

### WELCOME to the MODDRC/F2F PARTNERING TOGETHER!



he Missouri Developmental Disability Resource Center (MODDRC) and Missouri's Family-to-Family Health Information Center have joined together to give you an expanded set of resources. *Partnering Together* is just an example of the many tools we will be using to help you get connected with the information and resources available.

**Partnering Together** is for people who have, or care for others with, special health care needs or developmental disabilities. Inside, you'll find ways to meet others, news about programs & services, fun ways to strengthen your leadership and advocacy skills and the latest on everyday

life topics such as transition & insurance coverage. The stories inside come from people who are parents & caregivers of individuals with special health care needs and self-advocates who understand a not so "typical" life.

We're excited about the energy *Partnering Together* will bring to you and we want your stories to be a part of the info we pass along. Do you have news you'd like to share? Would you like to share your celebrations with others? We love receiving information on what's happening around the state, pictures of you, your kids & family or new resources. You can contact us for a consent form to share your story at moddrc.f2f.news@gmail.com.



# $M \cdot O \cdot D \cdot D \cdot R \cdot C$

THE MISSOURI DEVELOPMENTAL DISABILITY RESOURCE CENTER AND THE FAMILY-TO-FAMILY HEALTH INFORMATION CENTER

he Missouri Developmental Disability Resource Center (MODDRC) is operated by the University of Missouri Kansas City Institute for Human Development (UMKC - IHD.) The MODDRC began over 20 years ago with a mission to provide information specific to issues related to autism. However, over the last decade or so, the mission has expanded to include services for all developmental disabilities. The MODDRC provides information and referral, peer support and volunteer/leadership opportunities for families, individuals and professionals within the state of Missouri. The MODDRC is a project funded by the UMKC-Institute for Human Development, the Missouri Planning Council for Developmental Disabilities and the Department of Mental Health, Division of Developmental Disabilities.

In partnership with Family Voices of Missouri and the Missouri Bu-

reau of Special Health Care Needs, the UMKC-Institute for Human Development (UMKC-IHD) was recently awarded a federal HRSA grant through the Maternal & Child Health Bureau to establish a Family-to-Family Health Information Center (F2F). The addition of the F2F will increase the MODDRC's capacity to support families, children, teens and young adults with special health care needs as well as the professionals who interact with them. Other partners involved with this program are listed on the back page.

#### **INFORMATION**

Information and referral services are provided to individuals who call our toll free resource line, connect with us on-line or meet our staff in person at a conference display. We have over 500 packets of information on a variety of developmental disabilities/special health care needs and related topics. We also customize packets for topics we do not currently have on file.



We also have information available online at www.moddrc.org. Here you can read family stories and search for information by a specific health care need or disability and about a specific topic, like education or transition. You'll also find a calendar showing family-friendly events that are happening around the state. If you would like to receive our information in Spanish or another alternative format, just let us know and we will get them to you.

The MODDRC connects families to leadership and volunteer opportunities and provides training and resources to ensure that you can have the greatest impact on the organizations and individuals you support

#### PEER SUPPORT

The MODDRC is also home to the Sharing our Strengths (SOS) peer matching network. Individuals with special health care needs and/or a developmental disability and their family members can contact SOS when they would like to talk to another person who is dealing with similar circumstances. All mentors are trained and willing to positively share their experiences with someone else. Keep in mind that SOS isn't just for individuals and families, we also occasionally match professionals with other professionals.

#### VOLUNTEER AND LEADERSHIP OPPORTUNITIES

Individuals with developmental disabilities and/or special healthcare needs and their families who are actively involved in determining the types of services they receive and how they're services are delivered may not realize it but they are working to create successful family-professional partnerships. Being a member of a board or on a committee are also excellent ways to share your experiences about a developmental disability or special health care need are valuable not only to other families and individuals experiencing similar situations, but also to communities. The MODDRC/F2F can assist in building your individual, family and professional leadership skills through training and resources to connect to you with future leadership and volunteer opportunities to make a significant impact on programs and services that benefit others in your community.

To read more about specific volunteer opportunities see the article *We Need You* on page 8.



# JOIN OTHERS TO CREATE A STRONG VOICE IN MISSOURI

amily Voices of Missouri (FVMO) is looking for passionate people from throughout the state who have experience with special health care needs and would like to be a part of developing the structure and mission of the organization. Parents, caregivers, family members or professionals are all welcome! We will be holding a meeting in July to brainstorm on how we can develop FVMO as a statewide organization that will be here for our families now and in generations to come. Date, time and location will be determined by the schedule of those interested and announced later.

#### **ARE YOU INTERESTED?**

Would you like to be a part of the foundation of a grassroots community of leaders dedicated to making history? If so, contact Carla Sandwell by e-mail at familyvoicesmo@gmail.com or phone at 417.619.2609. We hope that you'll be able to join us and bring your ideas in July!





## EASIER ACCESS TO COMMUNITY SUPPORTS AND SERVICES

GOAL OF THE NEW INTEGRATED COMMUNITY SERVICES GRANT

he Maternal and Child Health Bureau of the U.S.
Department of Health and Human Services awarded a
grant to the UMKC-IHD, the Missouri Bureau of Special Health Care Needs and Family Voices of Missouri
"to improve and sustain access to quality, comprehensive, coordinated, community-based systems of services for Children and Youth
with Special Health Care Needs and their families in Missouri."

Among the key partners in this program are, Family Bridges, Missouri Families for Effective Autism Treatment (MO-FEAT), Missouri Parents Act (MPACT), Thompson Center for Autism and Neurodevelopmental Disorders at the University of Missouri-Columbia (MU), and the LEND Program at MU. These partners will be profiled in upcoming issues of the newsletter. As new partners are added, they too will be profiled.



The Integrated Community
Services (ICS) program recognizes the critical role of positive
"family-professional partnerships"
in identifying what children
and families need; developing a
responsive coordinated system of
supports and services that address
these needs; and working together
to sustain these supports and

services throughout the life-span. Recognizing that children with special health care needs become youth with special health care needs, having different requirements and interacting in a variety of different settings as they age, another focus of the program is on the involvement of youth in working for a successful "medical transition" from child to youth to adult health care systems.

Other areas of focus include: early and continuous screening; health insurance – public and private; the positive points/feasibility of a "medical home;" and the role of Emergency Medical Services.

According to the 2005/2006 National Survey of Children with Special Health Care Needs (SHCN) (www.shcndata.org), there are 223,070 children with special health care needs in Missouri. These numbers clearly show that there is a need in the state for well coordinated, community based services for these children and youth. In addition, while prevalence of children with SHCN ranges from 10% to 18.5% across the 50 states and the District of Columbia, Missouri's percentage is, on the high side, at 16.2% versus the national percentage of 13.9%.

During the three years of funding the ICS families and youth with disabilities will partner with professionals at the state and local levels and guide the effort to build the best possible system of health care services and supports in the state. What members of the initial partnership learn will be then shared with an everexpanding web of parents, youth, and professionals to ensure a broad based, sustainable, and culturally competent system of community-based care.



#### FOR MORE INFORMATION

- The UMKC Institute for Human Development: www.ihd.umkc.edu
- The National Survey of Children with Special Health Care Needs Data Resource Center: www.cshcndata.org
- The Department of Health and Senior Services -Children with Special Health Care Needs Program: www.dhss.mo.gov/SHCN/CSHCN.html
- The Department of Health and Senior Services Healthy Children and Youth (HCY) Administrative Case
  Management Program:
  www.dhss.mo.gov/SHCN/HCY.html

#### The Bureau of Special Health Care Needs



he Bureau of Special Health Care Needs (SHCN), of the Missouri Department of Health and Senior Services (DHSS), provides statewide healthcare support services, including service coordination, for children and adults with disabilities, chronic illness, and birth defects. State and federal funding support SHCN services, including the Title V Maternal and Child Health Block Grant. To be eligible for SHCN services, you must be a resident of Missouri, have a special health care need, and meet medical and/or financial eligibility when required. Both medical and financial eligibility vary between services, age or diagnosis. Financial eligibility is based on federal poverty guidelines.

Family Partnership is a program that SHCN began in 2001 from a national effort to recognize the value of learning from families through family involvement. Read more about Family Partnership on pages 6 and 7.

On March 18-19, SHCN service coordinators and staff met to learn valuable information to help meet the needs of those they serve. Topics included learning about grief and loss, caring for the caregiver, non-emergency medical transportation, and cultural sensitivity. On the second day of the meeting, attendees learned about People First language, medical home, Missouri's new Family-to-Family Health Information Center, peer-to-peer support, transition to adult health care and tools on early identification of Autism Spectrum Disorders.

For more information on SHCN services or to connect with your service coordinator, call 800.451.0669 or visit their web site at http://www.dhss.mo.gov/SHCN/.

# Over 100 Parents & Caregivers From Across the State Meet for the '08 Family Partnership Parent & Caregiver Retreat

he 2008 Parent/Caregiver Retreat was a tremendous success! We had over 100 parents, caregivers and family members of children and youth with special health care needs come together in Columbia from across the state on November 7 and 8. Each family received a night of hotel accommodations, free registration, meals and a stipend to help cover the costs for coming to the retreat.

Sometimes we over look how the smallest detailed information can make a difference in someone's life. When you have a child(ren) that requires you to live every day a little bit differently, you learn to appreciate the little things in life. Probably the best thing that we get from the retreat as Family Partners is when a participant comes to us sharing how much they appreciate being a part of the retreat. How fortunate they feel to know that they are not alone and there are so many other families out there facing the same challenges each day. That they are able to network with one another and keep in touch and help each other out throughout the year is what it's all about!!

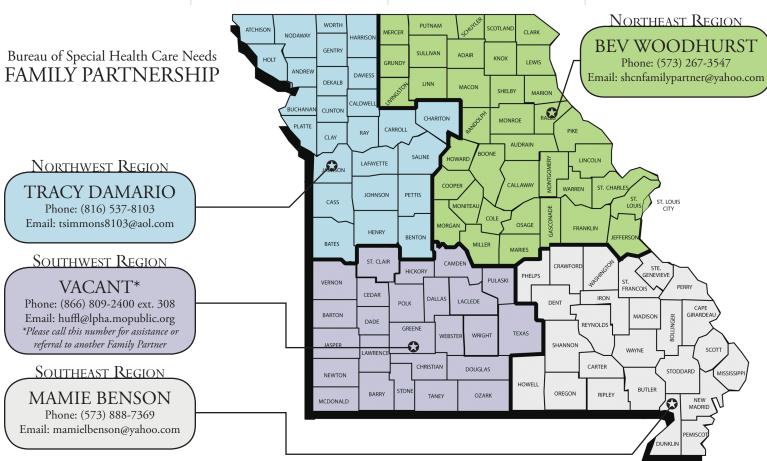
A big *THANK YOU* to all of the presenters who came and provided such invaluable information to our parents and caregivers on special needs planning, transitioning into adulthood, alternatives to guardianship and how to share our strengths with others. Rep. Jeff Grisamore shared his personal experience of caring for his daughter, Rebekah, who has special health care needs. The was topped off with many family-friendly exhibitors.

Thank you also to Gary Harbison, SHCN Chief, for giving a great overview of what Family Partnership is all about, what SHCN is doing to keep families at the table and for keeping Family Partnership going. Also, thanks to Kim Reinhardt with SHCN, for all the hard work she put in to the retreat and helping everyone out.

Last, but not least, a very special thank you to Lucretia Huff (Family Partnership Program Coordinator) and Miller County Health Center (MCHC) for doing a fabulous job of organizing registration information and making hotel arrangements for everyone. Great job, Lucretia, and MCHC!

MODDRC/F2F

#### Our Community | Our Community | Our Community | Our Community





# THE FAMILY PARTNERSHIP INITIATIVE

amily Partnership was formed in 2001 by the Bureau of 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. Family Partnership receives its funding from the Bureau of Special Health Care Needs through the Maternal and Child Health Title V Block Grant and is administered through an agreement with the Miller County Health Center.

Family Partnership is supported by four regional Family Partners who are parents, caregivers or family members of individuals

with special needs served by SHCN. The Family Partners provide information, referrals and support to individuals with special health care needs and their families.

Each of the four regions host interactive events designed to provide an opportunity for parents & caregivers to network and learn and provide input into the programs and services they are benefiting from. Family Partnership members include individuals with special health care needs, as well as parents, family members or legal guardians. However, professionals are encouraged to attend events in an effort to build positive family-professional partnerships.

#### HOW TO CONTACT US

www.dhss.mo.gov/FamilyPartnership Toll Free: 1-866-809-2400, ext. 308

#### Family Partners:

#### Northwest – Tracy Damario

- Phone: (816) 537-8103
- Email: tsimmons8103@aol.com

#### Northeast - Beverly Woodhurst

- Phone: (573) 565-2030
- Email: shcnfamilypartner@yahoo.com

#### Southeast - Mamie Benson

- Phone: (H) 573-919-4143
  - (C) 573-888-7369
- Email: mamielbenson@yahoo.com

#### Southwest - Lucretia Huff

- Phone: (866) 809-2400 ext. 308
- Email: huffl@lpha.mopublic.org

Family Partnership Administrative Office Miller County Health Center P.O. Box 2 Tuscumbia, MO 65082



#### TRACY DAMARIO

Welcome! As the Northwest Family Partner, I find working with families and professionals • very fulfilling! With over 16 years of experience of being a mom to our blended family's four children ages 3-16, I know the struggles and celebrations many families face. All of my children are so much more than their disabilities.

but I share their "diagnosis" with you to give you a glimpse of my experiences of navigating the pathway to find services and funding to meet the needs of our family. Our three oldest are on the Autism Spectrum while individually they have Epilepsy, learning disabilities and Reactive Attachment Disorder. Our youngest was born prematurely. Early on, I recognized the value of the support and information I received from other parents that had children with disabilities. I am here to help you with whatever information and support you need. Call me and I will get you connected!



I am mom to Keith, Darcy, Tanner and Evan and live with them in Northeast Missouri. Aside from being a Family Partner, I own my own insurance business. I have worked in the special health care needs/disability field in some shape or form for 20 years. Each of my children have very unique abilities and definitely keep things hopping at my house and in school. I very much enjoy getting to work with the families in my area as well as on a statewide level in finding resources and education information for their children, as well as empowering families to always take that extra step to make things happen for them! I have served on many panels and boards across Missouri and am also a 2001 Partners in Policymaking graduate. Feel free to contact me at any time if you have questions, needs, or need a parent to talk to!

# SOUTHWEST REGION



#### ARE YOU INTERESTED IN BECOMING A **FAMILY PARTNER?**

Miller County Health Center is looking for a dedicated and passionate family leader living in the Southwest Missouri area with experience of caring for a child or youth with special health care needs. For more information about benefits and responsibilities or to apply, contact Lucretia Huff at huffl@lpha.mopublic.org or by phone at (866) 809-2400 ext. 308.

#### **MAMIE BENSON**

Welcome from the beautiful bootheel area! I've been married to my husband, Michael, for 39 years and have four children, twenty grandchildren, and three great-grandchildren. Our oldest grandchild, Mandi was born with multiple developmental disabilities and I knew nothing about what there was available in the way of therapies, medicines, equipment or specialists. For more than 20 years, I have been very



active in working with those who have developmental dis-Abilities. Whether it is information or equipment, someone has to know the answer as to where to go or who to ask! I really try to help close that gap and give the families a little peace knowing there is someone out there who cares and that they can talk to, ask questions and help find what they need. Call me if I can help you!



# WE NEED YOU! MAKING A DIFFERENCE IN YOUR COMMUNITY

he MODDRC/F2F is excited to offer parents and family members numerous opportunities to be involved in volunteer and leadership activities. Volunteer opportunities can include such things as reviewing products to ensure that they are family friendly and provide the type of information that is most helpful to families. Other opportunities include writing your personal perspective about your experience with a disability or special health care need. The MODDRC/F2F also likes to connect family members and individuals to leadership opportunities in their community either through advisory committees or board membership.

Other opportunities include being a display assistant for the MODDRC/F2F or other family support program that might need assistance at an event. Keep in mind that as a display assistant your registration to conferences is covered. It could be an opportunity to not only volunteer your time and network with others but also attend conferences and events you otherwise might not be able to attend.

The Sharing our Strengths peer mentoring program also offers volunteer opportunities for those interested in being mentors. Peer mentors are always needed to support families. To learn more about the mentoring experience read the volunteer spotlight on this page.



#### VOLUNTEER SPOTLIGHT

#### **DEBBIE SMALL**

In August of 2008, Debbie Small became a new volunteer mentor for the Sharing our Strengths peer support program. Like most moms, Debbie wears lots of hats and has many responsibilities but she decided to be a volunteer mentor because she was grateful for those who had supported her when she was experiencing a new diagnosis for her son.

Debbie has already mentored a couple other moms for the Sharing our Strengths program. One mom had this to say about Debbie, "Debbie was wonderful, she listened to me and it was so nice talking to someone who understands what it's like when you just learn that your child has Autism. Debbie even offered to meet with me in person."

Being a mentor means just "being there." More often than not it only requires four or five conversations which can be done on the phone or by e-mail. "My experience has been really positive. I really appreciated having those people who have helped me navigate different circumstances with my son. If I can be that person for someone else, then I'm thrilled."



# COMMUNICATING YOUR POSITION EFFECTIVELY

ne of the most frustrating experiences we can have is when we are trying to share our point of view only for it to be misinterpreted or misunderstood. This can be particularly frustrating when we are trying to advocate on behalf of ourselves or a loved one. There are several steps you can take to increase the likelihood that your point of view is heard and understood.

#### SCHEDULE A TIME TO TALK

When communicating with someone about a need or issue that is important to you, make sure you have their undivided attention. If possible, schedule a time to meet and discuss the issue. If that isn't possible, try and meet in a location where you are not likely to be interrupted.

#### PRACTICE TELLING THE STORY

Practice what you might say. Remember that emotion certainly has its place but the more facts you can provide and the more concise you can be while still making a well thought out point, the more likely you will be heard.

#### **BE POSITIVE**

Your body language can sometimes tell a louder story than what actually comes out of your mouth. If you portray a defensive and angry demeanor then the person listening will probably become defensive as well. The same is true for what comes out of your mouth. Be genuinely polite and listen to the responses of the individual you are talking to.

#### LISTEN

Listen as much as you talk. Even though you may disagree and dislike the response you receive, keep in mind that becoming angry, interrupting or yelling stops productive communication. You can still disagree and express your dislike for the situation but you are more likely to start a process of coming to a compromise if you listen to the other person's point of view. By no means do you have to sacrifice your point of view but by carefully listening to another perspective you gain information that will help you to find a compromise. Listening intently also allows you to learn new information and even appreciate a different perspective. Mutual respect is a much better negotiator than angry words and closed minds.

Following these steps can improve your communication and hopefully create positive outcomes in your interaction with others. Keep in mind, however, that there are no guarantees. Effective communication takes more than one person. When the listener causes barriers to communication it can be very difficult to share your perspective. Model a communication style that is positive and respectful and at the end of the conversation you know you did all you could to reach an agreeable solution.



### How Can We Help Shape Policy? National and State Disability Issues

he national and state elections of 2008, along with the financial problems faced by the states and the country will have a direct impact on public policy related to children and adults with disabilities and their families. However, advocates have reasons to be hopeful. Two motivators are the commitment by the Obama-Biden administration to disability issues and the commitment of Governor Nixon to restoring life to MO HealthNet, Missouri's Medicaid program.

#### NATIONAL DISABILITY EFFORTS

When Barack Obama ran for president, he had a specific disability plan, which would:

- 1. Provide children and adults with disabilities with the educational opportunities they need to succeed by:
  - funding the Individuals with Disabilities Education Act;.
  - supporting universal screening and early intervention for children with disabilities;
  - improving college opportunities for high school graduates with disabilities, and making college more affordable; and .
  - Authorizing a a comprehensive study of students with disabilities and issues relating to transition to work and higher education.
- 2. End discrimination and promote equal opportunity by:
  - ensuring enforcement of the Americans with Disabilities Act and other important disability rights laws;
  - ensuring affordable, accessible health care for all: and
  - improving mental health care.
- 3. Focus on increasing the employment rate of individuals with disabilities and supporting independent community-based living so people can live in their communities rather than having to live in a nursing home or other institution by
  - creating a voluntary, budget-neutral national insurance program to help adults who have or develop disabilities to remain independent and in their communities, and
  - streamlining the Social Security approval process

President Obama and Vice President Biden also are very focused on supporting Americans with Autism Spectrum Disorders ("ASD"), their families, and their communities by:

- increasing funding for autism research, universal screenings, treatments, public awareness, and support services.
- improving life-long services for people with ASD for treatments, interventions, and supports and services for both children and adults with ASD.
- working with Congress, parents and ASD experts to determine how to further improve federal and state programs for ASD.

#### **MISSOURI DISABILITY EFFORTS**

When former Governor Blunt made drastic cuts to the Medicaid program, many children and adults with disabilities and their families were affected – and not in a good way. In fact, restoring access to Medicaid became one of the major campaign goals of the Missouri's newly sworn-in governor, Jay Nixon. At this point in time, Governor Nixon and his administration face numerous hurdles to accomplishing this goal. The state is facing financial problems (but not as bad as some other states). The state also is facing a large increase in the number of unemployed workers, many of whom have children, with or without disabilities, who may end up having to rely on either Medicaid or the State Children's Health Insurance Program.

If the state of Missouri spent \$265 million on restoring cuts to Medicaid, it would get at least \$400 million in federal matching funds Also, according to the Medicaid Calculator at http://www.familiesusa.org/issues/medicaid/other/medicaid-calculator/medicaid-calculator.html?state=Missouri, this investment would bring more than \$950 million in new business activity, more than \$,000 jobs, and more than \$350 million in salaries and wages. This is a win-win situation.

There are many challenges that lie ahead at both the state and national levels. This makes it more important than ever for people with disabilities, their families, friends, and other advocates to be "at the table" when decisions are made. Upcoming editions of this newsletter will address specific legislative and regulatory issues. However, we are wrapping up this column with contact information for your state and national senators and representatives.

It is critically important that we all come together to "educate our policymakers" on the values and goals of importance to children and adults with disabilities and their families.

#### WEB SITES/RESOURCES

- General and contact information for MO House Members http://www.house.mo.gov/
- General and contact information for MO Senate Members http://www.senate.mo.gov/
- Specific information on legislation in the General Assembly http://www.moga.mo.gov/
- General and contact information for U.S. Representatives http://www.house.gov
- General and contact information for U.S. Senators http://www.senate.gov
- Specific information on legislation in the U.S. Congress http://thomas.loc.gov/

### What's Happening Around the State

#### THINKING ABOUT GUARDIANSHIP?

The {Alternatives To} Guardianship Project seeks to empower individuals with developmental disabilities and their families to make informed decisions about guardianship issues and to explore less-restrictive alternatives to guardianship. The training is provided FREE of charge to participants.

#### Module I - The Pre-Determination Process

- Are you concerned about the safety or protection of a family member with a disability?
- Are you the parent or family member of an individual with a disability who is turning 18?
- Has someone suggested you should pursue guardianship for your family member?
- Did you know there might be options you're not aware of that would work for your situation?
- Do you work with individuals or families who may be considering these issues?

#### Module II - The Redetermination Process

- Are you a person who has a guardian? Did you know there might be options you're not aware of that would work for your situation and help you regain some of your rights?
- Are you a parent or family member who currently has guardianship of a loved one?
- Are you a professional who works with individuals or families who may be considering these issues?

The Project is funded by the Missouri Planning Council on Developmental Disabilities (MPCDD)

In collaboration between: Missouri People First, UMKC - Institute for Human Development, UCEDD (IHD), Missouri Protection & Advocacy Services (Mo P&A)

#### June 18 - Columbia Boone County Family Resources

1209 East Walnut • Columbia, MO 65201

Module 1 - 5:30pm - 7:30pm Module 2 - 8:00pm - 9:30pm

Participants may choose to attend one or both modules. Please specify when you RSVP.

#### June 26 - Osage Beach The Church at Osage Hills

5237 Highway 54 • Osage Beach, MO 65065 Sponsored by The Arc of the Lake

6:00pm - 8:00pm

#### July 14 - Kirksville Kirksville Regional Office

1702 E. LaHarpe • Kirksville, MO 63501

Module 1 - 6:30pm - 8:30pm

Module 2 - 4:30pm - 6:00pm

Participants may choose to attend one or both modules. Please specify when you RSVP.

For more information or to RSVP contact: Elizabeth Moran @ 816-235-5359 or morane@umkc.edu

REAL VOICES - REAL CHOICES: EXPANDING OUR VISION MISSOURI'S CONSUMER, FAMILY & YOUTH LEADERSHIP CONFERENCE Tan-Tar-A Resort, Osage Beach, MO August 23 - 25, 2009

#### Sponsored by:

Missouri Department of Mental Health Missouri's Mental Health Transformation Initiative

For on-line conference-planning updates, go to: www.missouridmh.typepad.com/realvoicesconference

#### For more information:

call Carol Dickneite in the Office of Consumer Safety at 573-751-8088 or 1-800-364-9687 (toll-free outside of Jefferson City)

SAVE THE DATE:
2009 FAMILY PARTNERSHIP
ANNUAL PARENT &
CAREGIVER RETREAT
December 4 - 5, 2009
The Inn at Grand Glaize
Osage Beach, MO

Would you like others to know about your upcoming event?

Share your event information with the *MODDRC/F2F Partnering Together* team at moddrc.f2f.news@gmail.com.

2220 Holmes St., 3rd Floor Kansas City, MO 64108

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### PARTNERING



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#### Our Partners.

TIPS



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#### 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.



**UMKC - IHD** 

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. 800-452-1185 | www.ihd.umkc.edu



**FAMILY VOICES OF MISSOURI**FVMO is a

statewide organization dedicated to informing, strengthening, educating and empowering Missouri's children, youth and adults with special needs and their families to become respected & valued leaders and to collaborate with professionals who care for

them to design and improve efficient policies, programs, services and systems of care that affect them personally and the community they live in. 417.619.2609 | www.fvmo.org



#### DHSS

The Department of Health and Senior Services serves the citizens of Missouri by working to improve the health and quality of life for Missou-

rians of all ages. Within DHSS is the Special Health Care Needs which provides services for children and adults with disabilities, chronic illnesses, and birth defects. The services available from SHCN depend on the condition or illness of the individual and include diagnostic and treatment services, service coordination and Adult Head Injury Rehabilitation Services. 800.451.0669 | www.dhss.mo.gov/SHCN/index.html



#### **MPCDD**

The Missouri Planning Council for Developmental Disabilities is a 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| www.mpcdd.com

#### **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.



#### Missouri Developmental Disability Resource Center/Family-to-Family Health Information Center

At the MODDRC/F2F, we offer Missouri individuals with disabilities and/or special health care needs of all ages, their families and professionals support, connections and opportunities to strengthen leadership skills and participate in program & service decision-making. When you connect with us, you are linking directly with self-advocates, parents, caregivers and family members whose lives are touched daily by health-care or disability celebrations and challenges. Because of our experiences, our information is offered in a personcentered, easy to understand, and culturally friendly way. 800.444.0821 www.moddrc.org