families and individuals to obtain their unique perspectives.

The Division of DD recently improved the way in which it helps families and individuals initially navigate the service delivery system. During the intake and eligibility determination process, some families and individuals were often overwhelmed with the amount of paperwork and forms they received and were required to return before a determination could be made. After an extensive review, the paperwork was significantly reduced making the process for all involved much easier.

In addition, intake and eligibility staff across the state in each regional office have the ability to automatically connect a family or individual to Missouri's Family-to-Family (MOF2F) peer support and health information center housed through the University Center for Excellence in Developmental Disabilities (UCEDD) at UMKC. This helps better support families and individuals by directing them to useful information/resources and unique peer-to-peer services, which they can begin accessing even while waiting eligibility determination from the Division of DD.

If you are a family member or individual in need of information and resources or would like to make a connection to another family member or individual for peer support, feel free to visit the Missouri Family-to-Family Health Information Center at: <http://mofamilytofamily.org/f2f/for-families/>

## Supporting Families to Foster Self-Determination

The Parent Advocacy Coalition for Educational Rights (PACER) describes self-determination as a combination of attitudes and abilities that lead people to set goals and to take the initiative to reach these goals. It means making choices, learning to effectively solve problems, and taking control and responsibility for one's life.

Self-determination is important for all people, but it is especially important for young people with disabilities. The development of self-determination skills is a process that begins in childhood and continues throughout one's life. It is often parents and teachers who help children begin developing self-determination skills. Throughout life, individuals should have opportunities to make choices for themselves about the things they like and dislike or what they want and do not want.

Supporting families to encourage self-determination means providing them with education and resources so they are better prepared to help plan for future needs of family members. PACER's National Parent Center on Transition and Employment offers families links to a variety of information about planning, school, transition, employment, and other important topics; visit its website at:

<http://www.pacer.org/transition/>.

*Fostering Self-Determination Among Children and Youth with Disabilities* is a guide for families and caregivers to help lead them in the process of promoting self-determination beginning in early childhood. The guide, published by Waisman Center, University of Wisconsin-Madison, can be downloaded at:

<http://www.waisman.wisc.edu/naturalsupports/pdfs/FosteringSelfDetermination.pdf>

***“The only person you are destined to become is the person you decide to be.”***

***-Ralph Waldo Emerson***



# Community Calendar

**June 9, 2015** – Mental Health Champions’ Banquet, Jefferson City, Missouri  
For more information, click on: [http://www.missourimbh.org/?page\\_id=353](http://www.missourimbh.org/?page_id=353)

**August 16-18, 2015** – 2015 Real Voices, Real Choices Conference,  
Tan-Tar-A Resort and Conference Center, Osage Beach, Missouri  
For more information, click on: [http://www.missourimbh.org/?page\\_id=716](http://www.missourimbh.org/?page_id=716)

*“If a man does not keep pace with his companions,  
perhaps it is because he hears a different drummer. Let  
him step to the music which he hears, however measured  
or far away.”*

-Henry David Thoreau

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Improving lives THROUGH  
supports and services  
THAT FOSTER self-determination.

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**Fostering Self-determination**



**Supporting Families**



**Facilitating Individualized Services and Supports**



**Developing Accessible Housing**



**Promoting Employment First**

[www.dmh.mo.gov/dd](http://www.dmh.mo.gov/dd)

MISSOURI DEPARTMENT OF MENTAL HEALTH