

PARTNERING TOGETHER



PAGE 3
TRANSITIONS:
Life After High School



PAGE 4
OUR COMMUNITY
Updates from the Family Partnership Initiative



PAGE 6
HELPING YOUTH TRANSITION:
The Role of the Parents



TIME FOR TRANSITION

Everyone experiences times of transition in life. Transition is moving from one stage in life to another. We are always in transition. Some important transition points are going to school for the first time, going to middle and high school, graduation, moving, or getting married.

One of these transitions is medical transition. This happens when you move from pediatric to adult health care. Medical transition is important because it helps your child take control of health care and be more self-determined. It also helps you understand the adult health care

system before you get there. Medical transition provides you the opportunity to have health insurance in place when youth become adults. When making this transition it is important to start slow, start small, and start now.

By starting slow your plans and progress through transition is manageable for you. Starting small allows you to do the simple things and plan for the bigger pieces. If you start now, even if your child isn't old enough for the transition, you have the time and tools to make the transition effective and meaningful for your child. ●



SHARING OUR STRENGTHS

PEER MATCHING NETWORK



M•O•D•D•R•C

MISSOURI'S FAMILY-TO-FAMILY DISABILITY & HEALTH INFORMATION RESOURCE CENTER

Exciting things have been happening with Missouri's Family to Family Health and Disability Information Resource Center. In July, The Thompson Center in Columbia hired a Family Mentor. The Family Mentor connects families coming in for diagnostic and therapeutic services to our Sharing Our Strengths peer matching network. The Family Mentor at Thompson Center uses the MODDRC Volunteer Database and it is exciting to be utilizing more of our trained parent and peer mentors. In the fall, Children's Mercy Autism Center in Kansas City and Cardinal Glennon Autism Center in St. Louis, hired Family Mentors, who connect families to mentors as well. Through these new doors we have been able to significantly increase the number of families that are using the Sharing our Strengths peer to peer network. We aren't stopping there; because of the connections through the Autism Centers of Excellence within the Children's Hospitals we are now finding inroads directly to the physicians and social workers who can connect any family with a disability or healthcare need to the Sharing Our Strengths network.

It is exciting to hear the comments from parents who have received mentoring. Talking to someone who has been there is an invaluable resource. In a time when resources for direct services are dwindling, providing a family with the emotional and social support necessary to problem solve and feel connected can make a world of difference. Not only is that a value we believe in, but it's what families are telling us when we evaluate their mentoring experience. We are continuing to look for ways to infuse the peer mentoring into service systems. If you have ideas for doing that, let us know. Also, the increased use of our mentors is increasing our need for more volunteers to share their story with other individuals who are on a similar journey. If you would like to be the voice on the other end of the phone that provides a listening ear and a positive perspective to a family needing an affirming connection with someone who has been there, please call us at 1-800-444-0821. ●





TRANSITIONS: LIFE AFTER HIGH SCHOOL

The daily routines of you and your child involving school have been the same Monday through Friday, with the exception of breaks and teacher work days. Since your child has been in the school system, maybe earlier, you have followed the routine of the school year. The summers are made up of extended school year (ESY) and camps to maintain skill progress. A time is coming when you will begin a new season of life, one where the school bus has stopped coming. This is a big change that you will need to prepare for. How does your child become as independent as possible during and after this transition? This process takes time, so start before your child graduates. Take small steps back as you teach your child the skills needed to live as independently as possible. Start planning for the future before graduation and discuss your child's strengths and goals with your child so that the future is one that he/she wants.

When youth transition out of the school system, they become eligible for services; rather than being entitled to them. Eligibility depends on availability of funding and openings. In the state of Missouri entitlement for education is through age twenty-one. For health care this age varies. With recent legislation individuals can remain on their parents' private insurance coverage up to twenty-six. Other changes begin occurring at age eighteen. When your child turns eighteen it is his/her finances, not the parents' to determine eligibility for supplementary security income (SSI) and eligibility for MO HealthNet. One option for individuals with disabilities is the Medicaid Home and Community-Based Service (HCBS) Waiver. The HCBS Waiver makes it possible for individuals to receive support from Medicaid regardless of their living arrangements. Individuals receiving supports through this

waiver are guaranteed certain rights such as the right to file an appeal within 90 days of decisions you don't agree with decisions to deny, reduce, change, or stop a funded service. When decisions to reduce or end a service you are currently receiving are made, you can continue receiving it during the appeals process if you file your appeal within ten days of the notice date. Some agencies also provide non-Medicaid funded programs. Centers for Independent Living (CILs) offer advocacy and direct services such as information, independent skill training, peer support, and employment counseling. The Missouri Department of Mental Health (DMH), Division of Developmental Disabilities provides service coordination and funding of services for individuals with developmental disabilities. When it comes to independent living, a range of options is essential so that across the lifespan individuals can choose the kind of home that meets their needs. For more information about options in Missouri visit the Missouri Family-to-Family Health and Disability Resource Network www.moddrc.org

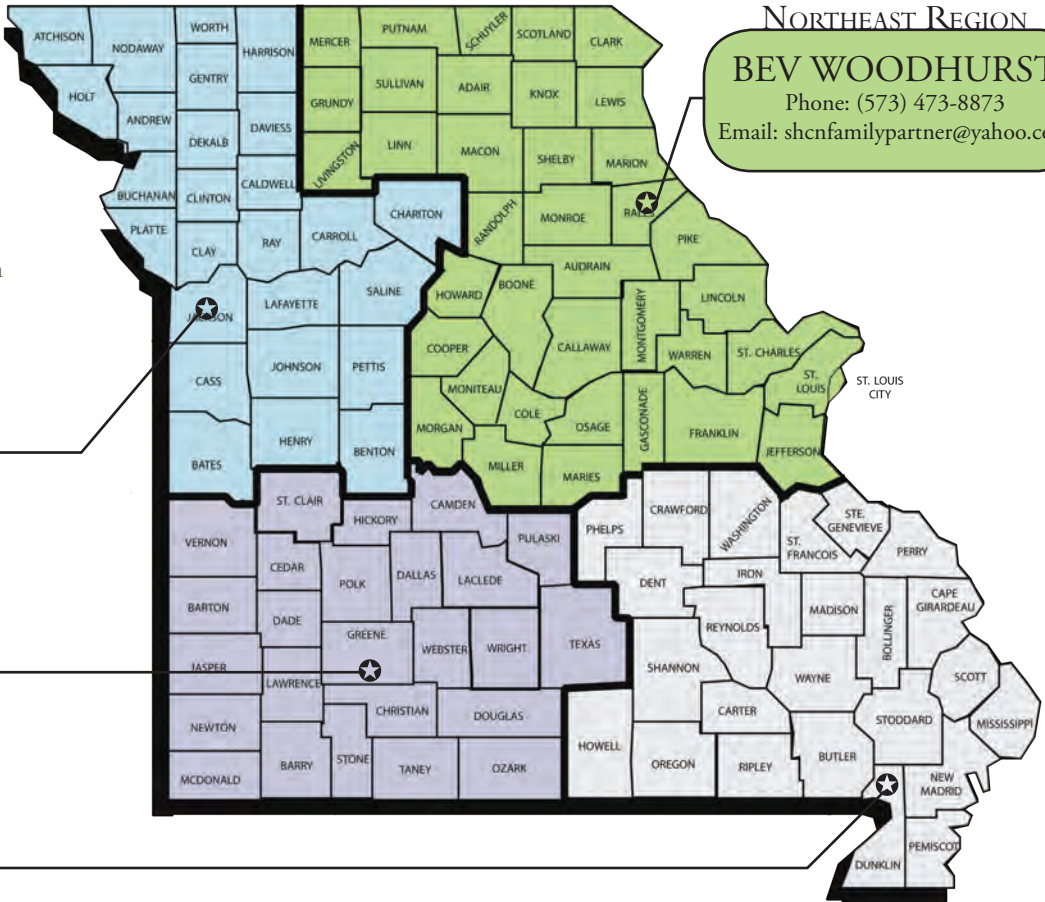
Home and community-based services provide greater opportunities for independence and participation in community life, enriching the diversity of the community. It is important to begin planning for transitioning early since the process can take time. Through the transition process and working with organizations that use flexible models young adults are able to achieve their goals of greater independence. The time after the school bus stops coming doesn't have to be scary and your days can be meaningful (Hornstein, 2008.) By starting the transition process early and teaching youth independent living skills you can break down barriers and help your child to live independently with the desired quality of life. ●

For more information on home and community-based services in Missouri go to <http://www.disabilityinfo.mo.gov/gcd/PIC/HCBServices.pdf> or contact the Missouri Developmental Disability Resource Center at (800) 444-0821. Additional information, some of which is specific to the state of Maryland is available in the 2008 article, *After the School Bus Stops Coming ... It's Not as Scary as You Fear!*, by Sari R. Hornstein, Ph.D. and available at http://www.transitiontocollege.net/percpubs/hornstein_afterSchoolBus.pdf



Bureau of Special Health Care Needs FAMILY PARTNERSHIP INITIATIVE

The Family Partnership's mission is to communicate, advocate, and network through a family and agency team-supported effort to enable individuals with special health care needs to reach their fullest potential throughout life. ●



NORTHEAST REGION
BEV WOODHURST
Phone: (573) 473-8873
Email: shcnfamilypartner@yahoo.com

NORTHWEST REGION
TRACY DAMARIO
Phone: (816) 213-8103
Email: tsimmons8103@aol.com

SOUTHWEST REGION
KELLY BASS
Phone: (417) 833-2349
Email: klybass@yahoo.com

SOUTHEAST REGION
MAMIE BENSON
Phone: (573) 919-4143
Email: mamielbenson@yahoo.com

NORTHWEST REGION



When I think about transitions I wonder if they have been more difficult on me or my children. When transitioning from First Steps to the school district I remember very clearly that first IEP meeting. I was fortunate to have participated in MPACT trainings prior to the meeting which did assist me with the process. Then just when my daughter was settled into early childhood it was time to transition into elementary school. There she remained until 7th grade at which time it was again time to make the move to middle school for the next 2 years, then into high school. My daughter, Taylor is now 17 years old and a junior in high school. Soon we will face another transition at the age of 18 as she will then be considered an adult. And then ... comes 21 and we transition out of the Children's Mercy Hospital system and into a whole new arena of medical providers and the adult service system.

None of these transitions have been simple; however with the assistance of a variety of agencies, organizations and most importantly networking with other parents, we have persevered and will continue to do so with upcoming transitions.

It's important to reach out and seek assistance and support from others. We can all learn from these transitions and even more important we can share those lessons with others. ●

NORTHEAST REGION



Transition can be looked at in many ways. We start transitioning the day our child is born, but sometimes the transition obstacles need a little help getting past. We're here to help!

To some, transition can be a huge step from school to the work force, or it can be as simple as going from 1st steps to early childhood. Regardless of the time in your family member's life, transition from one stage in life to the next can be scary, but it doesn't have to be.

The best thing you can do is always prepare ahead. When your child is getting ready to go to school, you prepare for it, whether your child goes to a preschool, early childhood program, or a public or private school. As parents, we always want it to be a good experience for our children and most generally will do whatever it takes to make it successful.

Having other parents, educators, and family members helping with this could be the most important part of the process of transitioning in any situation. No matter what it is, know you don't have to do it alone ...

For more specific details on transitioning assistance, or for parent to parent support, contact your Family Partner! ●



SAVE THE DATE!

The Family Partnership annual Parent & Caregiver Retreat will be held October 22-23, 2010 in Osage Beach.

SOUTHWEST REGION



Simply put transition is a process that prepares parents and children with disabilities for the adult life; when they complete high school and or turn 18. For most of us it seems like a long way away however, many suggest beginning this process at around age 14. As in the education process there needs to be a long range goal plan set in place otherwise known to most as an IEP. This must keep in mind the wishes and ability of the student and what

the parent is comfortable with. Consequently this must also address the capability of the soon to be adult to make his/her own decisions. Some of the questions you will want to address are long term living arrangements, possible employment, and financial responsibility. This process can be a tedious one but a very necessary one to help guide your child's future in the right direction. ●

SOUTHEAST REGION

Transition comes in different stages of one's life. It starts at birth and goes to adulthood. How we handle transition is very important. We need to prepare for each stage.

As a person with disabilities/special needs enters adulthood, there should be planning made by those who care about them. This is a team made up of the person, family, friends, service coordinator, voc rehab, independent living, activity center and anyone you feel might be of interest to help contribute ideas that would benefit in helping to ensure that the person with a disability has quality of life. Never forget that transition needs to include the person and the community in which they will be a part of. Think of reachable goals, if it is education, job training, attending an activity center or simply to be at home. Think of what is best for the person and keep their interest in the decisions.

Make sure to write down the steps to stay coordinated and keep in sync with all providers and services. Keep in mind the end result and how it will affect the person for whom the services are for. One good place to start is the National Dissemination Center for Children with Disabilities' (NICHCY) "State Resource Sheet" which can be found at: <http://www.nichcy.org/pages/statespecificinfo.aspx> ●



NATIONAL SELF ADVOCACY CONFERENCE

ABOUT THE CONFERENCE

This year's theme is *"Jazz It Up: Celebrating 20 Years of Self Advocates Being Empowered,"* which marks the anniversary of the ADA and acknowledges the last twenty years of the disability movement in the United States! For the last decade, this conference has been the largest gathering of self advocates in the United States.

CONFERENCE HIGHLIGHTS

- Self-Determination Showcase
- Self-Determination in 2020 and World Café
- Renowned Keynote Speakers
- Peer-Reviewed Break-Out Sessions
- Celebration of a movement

FOR MORE INFORMATION

(800) 558-8652
sabekc2010@gmail.com

September 23 - 26, 2010 | **Westin Crown Center** | Kansas City, MO



www.sabekc2010.org



HELPING YOUTH TRANSITION:

THE ROLE OF PARENTS

The important job of a parent is even more significant during the transition process. Throughout this time of change you are helping your child develop into an adult, living the life he/she wants to live. This process takes time, so start small, start slow, and start now. Everyone's role is vital in transition. Some things are done independently, while other things you and your youth do together. Remember to involve your doctor in the process.

- 1. Know what happens with health insurance.** When will your child age-out and what insurance options are available? Teach your youth about health insurance so that he/she knows how to use his/her insurance card and access medical services. Discuss how to pay for health care. Between ages 12 and 18 begin looking for adult healthcare and finalize coverage before your child ages-out.
- 2. Remember that legal adulthood begins at age 18.** Before your child turns 18 begin checking into SSI eligibility. At age 18 this eligibility is based on youth finances not yours as parents.
- 3. Encourage your youth to be active in his/her own health care.** Teach and re-teach about health care needs at the appropriate level, how to manage medications, and keep track of appointments with the doctor. Support your child's communication with doctors encouraging him/her to talk directly to them.
- 4. Involve your pediatrician by working together to support your child.** Your pediatrician has a responsibility to you and your child and can help youth understand the job of physicians and medical staff. They should support you as you interview adult physicians and staff. Finally, your physician can provide your new provider with a health record

and give youth a one to two page transition summary.

- 5. Begin searching for a doctor who treats adults.** Ask your pediatrician or a support group for recommendations. Talk with your child about what is important such as transportation, office hours, knowledge, and bedside manner. Make a list of questions you want to ask and interview potential new doctors; remember that this type of visit is not covered by insurance.
- 6. Organization of medical records and health documents is essential.** Develop a health record together and encourage your youth to maintain personal medical records.
- 7. Talk about the future** and how a special health care need may affect the ability to achieve certain goals so that you can plan to remove barriers. It is helpful to think in five year segments.
- 8. Nobody knows your family better than you.** Become an expert in what is required to manage your child's health care needs and teach your child these skills. Understand what resources, supports, and information is available. Connect with others who have been there. Advocate for your youth and teach him/her how to advocate for individual needs.

Remember that transition takes time so start now, start slow, and start small. You are essential in making it successful. You know your family's needs best. Continuous communication with your youth helps everyone think about the future and what is important for independent living. Your physician is a resource for you and is responsible to continue managing health care needs through the transition process. It's vital that you are informed about health insurance. The more responsibility youth can take over time increases their comfort and independence throughout the transition process. ●



THE YOUTH ADVISORY COUNCIL

“THE POWER OF STORIES”

The Youth Advisory Council is an incredible team of young men and young women at different stages in the process of transitioning from pediatric to adult services. We continue to find and create ways to make transition seamless and effective for all by providing a forum to share ideas and develop plans to inspire change.

Recently the team participated in “The Power of Stories” presentation and began developing their own stories to share their experiences and advocate for their needs. These stories will debut on the upcoming transition module they are developing for the MODDRC web site. We look forward to this becoming a place to share experiences as well as a great place to find tips and resources to guide your successful transition throughout the process.

The Youth Advisory Council plans to continue addressing needs related to transition for the development of tools that support smooth transitions and promote greater independence and success. Watch for these resources on the MODDRC website (<http://www.moddrc.org>). ●

RESOURCES

Many transition guides and checklists are available and each one is a little different. For links to these and additional resources visit the Missouri Family-to-Family Health and Disability Resource Network www.moddrc.org.

- ***Since You're Not a Kid Anymore*** is a guide for transition designed for youth ages fourteen and older. This guide begins with the transition to middle school. It provides steps to guide youth through the process of taking more responsibility for individual health care needs. It also has some general future planning to start thinking about the future.

- **The Waisman Resource Center** and the **Wisconsin Children and Youth with Special Health Care Needs (CYSHCN)** Centers have multiple trainings available to guide youth and parents through transition and prepare youth for adult life. Materials can be used by individuals to organize health information, assess skills, and prepare for transitions.

- **Carolina Health and Transition (CHAT)** has designed resources for parents and caregivers designed to cover barriers to transition, medical home, pediatric vs. adult health care, healthcare transition planning, cultural competence, and advocacy. The resources include timelines, checklists, a description and definition of medical home, and emergency forms.

- **The Health Care Transition Initiative** at the University of Florida has multiple videos on health care transition. These videos cover information such as talking with your doctor, health care in college, overviews of health care transition, and individual stories. Online and printable training resources are also available to increase awareness of, gain knowledge about, and promote cooperative efforts to improve the process of transitioning from child-centered (pediatric) to adult oriented health care.

- **NY Healthy Transitions Web Resource:** This web site was created by the New York State Institute for Health Transition Training for youth ages 14-25 years, family caregivers, service coordinators, and health care providers. Videos demonstrate health transition skills, while the interactive tools build self-determination and collaboration. Use this site to develop skills for transitioning from pediatric to adult healthcare. This ADA accessible site is available for non-readers and in Spanish. It teaches skills and provides tools for care coordination, keeping a health summary, and setting priorities during the transition process.



A free online training module on Understanding Autism in Young Children is now available!

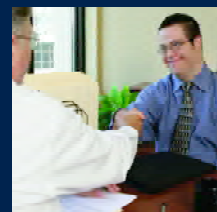
The module is an overview of the characteristics of autism spectrum disorders (ASD) and the criteria used to diagnose children with ASD. It is hosted on the University of Missouri Extension web site and persons who wish to view the training will need to register for an Extension Passport and select the Understanding Autism course to view. There is no charge for the Passport or to view the training. A link to the Extension website is available through the Thompson Center for Autism and Neurodevelopmental Disorders web site at <http://thompsoncenter.missouri.edu/training/index.php>

The Understanding Autism training module is now available in DVD format for any professionals who are conducting training to others and do not have access to high speed internet.

The Understanding Autism training was developed by the Mid-Missouri Rapid Response Initiative, which is funded by the Missouri Department of Mental Health Division of Developmental Disabilities. An online module was created from the training through a partnership with the Thompson Center for Autism and Neurodevelopmental Disorders, University of Missouri Extension, and the Division of Developmental Disabilities, Office of Autism Services.

WE APPLAUD YOUR GOOD BUSINESS SENSE

84%
OF YOU WOULD PATRONIZE
BUSINESSES THAT
HIRE PEOPLE WITH
DEVELOPMENTAL DIABILITIES



We heard you. In a recent poll by Missouri State University, you expressed your belief that most people with disabilities can be very productive workers. So you know that ability is far more important than disability in the business world. Thanks to your support we're increasing our efforts to get more of those with disabilities into the workplace. For more information, visit www.mpcdd.com

PARTNERING TOGETHER

VOL. 1, ISSUE 4 • 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



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



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/



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



Missouri Planning Council For 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



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