

PARTNERING TOGETHER



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IT'S THAT TIME AGAIN! BACK TO SCHOOL ...



Starting a new school year means a lot of things. Often it's the sign that summer fun is over.

For students, it's the thrill of getting to see or hear friends they've missed or possibly the anticipation of meeting new ones and going to pick out new school supplies and clothes!

For parents and family members, it's the thought of buying school clothes and supplies ... or maybe wondering how they'll do themselves on the first day of school watching their child enter the school doors or get on the bus for the first time ... or being a strong part of getting their child's IEP or 504 plan together.

For educators, it's time to start getting their rooms together, figuring out lesson plans and sometimes even launching their year at a new school.

For us at the MODDRC/F2F, we're excited to bring this issue of Partnering Together to you because we've filled it with articles and tips on education to help you get a jump on the school year. For example, individualized education plans, alternatives to guardianship, and planning for the future!

We wish you a great start to the '09-'10 school year and if you need other resources after the school year gets underway, connect with us! We're here to help you and your student(s) have the best school year ever ...





M•O•D•D•R•C

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



PARTNERS MEET TO TALK ABOUT ENSURING RESOURCES FOR THE FUTURE

“Sustainability” was the topic of the day ... and what usually can be a depressing topic (because of lack of money) actually turned a group over 30 self-advocates, families and professionals from across Missouri into a group trying their best to wait for their own turn to share ideas. One could literally feel the enthusiasm of the group raising their arms to non-verbally say “pick me, pick me!”

emotional support. On nearly table size paper, a large list quickly came from all of the groups with thoughts like:

- *knowing where to start and starting early*
- *understanding how to work with more than one system*
- *developing a positive vision for their future*
- *the feeling of empowerment families get when they help other families traveling a similar path*



On June 30, the group met at the UMKC-Institute for Human Development to talk about how to partner together to keep the MODDRC/F2F resources available for the next generation of users. The MODDRC/F2F provided the group with a yummy lunch and reimbursement of travel expenses for self-advocates and family members.

The break out groups continued their discussion asking each other if the MODDRC/F2F is meeting the needs of those they serve and how they could do better.

Jim Collier, Director for the Sickle Cell Disease Association of America’s Kansas City Chapter, enjoying his first MODDRC/F2F stakeholder meeting announced within his group, “Sounds like they’re doing a great job!”

MODDRC is a MUST for referrals! They’re thorough, expedient, consistent, reliable, deep, comprehensive, connected!

- GEORGIA MUELLER

The group began talking about how they describe the MODDRC/F2F and its services to others.

Richard Enfield, a dad, creatively summarized it by saying, “It’s a safety net when you’re in freefall.”

Georgia Mueller, a mom and MPact Regional Coordinator says, “MODDRC is a MUST for referrals! They’re thorough, expedient, consistent, reliable, deep, comprehensive, connected!”

As far as doing better ... the group was quick to point out that more self-advocates, families and professionals need to know about the services the MODDRC/F2F offers. So how do they do that? The group rapidly responded with cost-efficient methods like writing articles for other organizations newsletters, using public service announcements, creating videos to share on social networking sites like YouTube, Facebook and Twitter and having MODDRC volunteers pass out information.

Breaking into five groups, the participants shared within their group what they felt are the greatest needs of their family or those they offer their programs and services to on information, volunteer-leadership and

Sounds great! When do we meet again? Sheli Reynolds has that answer, so if you’re interested in being a part of the next meeting, contact her by e-mail at reynoldsmc@umkc.edu or 816.235.1759! ●

SHARING OUR STRENGTHS ...

YOU ARE NOT ALONE!

It's that time again! School will be back in session in a few weeks. During this time, the MODDRC/F2F gets more calls from parents, family members and other individuals wanting to know how to prepare for the new school year.

For many people, this time can be very stressful. You are NOT alone! Sharing our Strengths can help you connect with mentors who are also parents, family members or caregivers and have had similar educational or other experiences. SOS trained mentors are supportive and can help you with whatever is happening in your life because they have been there also.

Here are just a few of the connections the MODDRC/F2F makes for family members and self advocates.

- Sarah is a mom with three children who moved to Missouri this spring. The family is experiencing a new town, new home, new people, new school and everything in between. Sarah's oldest daughter has Autism while her youngest daughter has Cerebral Palsy. Both girls struggle with school. Mom doesn't drive and feels isolated. Sarah contacted the MODDRC/F2F looking for resources and ways to connect with her community. She really wanted to talk to another parent or family member in her school district to get the "lay of the land" as she put it.
- "Some strange things are happening here." That was what Kate told the Sharing our Strengths Coordinator when she connected with us looking for help understanding the changes happening in her school district. She didn't want to talk to the



Special Education Coordinator or her child's teacher. She just wanted to talk to another person with a child receiving Special Education Services in her district to see if their experiences were like hers.

- Bob is a single dad whose son has just been re-diagnosed as having a severe emotional disturbance (SED) by his school. He is working with MPact (Missouri Parent Act) to help him advocate to make positive changes and make sure that his son is receiving the supports he needs to help him learn at school. But outside of that, Bob also wants to talk to another person who has been there of having his or her child diagnosed with a severe emotional disturbance.

Besides being able to talk with others who have been there too, they also received family friendly information on services and supports that could help them more. ●

Would you like information on helping your student with their education planning? Have you been there before and would like to help others as an SOS mentor? Just call us at 800.444.0821 or find us on the web at www.moddr.org.

Remember, you are NOT alone!

FAMILY VOICES[®]
of Missouri

JOIN THE TEAM

INTERESTED IN BECOMING A PART OF OUR BOARD?

We're looking for people from across the state with a variety of experience, skills and passion for strengthening the lives of children, youth and young adults with special health care needs to help us expand our Board of Directors. This includes self-advocates, parents, family members and professionals! If you're interested, contact Carla by e-mail at familyvoicesmo@gmail.com or 417.597.3197.

LOOK FOR OUR NEW PORTAL COMING SOON!

We're excited about the development of our new web site. You'll soon be able to find us online at www.fvmo.org. If you'd like to help us build our new portal by allowing us to share your information with others or your organization's interested in becoming one of our partners, e-mail it to us at familyvoicesmo@gmail.com. Be sure to let us know you'd like us to share your information on our web site.

ARE YOU ON FACEBOOK? WE ARE!

Find our group by searching "Family Voices of Missouri". Here we're tracking the most recent developments on Health Care Reform initiatives, listing events of interest and sharing ways that you can become more involved in advocacy for children and youth with special health care needs! ●





ALTERNATIVES TO GUARDIANSHIP

ATTEND TRAINING TO LEARN ABOUT YOUR OPTIONS

In partnership with Missouri Protection and Advocacy, People First of Missouri, and UMKC'S Institute for Human Development, The Missouri Planning Council for Developmental Disabilities is sponsoring a series of workshops on "Alternatives to Guardianship".

Many assume that people with developmental or physical disabilities automatically require a "guardian" when actually, they may need help understanding the decisions they're making. Guardianship can provide a person with needed assistance, but sadly it also takes away many of their rights.

Module One of the training (Pre-determination) is for those who might be considering obtaining guardianship for a loved one, so that they might consider less restrictive alternatives. Module Two (Re-determination) is for those who would like to either overturn

or reduce the level of guardianship for themselves or a loved one. Participants learn about a "tool" to assist with identifying a person's ability to make decisions and manage key areas of life such as employment, money, community living, and directing their own supports & services. Then, they learn about options that often meet the unique needs of people with disabilities and do not require obtaining full guardianship.

Co-Trainers Lisa Sutherland, an attorney with Missouri Protection & Advocacy Services (Mo P&A); Elizabeth Moran, an attorney with the Institute for Human Development at UMKC (IHD); and Jane St. John, a parent & Community Inclusion Specialist with IHD will be presenting workshops throughout the early fall. Watch for dates in your area.

For more information, call 816-235-5359. ●



PARTNERING WITH YOUR CHILD'S SCHOOL NURSE TO DEVELOP AN INDIVIDUAL HEALTH PLAN

Students who have serious, acute, chronic or life threatening medical conditions often have special health care needs at school and school events. They may need an Individual Health Plan (IHP). An IHP is a formal written plan developed by the school staff together with the student's family, school nurse, health care professionals and the student.

What is an Individual Health Plan (IHP)?

- Formal plan that defines student's needs due to the health condition
- Plan to resolve needs with goals, outcomes, priorities and timelines

Why an IHP?

- Ensures the school has information & authorization
- Specifies changes to the student's needs
- Addresses family & school concerns
- Clarifies roles & responsibilities
- Establishes ongoing teamwork, communication & evaluation
- Addresses transportation needs

Students Who Might Need an IHP

May include, but are not limited to those with:

- Asthma
- Seizure Disorder
- ADHD
- Chronic or acute medical conditions (cystic fibrosis, diabetes, cancer)
- Physical disabilities
- Medication and medical needs
- Serious allergies

If Your Child's Health Issues Impact Him/Her in Ways Listed Below:

(You will want to meet with School Personnel to ensure medical and educational needs are being met)

- Medication administration and management
- Emergency planning
- School attendance
- Fatigue & endurance issues
- Need for hygiene assistance
- Disease symptoms & medication side effects that may affect learning
- Pain or pain medication that impairs concentration and stamina

- Disease/condition that places student at increased risk of infection
- Management and administration of health care intervention (e.g., tube feedings, trach suctioning, chest percussions, etc.)

What Should an IHP Include?

- Child's diagnosis and health care needs
- Required accommodations
- Goals, interventions, outcomes & timelines regarding appropriate self-care
- Make-up instruction for those with temporary or chronic illnesses or injuries
- How instructional time is impacted by health care needs
- Medication dosage schedule or necessary medical interventions
- Emergency plan
- Special services required, including field trips
- Support from staff on health care needs

How do I Participate in the IHP?

- Get medical orders from child's doctor/providers
- School nurse creates plan after review of medical orders from doctor/providers
- Can be part of a Section 504, IEP or stand alone plan (see definitions below)
- Each plan is unique to student's needs

Individual Education Plan (IEP) - See page 8 for more info

An IEP may be the appropriate place to include a student's IHP if the disability adversely affects the student's educational performance and/or falls within the Other Health Impairment (OHI) or any other special education eligibility criteria. Students who have an IEP are protected under the Individuals with Disabilities Education Act (IDEA).

Section 504

The IHP may also be included in a student's Section 504 plan. Section 504 is a law that protects students with disabilities and ensures that they have equal access to an education. - See page 9 for more info.

Contact us at the MODDRC/F2F if you have questions on how to develop and IHP for your student. ●



THE FAMILY PARTNERSHIP INITIATIVE



9TH ANNUAL PARENT & CAREGIVER RETREAT

Are you tired of striking out when trying to get supports and services for your child with special health care needs? OR have you been benched more times than you can count? If so then don't miss this year's retreat where we will get you in the game!

Family Partnership is excited to host their **9th Annual Parent & Caregiver Retreat "Get in the Game,"** an event designed especially for Missouri parents, legal guardians and caregivers (18 and older) of children, youth and young adults with special health care needs. This year's Retreat will be held at The Inn at Grand Glaize in Osage Beach, MO on December 4th-5th. We hope to see you there! ●

HOW TO CONTACT US

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

Family Partners:

Northwest – Tracy Damaro

- Phone: (816) 213-8103
- Email: tsimmons8103@aol.com

Northeast – Beverly Woodhurst

- Phone: (573) 473-8873
- Email: shcnfamilypartner@yahoo.com

Southeast – Mamie Benson

- Phone: (573) 919-4143
- 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

NORTHWEST REGION



TRACY DAMARIO

Fall is fast approaching and once again the school year will begin. Having children with disabilities can always make for a stressful start of any school year. If you have any educational concerns be sure to contact our local MPACT office at 816-531-7070 so that their staff may assist you.

Our next regional meeting will take place in September or October in the Warrensburg area. We hope that this will allow some new and old families to participate. Please watch your e-mail and mail box for the meeting notice.

We are looking forward to our annual retreat the 1st weekend in December. We are very excited for the opportunity to spend face to face time with our families.

Please don't hesitate to contact me via e-mail: tsimmons8103@aol.com or phone: 816-213-8103. ●

NORTHEAST REGION

BEV WOODHURST

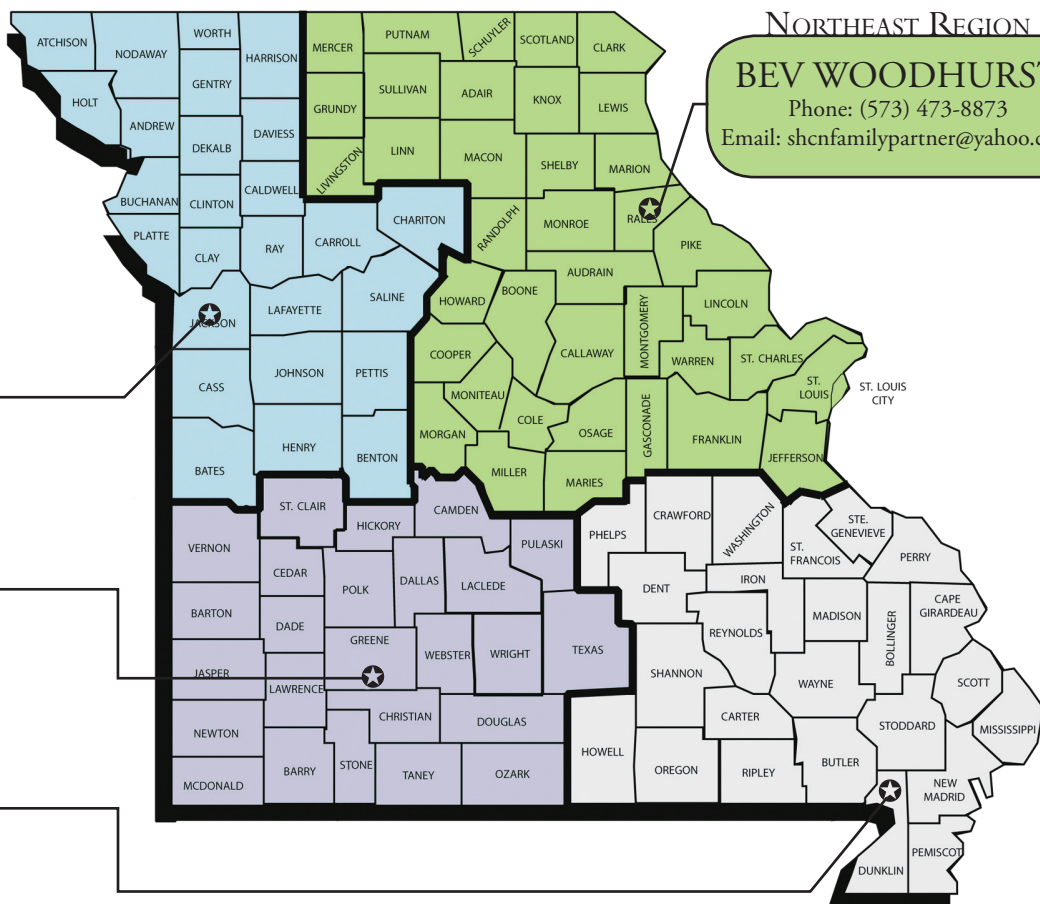
School is just around the corner. If you haven't started thinking about supplies yet, now might be a good time to get a head start on it. If you think you may have some trouble getting what your child needs to start, try calling your local community action corporation. This is one of many organizations that can help find what you need. Call 573-324-2213 to find the local office near you.

If you have an IEP meeting coming up, or one later in the year, it's always good to brush up on your educational knowledge, rights, laws, etc. For assistance contact MPACT (Missouri Parents Act) at www.ptimpact.org for more information.

Be watching your mail for updates on our regional meeting in September, as well as our annual retreat December 4-5 in Osage Beach!! ●



Bureau of Special Health Care Needs
FAMILY PARTNERSHIP



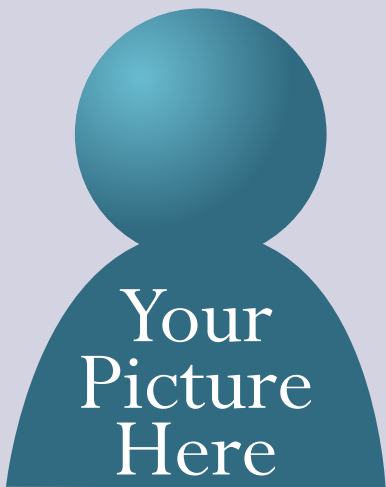
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**Please call this number for assistance or referral to another Family Partner*

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MAMIE BENSON
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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. ●

SOUTHEAST REGION

MAMIE BENSON

The Southeast Region for the Family Partnership has been a busy one. There are so many families and individuals that need help but don't know where to turn for it. As a Family Partner for SHCN, I am trying to reach those families. Getting information out to families makes a difference, in everyone's life. There is help out there, let's get it out to families and the people who need it. Every mile traveled, every phone call made, every e-mail, and each meeting is worth it, the rewards of knowing people who need help and information is getting it!



I look forward to seeing everyone at our retreat this year on December 4th-5th at the Inn at Grand Glaize in Osage Beach, MO. ●



WHAT'S AN IEP?

SUPPORTING STUDENTS IN SPECIAL EDUCATION

Once determined that a student qualifies for special education and related services, the next step is to develop an Individualized Education Program (IEP). According to the Individuals with Disabilities Education Act (IDEA), parents are to be full participants in the decision process when it comes to identification, evaluation, educational placement and the provision of a free and appropriate public education (FAPE).

IDEA §300.503(a)

NOTIFICATION OF IEP MEETING

The district must ensure that parents are notified of and have a chance to participate in the development of the IEP. Parents should be notified, in writing, at least 10 days (MO Standards & Indicators Manual 300.360(f)) before the proposed meeting date. The notice must include the time, date and location of the meeting. It must also include who will be attending and the purpose of the meeting. If the date proposed does not work for a parent they should notify the school, in writing of dates and times that would work for them.

IDEA §300.503(a)

DEVELOPING THE IEP

The purpose of developing an IEP is to ensure that a student with a disability receives special education, related services and supports

necessary to meet the students unique needs; is involved and progresses in the general education curriculum; and is educated with non-disabled peers in the least restrictive environment. This plan must be developed before services can be implemented.

IDEA §300.503(a)

TEAM MEMBERS

The IEP team must include: the parents of the student; if the student participates in the general education environment, at least one general education teacher; a representative of the district who is knowledgeable about the general education curriculum and available resources of the district; other individuals at the discretion of the parent or the district; the student, if considering transition services needs or needed transition services. IEP members can be excused from all or part of an IEP meeting if they submit their information and if parent agrees to excuse them.

IDEA §300.503(a)

WHAT SHOULD AN IEP INCLUDE?

Several components to the IEP need to be discussed and developed at the meeting and stated in the IEP document, below is a list of needed components:

- *Present Level of Academic Achievement and Functional Performance*



- *Measurable Annual Goals and Objectives*
- *Special Education and Related Services*
- *Supplementary Aids and Services*
- *Program Modifications and Accommodations*
- *Testing Modifications and Accommodations*
- *Support for School Personnel*
- *Transportation Needs*
- *Participation in General Education*
- *Participation in Non-Academic and Extra Curricular Activities*
- *Participation in State and District-wide Testing*
- *How student Progress will be measured*
- *Initiation and Duration of Services and Modifications*

- *Transition Services (beginning at age 16)*
- *Placement Options Considered*

IDEA §300.320

Once an initial IEP is developed and placement determined, the parents must give written consent to the initial placement decision before services may be implemented. ●

IDEA §300.324

Courtesy of Missouri Parents Act (MPACT)

For more information about IEP's, contact MPACT at 800-743-7634 or www.ptimpact.org.



UNDERSTANDING SECTION 504

EDUCATIONAL ACCOMMODATIONS FOR SUCCESS

Section 504 is not a “place” but an anti-discrimination law (Section 504 of the Rehabilitation Act of 1973) which says that a person can't be excluded from a federally-funded program or activity because they have a disability.

A “504 plan” basically allows accommodations in education for a student with a disability. Section 504's definition of a disability is the same as the American's with Disabilities Act of 2008, which is now more broad and inclusive than it had been.

Requesting an evaluation is the first step to see if the student qualifies for a 504 plan. Requests can be made by the student, their parent/caregiver or a professional. The evaluation is not a “test” but a look at the student's learning progress by a team of people who know the student like the student, family members, teachers, education advocate, Section 504 Coordinator, etc. Grades and observations from family members, healthcare professionals & teachers help determine the educational needs of the student and how to provide them with a least restrictive

environment. If a student requires “related services” then the team should consider implementing an IEP instead. Just as with an IEP, the student's parents/caregivers are required to receive a copy of procedural safeguards and should be involved in all team meetings.

For more information on 504 plans, contact Missouri's Parent Training and Information Center, MPACT, at (800) 743-7634, www.ptimpact.org or info@ptimpact.org. ●

QUICK INFO ON 504'S ...

- *Protecting Students With Disabilities*
Frequently Asked Questions About Section 504 and the Education of Children with Disabilities
<http://www.ed.gov/about/offices/list/ocr/504faq.html>
- *What's the difference between an IEP or 504 plan?*
<http://ptimpact.org/eSource/Documents/Differences504IDEA.pdf>





RESTRAINT AND SECLUSION IN SCHOOLS

A STUDENT AND THEIR FAMILY'S RIGHT TO KNOW

More on Restraint and Seclusion

- Should Schools Use Restraint and Seclusion Parade Magazine, July 26, 2009 <http://www.parade.com/news/intelligence-report/archive/090726-should-schools-use-restraints-on-students.html>
- School is Not Supposed to Hurt National Disability Rights Network (2008) www.ndrn.org/sr/SR-Report.pdf
- Seclusions and Restraints: Selected Cases of Death and Abuse at Public and Private Schools and Treatment Centers (Report # GAO-09-719T) U.S. Government Accountability Office (2009) www.gao.gov

The use of restraint and seclusion in schools is an issue that everyone should be concerned about. Currently, there is no federal law defining and restricting the inappropriate use of restraint and seclusion in public and private schools. State laws are inconsistent on their definition and policies.

Disability advocates in Missouri have been hard at work investigating this issue and trying to get legislation that defines restraint and seclusion with rules that will guide or prohibit their use. On July 13, 2009, Gov. Nixon signed into law SB 291 which changes the requirements relating to education including the use of seclusion rooms. It requires “school district discipline policies to prohibit confining a student in an unattended, locked space except for an emergency situation while awaiting the arrival of law enforcement personnel.” As a part of this Act, DESE is required to collaborate with “associations, organizations, agencies, and individuals with specialized expertise in behavior management” (this includes parents and family members), to develop a model policy by July 1, 2010. School districts are required to adopt their own written policy to address “the use of restrictive behavioral interventions as a form of discipline or behavior management technique, as described in the act” by July 1, 2011. (See www.senate.mo.gov on SB 291)

The National Disability Rights Network’s (NDRN) issued a report *School is not Supposed to Hurt* (December, 2008) showing the risks of restraint and seclusion like severe physical injury, mental trauma

and even death. It offers positive solutions instead of restraint and seclusion such as training staff on the student’s needs and the use of positive behavior supports.

When members of the US Congress read NDRN’s report, they ordered the U.S. Governmental Accountability Office (GAO) to do a study on the issue. The GAO report, *Seclusions and Restraints – Selected Cases of Death and Abuse at Public and Private Schools and Treatment Centers*, (May, 2009) looked at 10 restraint and seclusion cases where there was a criminal conviction, a finding of civil or administrative liability or a large financial settlement. The cases all had a common bond involving students with disabilities who were restrained and secluded, most often when they were not physically aggressive and without their parents/caregivers consent.

As a result of both reports, the agendas of Rep. George Miller (D-CA) and Sen. Christopher Dodd (D-CT) include introducing and passing federal legislation addressing this topic. Secretary of Education, Arne Duncan, has asked every state to submit to his office its plan for the use of restraint, seclusion and other practices of physical limitation. This information will be used to develop a plan for monitoring how states address restraint and seclusion.

To read the reports and legislation, see the box on this page. As more information becomes available, we’ll post it to the MODDRC/F2F website at www.moddrc.org. ●



BUILDING A STRONG PARTNERSHIP WITH YOUR CHILD'S EDUCATORS

Making sure your child has a positive learning experience is a team effort. Here are some tips families and educators have told us that will help you create encouraging family-professional partnerships!

- 1. Help the teacher get to know your child.** Sometimes teachers will have a “get to know you” form you can fill out for your child that helps them learn about them more quickly. If you have other children who don't receive one, make a copy and complete one for their teachers too. Keep it positive, but also share what things may bother your child and strategies to avoid those situations.
- 2. Know your child's rights and responsibilities.** Read the student handbook with them before you sign the “*I received it*” notice and send it back to the school. Knowing what your child's responsibilities are will help you know what to expect if they do or don't follow through. Don't forget that you can also learn what the responsibilities are of the school and staff.
- 3. Be an ally...not an enemy.** Stay positive! Using “I” statements helps remove emotion from a conversation and reduces the chance of your listener becoming defensive. Take responsibility and play “keep away” from the “blame game.”
- 4. Practice random acts of kindness.** Not only are educators and staff members responsible for a lot of kids each day, but they also have families at home to care for. Even if your schedule doesn't allow you to help within the classroom, a small gift card for a massage, lunch or mani-pedi will help relieve any stress they may be feeling.
- 5. Recognize kids aren't always angels.** All parents dread that phone call where we find out our child may have made a “not so positive” choice at school. But if it happens, listen to both sides (the school and your child's). If you're hearing something that doesn't add up, ask questions that provide more facts or request a team meeting. Then, if necessary, decide with your child and their school together what discipline action should be taken based on the needs of your child and school policy in the student handbook.
- 6. Keep in touch!** Most often, teachers and administrators will offer their e-mail address or list it on the school's web site. If not, ask for it. If you have concerns, this can be a speedy way to make an appointment to meet with them and avoid phone tag. You can also let them know if changes to medications have been made or about other important life events that may affect your child's learning. Keep your e-mails to them on the subject of your child. Avoid sending unnecessary e-mails like jokes or inappropriate items.





START EARLY, START NOW!

T R A N S I T I O N I N G T O A D U L T H O O D

Transition planning generally begins at age 14 but can start as early as middle school. It requires teamwork between the youth with special health care needs (YSHCN), their family and professionals. Transition helps prepare YSHCN for adult life activities like college, adult health care, a career and independent living. It also promotes self-determination and empowerment by participating in the decision-making process for their life's future.

There are many “in demand” careers available for individuals with SHCN or disabilities—especially those with a college education or specialized training. Places like a college, university or other training location will help prepare them for an “in-demand” career. The first step is for you and your child to meet with their guidance counselor and/or IEP team who can help identify educational programs that may interest your child. Also, high schools often will hold an annual “transition fair” where you can do a “one-stop” shop and talk with representatives of area colleges and programs.

Once you have identified a college or program your child is interested in, contact their Office of Disability Services to learn about the types of support services they offer. For assistance with career planning, visit the school's career center. Here they can help your teen develop a

career plan by looking at their personal strengths and interests. When they decide on an occupation, then with the assistance of an advisor, an education plan can be created. While at the university, be sure to visit the health care facility for a tour and to introduce them to your child and their health care needs. Don't forget to stop by the financial aid office to pickup helpful information on the scholarships, grants and loans available to help finance your child's education.

Another part of transition planning is the move from pediatric health care to an adult system. This is especially important because the two systems of care are very different. In pediatric care, usually the pediatrician coordinates the care the YSHCN receives – like in a medical home. In the adult system, many with special health care needs have trouble finding a doctor who is familiar with childhood health conditions and provides coordinated care. Connecting with your child's Service Coordinator can help you locate a provider based on his or her specialized needs.

By thinking, planning and practicing for the move into adulthood early, YSHCN can look forward to a happy and independent life as adults.

So Start Early, Start NOW! ●

VOLUNTEER SPOTLIGHT



SHELLY SHETLEY

Shelly Shetley does not take “NO” for an answer and is a true inspiration to anyone who thinks they “can’t” or “won’t” be able to go to college. Shelly Shetley models the dream of most parents when it comes to their children’s education.

After a car accident when she was two, Shelly was diagnosed as having Cerebral Palsy. Now 35, Shelly is a three time college grad (see Shelly’s College Survival tips on this page). Just like many students, she had no idea what to expect when she first started. She says it was “totally different than high school” with longer classes and the amount of papers due. Sadly, she says she’s had people tell her that she “couldn’t learn” or that she “wouldn’t be able to keep up”. She even had a professor at KU tell her that she couldn’t process the information they were lecturing on. She said she just sat back and said to herself, “Just watch me.”

Shelly didn’t live on campus, so her mom drove her to and from school. Fortunately, her classes were fairly close together so she often made it to her next class on time. But, if she needed a few extra minutes in between them, she says most of her professors were understanding.

Shelly didn’t go from earning her high school diploma to a Master’s overnight. It took baby steps that each lead to celebrations, like starting with working towards an Associate’s Degree from Park University. Then, she set a higher goal for a Bachelor of Arts degree in Human Services to finally her Master’s which she earned with a 3.2 grade point average.

“Expect everything and nothing,” Shelly says to all future college students and their family members, and “never take “No” for an answer.” ●

SHELLY’S COLLEGE SURVIVAL TIPS:

- For all the self-advocates out there, you are the expert on you. You know your limitations and what your capabilities are.
- For parents/family members, don’t take “No” for an answer. You know what your child’s capabilities are and what his/her limitations are.
- Take full advantage of any and all resources that your college or university offers like their disability resource center.
- Be aware of your rights.
- Do not let any “Professional” discourage you from accomplishing what you know you can accomplish.
- Ask questions, ask questions, ask questions!



YOUTH ADVISORY COUNCIL

MEETS TO TALK ABOUT TRANSITIONING INTO ADULT HEALTH CARE

Members of the Youth Advisory Council (YAC) met recently to share their thoughts on moving into adult health care and having a special healthcare need.

The newly formed YAC, whose members are between the ages of 15-25, creates networking opportunities of information sharing and learning which will help members direct the activities on health care transition for the Integrated Community Services (ICS) project. For participating in meetings and activities, members receive a stipend.

Contact George at gottog@umkc.edu or 800.444.0821 if you or someone you know would like to become a member and attend the next meeting. ●





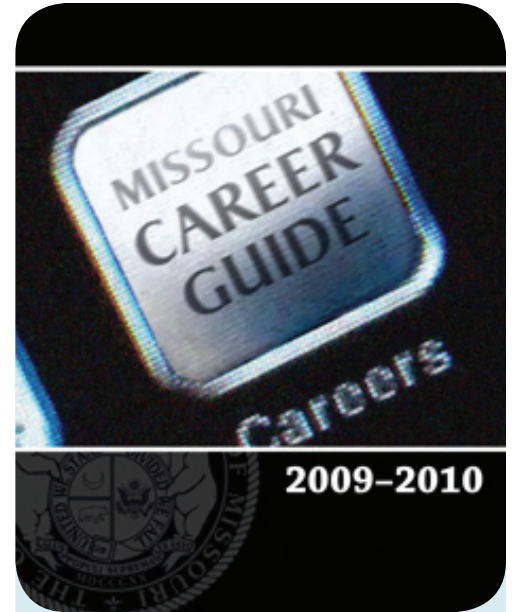
HEALTHY & READY TO WORK

Healthy & Ready to Work (HRTW) is a program supported by the federal Maternal and Child Health Bureau's Division of Services for Children with Special Health Care Needs (MCHB/DSCSHN). The program began in 1996 to address the transition needs of the first recognized generation of youth with special health care needs, chronic health conditions and disabilities who survived into adulthood. The goal of the program is to ensure that "all youth with special health care needs receive the services necessary to transition to all aspects of adulthood, including adult health care, employment, and independence."

The HRTW National Resource Center (www.hrtw.org) is a useful and easy-to-navigate website with information about transition issues for youth, families, and service providers about transition issues. One of the most useful parts of the web site is the "Tools

& Solutions" page. It includes youth and family-friendly tools and checklists related to policy statements, transition planning manuals and brochures, care plans, and youth/family education among others. Another valuable aspect of the HRTW Resource Center is the HRTW University (HRTW-U), which is designed to share "innovative, cutting edge, and promising practices in interagency collaboration, medical home, transition/youth, and family partnerships." It uses a variety of interactive platforms to share information with youth, families and professionals like email news, topical conference calls, podcasts and online courses.

These are just a couple of the fantastic resources available at the HRTW National Resource Center. If you are looking for information related to health care transition or have questions, this is an excellent place to start! ●



2009-2010 MISSOURI CAREER GUIDE

When looking for potential careers, there are many things to consider. What are your interests? What are your goals? Where are the high-demand, high paying jobs? How much education do you have? How much are you willing to get? This guide has been developed to provide information to help answer these questions and to assist you in making informed career and educational choices.

Missouri needs well educated, motivated, and talented students in our workforce to help us move forward and to make Missouri the best place to live, work and play. We hope you use this guide to assist you in making the most of your opportunities.

The 32-page guide is available online in .pdf format at:

http://www.dese.mo.gov/divcareer/documents/Missouri_Career_Guide_2009-10.pdf ●

WHAT'S HAPPENING AROUND THE STATE ...

MPACT'S TOOLS FOR LIFE TRANSITION SUMMIT

FRIDAY, SEPTEMBER 18, 2009
TRUMAN STATE OFFICE BUILDING
JEFFERSON CITY

FREE for youth with disabilities, special education transition personnel and youth teams, family members, case managers, VR counselors, and Centers for Independent Living personnel that are committed to the preparation of youth for transition to postsecondary education, employment, independent living and community experiences.

For more information:
1.800.743.7634
www.ptimpact.org
info@ptimpact.org

BSHCN FAMILY PARTNERSHIP'S 9TH ANNUAL PARENT & CAREGIVER RETREAT

"Get in the Game"
December 4 - 5, 2009
The Inn at Grand Glaize
Hwy 54 at Lake Road 40
Osage Beach 65065

An event designed especially for Missouri parents, legal guardians and caregivers (18 and older) of children, youth and young adults with special health care needs. (See pages 6 and 7 for more information about the Family Partnership)

For more information:
866-809-2400 ext. 308
www.dhss.mo.gov/FamilyPartnership/index.html

PARENT'S GUIDE TO SPECIAL EDUCATION IN MISSOURI

Published by Missouri's Department of Elementary and Secondary Education, this booklet offers parents and family members information on the process involving special education services in Missouri. For a personal copy, visit: <http://dese.mo.gov/divspeced/Compliance/documents/ParentGuide.pdf> or call them at 573-751-4212 | TDD: 800-735-2966. Their office hours are Monday through Friday, 8am - 4:30 pm.

MISSOURI DONATED DENTAL SERVICES (DDS) PROGRAM

Missouri Donated Dental Services (DDS) is a collaborative program in which the dental profession reaches out to individuals with special needs.

Qualified applicants must be permanently disabled, critically ill or elderly and have no financial resources with which to receive dental care. Applicants must need extensive dental care, not just a cleaning and checkup. DDS can also accept children who are financially disadvantaged, although Missouri Medicaid covers most of these cases. There is generally no cost to qualifying individuals; occasionally, people in a position to pay for part of their care may be encouraged to do so, especially when laboratory work is involved.

Due to lengthy waiting lists, Missouri DDS is currently accepting applications only in limited counties. For an application and to find out if you're in this area, contact Teena Paris at 866.792.9988 or visit the Missouri Dental Association (www.modental.org) or MODDRC/F2F websites.

WANT TO LEARN MORE ABOUT SPECIAL NEEDS EDUCATION?

Check out the MODDRC/F2F website at www.moddrc.org or get in touch with MPACT for a list of training events in your area:

www.ptimpact.org
1.800.743.7634
INFO@PTIMPACT.ORG

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.

SUPPORTED WITH FUNDING FROM:



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



PARTNERING TOGETHER

VOL. 1, ISSUE 2 • WWW.MODDRC.ORG

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 | www.tips4kids.org



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

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

UMKC - IHD

The Institute for Human Development, located within the University of



Family Voices of Missouri

FVMO is a

statewide organization dedicated to informing, strengthening, educating and empowering Missouri's children, youth and young adults with special needs and their families to become respected & valued

leaders and to collaborate with professionals who care for them.

417-597-3197 | www.fvmo.org



The Department of Health and Senior Services

The DHSS serves the citizens of Missouri by working to improve the health and quality of life for Missourians 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



Missouri Planning Council on Developmental Disabilities

MPCDD 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.

866-809-2400 ext. 308 | www.dhss.mo.gov/FamilyPartnership/



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 healthcare or disability celebrations and challenges. Because of our experiences, our information is offered in a person-centered, easy to understand, and culturally friendly way.

800-444-0821 | www.moddrdc.org