DISABILITY & HEALTH
INFORMATION CENTER
A PROGRAM OF MISSOURI FAMILY TO FAMILY RESOURCE CENTER | UMKC INSTITUTE FOR HUMAN DEVELOPMENT | UCEDD

A NEW WAY TO
SUPPORT
FAMILIES

Surviving the Transition to Adult Healthcare

Welcome to the Missouri Family-to-Family Disability & Health Information Center. You are receiving this letter with an enclosed packet of information because a request was made by you (or someone on your behalf) to the MOF2F.

We have compiled information from a number of sources and have included them in this packet, which is divided into the following sections:

- **Overview**
- **Personal Stories**
- **Family Support, Advocacy, and Services**
- **Missouri Service Systems**

The MOF2F seeks to inform and connect individuals with disabilities or special health care needs and/or their families to peer support. We provide opportunities for leadership development and volunteerism. We also seek to provide information and training to community agencies so that they can provide services to individuals with disabilities or special health care needs and/or their families. When contacting the MOF2F, you are connecting to staff with first-hand knowledge about disability related issues because they have the experience of living with the disability, either as an individual, parent or family member.

Thank you for connecting with us. This packet of information is one of the many ways that the MOF2F can support you in your journey with disability.

MISSOURI FAMILY TO FAMILY RESOURCE CENTER
DISABILITY & HEALTH INFORMATION CENTER

Missouri Family to Family Disability & Health Information Center is housed within Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) at the University of Missouri-Kansas City, Institute for Human Development.

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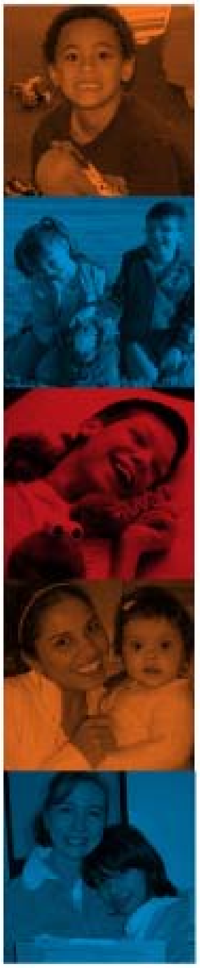
OVERVIEW



The purpose of this section is to help you gain a better understanding of a specific topic related to disability or special health care need. It is intended to provide a basic explanation of the topic and specific tips for success.

If you would like more in-depth information on this topic, other topics of information or, if it is not the topic you requested, please feel free to contact us again.

Overview: Medical Transition

What is 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 preschool and kindergarten, leaving elementary for middle school, high school graduation, and making decisions after high school such as: moving, getting a job, going to college, or getting married. One of these transitions is medical transition.

When you are preparing for transition it is important to start slow, start small, and start now. By starting slow you can manage your plans and progress through transition. Starting small allows you to do the simple things and plan ahead for the bigger pieces. If you start now, even if you are not old enough for the transition, you have the time and tools to make the transition effective and meaningful.

You are not alone in transition. Many people can contribute to your success. Your parents and physicians are some of the people who can help you.

Medical Transition

Medical transition is important for everyone. It happens when you move from pediatric to adult health care. Medical transition is important because it helps you take control of health care and become more self-determined in your life. It also helps you understand the adult health care system before you get there and have health insurance in place when you are an adult.

Your needs as an adult are different than your needs as a child. The care you need as an adult is also different than the care you need as a child.

Pediatric	Adult
Focuses on family	Focuses on individual
Nurtures and provides emotional support	Focuses on a specific need
Doctors work as a team	Doctors are not teams– a doctor for each need
Parents provide consent	Patients provide consent

Benefits of Moving to Adult Health Care

- Promotes social and emotional development.
- Promotes positive self-concept and sense of competence.
- Supports positive self-image and self-reliance.

- Promotes independent living.
- Supports long term planning and life goals.
- Broadens system of interpersonal and social supports.

Adult health care promotes independent living and self determination. You get to develop your own system of support. It allows you to receive necessary adult care such as: screenings and treatment of adult health problems, reproductive health care, specialists in treatment for adults with special health care needs, and access to adult inpatient services and specialists.

Why Self-Determination?

Self-determination is defined as: "...acting as the primary causal agent in one's life and making choices and decisions regarding ones quality of life, free from undue external influence or interference." Simply put, it is free choice of one's own acts.

It is important in health care because it has been shown to improve quality of life. A healthy lifestyle requires skills and knowledge related to health.

What is Important for Successful Medical Transition?

Youth have identified certain things as important. They want to know what to do in an emergency, how to get health insurance, what can happen if their condition gets worse, and learn how to stay healthy.

Medical transition needs vary from person to person based on their level of understanding and abilities. Remember that medical transition is one part of transition to adult life, so practice the skills along with other skills you will need to live the life you want. It is important to remember that transition takes time so start slow, start small, and start now.

Skills for Young Adults with Special Health Care Needs*:	
Understand their condition and treatment or intervention needed.	"I have cerebral palsy because I lost oxygen at birth...I need help with...
Explain their condition and needed treatment or intervention to others.	"I am on three medications for spasticity."
Monitor their health status on an ongoing basis.	"I use my communication device to let others know how I am feeling."
Ask for guidance from their pediatric health care provider on how and when to make the move from pediatrics to adult care.	"I'm going to ask my pediatrician when I should start seeing a family practice doctor for my general care instead of a pediatrician."
Learn about the systems that will apply to them as adults.	"I have applied for medical assistance through Social Security because I have a disability/special health care need and need to be able to get medical care."
Identify formal and informal advocacy services and supports they may need.	"I ask my parents for advice because they have known my medical care the longest."
** Skill milestones vary for each individual's ability and understanding.*	

During the medical transition process everyone has important roles to do independently and together.

Role of Youth

- Understand your health care needs.
- Begin helping schedule your appointments and maintain a calendar.
- Learn about and begin managing your own medications.
- Talk directly to your doctor about your symptoms and questions.
- Start thinking about what you want to do in the future after school.

Role of Parents

- Find out about insurance options.
- Know when your child will age-out of your current insurance plan.
- Begin identifying and interviewing adult doctors.
- Organize medical records/health documents.
- Teach your child to manage own medications as much as possible.
- Support your child in communication with the doctor-encourage him/her to talk directly to the doctor.
- Advocate and teach your child to advocate.

Role of Parents and Youth Together

- Develop a health record.
- Teach the health care need at the appropriate level.
- Begin talking about the future (college, work) and how a special health care need affects their ability to achieve those goals, plan to overcome barriers.
- Know what insurance is available for the future.
- Make a plan (think in five year segments).
- Discuss how to pay for health care.

Role of Physicians

- Continue to manage health care needs.
- Encourage youth to co-sign and become part of the health care process.
- Help youth to understand what physicians and medical staff do.

- Encourage families to visit and interview adult physicians and staff to transfer care.
- Provide a health record to new providers and give youth a copy (1-2 page summary).

Guardianship or Not

You may also need to consider whether or not to seek some form of guardianship or power of attorney.

Consider the following:

- What is your child's capacity to make decisions or indicate preferences regarding healthcare?
- What alternatives are available to assist them?
- Who is available to assist them?
- Would guardianship "solve" the issues that concern you?
- If guardianship seems like the only option, consider limited guardianship (only for needed areas).

There are alternatives to guardianship that may assist when it comes to healthcare issues.

- Power of Attorney (General vs. Healthcare Power of Attorney)
- Personal Contract/Agency Agreement
- Joint bank account/debit card
- Living will/advance directive

Things to start working on:

- Carrying and presenting insurance card
- Knowing your doctors' names
- Greeting your doctors and medical professionals at appointments ("Hello, Dr. Yankem")
- Telling what is wrong/why you are seeking care
- Giving basic information about yourself (name, date of birth, address, etc.)
- Giving as much medical history as you are able
- Knowing and relaying disability information
- Knowing the names of your prescriptions
- Paying your co-pays
- Calling in prescriptions or refills
- Learning about choice (of doctors, providers, hospitals, etc.)
- Preparing for doctor visit: 5 questions
- Learning your insurance information – what insurance company, how much is the co-pay, etc.
- Learning about other benefits that affect healthcare: SSI, Medicaid/Medicare, VR

Important Ages in Medical Transition

- Age 18, Missouri legal adulthood begins.
- Before age 18, begin checking into SSI eligibility.
- Between ages 12 and 18 look for adult health care.
- Between 18 and 25, finalize adult health care (age depends on status as dependent).
- Consider guardianship and its alternatives prior to turning 18.

Advocacy

- No one knows your needs better than you.
- Become an expert in what is required to manage your health care needs.
- Understand what resources, supports, and information are available.
- Get connected with others who have "been there."
- Seek help when/if you need it.

Works Cited

Adolescent Health Transition Project (2005). Adolescent to Adult: Health and Other Transition Issues for Children and Youth with Special Health Care Needs. Retrieved from http://depts.washington.edu/healthtr/powerpoint/transitiontalk_files/frame.htm

Eiser, C., Flynn, M., Green, E., Havermans, T., Kirby, R., Sandeman, D. & Tooke, J.E. (1993).

Coming of age with diabetes: Patients' views of a clinic for under-25 year olds. *Diabetic Medicine,* 10(3): 285-289.

Freeman, T. (2010). Issues in transitional care: Autism spectrum disorder. Retrieved March 24, 2010 from State Public Health Autism Resource Center (SPHARC): Topical Webinar on Transition.

The University of Illinois at Chicago (2006). Transition information sheet for families. Retrieved November 11, 2009 from http://internet.dscc.uic.edu/forms/psu/0592.pdf

Wehmeyer, M. (1996). A self-report measure of self-determination for adolescents with cognitive disabilities. *Education and Training in Mental Retardation and Developmental Disabilities,* 31, 282-293.

PACER (1997) Survey and The National Youth Leadership Network (2001)

On the following pages, you will find more information on working with children and youth with disabilities and/or special health care needs (CYSHCN) and their families from sources the MOF2F regards as respected and trustworthy. All information has been reprinted with permission and is for educational purposes only. For more information regarding your personal situation, please consult your team of medical professionals.

Transition Timelines and Checklists

No matter how old you are there are things that you can do to get ready for transition.

Transition Timeline for Children and Adolescents with Special Health Care Needs:
Chronic Illnesses/Physical Disabilities

Parent and Child Interactions that Encourage Independence

Birth to 3-5

Assure your infant the world is a good place in which to live. The development of a sense of trust is essential to the development of a healthy personality.

- You are your child's first teacher.
- Allow your child to develop at his/her own individual rate
- As a parent it is important to take short breaks from your child to renew energy with which to enjoy your child.
- Begin keeping a record of your child's early intervention educational and medical history, including immunizations.

By ages 3-5

- Assign your child chores appropriate for his/her ability level.
- Encourage decision making skills by offering choices.
- Continue involvement in community and recreational activities that include children with and without special needs.
- Begin asking, "What do you want to do when you grow up?"
- Begin teaching your child about his/her special health care need.
- Begin teaching your child self-care skills: general skills and those related to his/her special health care need.
- Begin helping your child interact directly with doctors, nurses, therapists, and teachers.
- Begin teaching your child about relationships, their body, and personal space.

By ages 6-11

- Assess your child's perception oand basic knowledge of his/her special health care need. Build on their understanding.
- Continue teaching your child general self care and health skills as well as skills related to his/her special health care need.
- Discuss relationships and personal safety with your child.
- Determine whether reasonable accommodations are needed to ensure equal access to school programs. If so, ask if your child qualifies for a 504 plan.

- Encourage hobbies and leisure activities; include exploring community and recreational activities/clubs (4H, scouts, YMCA, sports, etc.)
- Continue to encourage decision making skills by offering choices
- Continue assigning your child chores appropriate for his/her ability level.
- Take your child shopping whenever possible so he/she can help in choices
- Let your child choose how to spend some/all of their allowance
- Teach your child the consequences of his/her behavior and choices
- Allow your child to experience the consequences of a poor choice as well as a good choice
- Begin teaching your child self-advocacy skills
- Continue asking your child, "What will you do when you grow up?"

By ages 12-18

- Assess your teen's perception and basic knowledge of his/her special health care need. Fill in gaps in understanding.
- Continue teaching self help and health skills as well as skills related to his/her special health care need.
- Begin helping your teen keep a record of his/her medical history, including conditions, operations, treatments (dates, doctors, recommendations) and 504 plan if she/he has one.
- If teen has a 504 plan, encourage participation in any 504 meetings.
- Begin helping your teen take responsibility for making and keeping medical appointments, ordering supplies, etc.
- Begin exploring future health care coverage around age 17
- Discuss relationships, sexuality, and personal safety with your teen
- Help your teen identify and build on his/her strengths
- Explore support groups if teen is interested
- Begin to explore and talk about possible career interests with your teen
- Help your teen find work and volunteer activities
- Continue to have your teen help with family chores
- Continue to encourage hobbies and leisure activities
- Help your teen identify and be involved with adult/older teen role models
- Begin, with your teen, looking for an adult health care provider
- Encourage teen to contact campus disability services to request accommodations if he/she is attending college
- Check eligibility for SSI the month your teen turns 18, when his/her financial resources are evaluated

By ages 18-21, or according to your child's developmental ability

- Act as a resource and support for your child
- Encourage participate in support groups and/or organizations relevant to his/her special health care need
- Finalize transfer of care to an adult provider with your child
- Encourage continued contact with the disability services office on campus
- Encourage your child to investigate services provided by Vocational Rehabilitation if he/she has not already done so.

Adapted from the Adolescent Health Transition Project sponsored by the Children with Special Health Care Needs Program, Washington State Department of Health and the Clinical Training Unit, University of Washington, 1995. Based on a model Dr L developed by Dr. Stephen L. Kinsman, Kennedy Krieger Institute. 206-685-1358. http://depts.washington.edu/healthtr/

Transitions - Changing Roles for Youth

Health & Wellness 101 **The Basics**	**Yes** I do this	I want to do this	I need to learn how	Someone else will have to do this - Who?
1. I understand my health care needs, and disability and can explain my needs to others.				
2. I can explain to others how our family's customs and beliefs might affect health care decisions and medical treatments.				
3. I carry my health insurance card everyday				
4. I know my health and wellness baseline (pulse, respiration rate, elimination habits)				
5. I track my own appointments and prescription refills expiration dates				
6. I call for my own doctor appointments				
7. I call in my own prescriptions refills				
8. Before a doctor's appointment I prepare written questions to ask.				
9. I know I have an option to see my doctor by myself.				
10. I carry my important health information with me every day (i.e.: medical summary, including medical diagnosis, list of medications, allergy info., doctor's numbers, drug store number, etc.)				
11. I have a part in filing my medical records and receipts at home				
12. I pay my co-pays for medical visits				
13. I co-sign the "permission for medical treatment" form (with or without signature stamp, or can direct others to do so)				
14. I know my symptoms that need quick medical attention.				
15. I know what to do in case I have have a medical emergency				
16. I help monitor my medical equipment so it's in good working condition (daily and routine maintenance)				
17. My family and I have a plan so I can keep my healthcare insurance after I turn 18.				

HRTW Tool developed by Patti Hackett, Ceci Shapland and Mallory Cyr, 2009.

The HRTW National Resource Center is headquartered at the Maine State Title V CSHN Program and is funded through a cooperative agreement (U39MC06899-01-00) from the Integrated Services Branch, Division of Services for Children with Special Health Needs (DSCSHN) in the Federal Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS). Activities are coordinated through the Center for Self-Determination, Health and Policy at the Maine Support Network. The Center enjoys working partnerships with the Shriners Hospitals for Children and the KY Commission for CSHCN. HRSA/MCHB Project Officer: Lynda Honberg, of the HRSA/MCHB, Rockville, MD.

Information courtesy of Patti Hackett, Healthy and Ready to Work Resource Center http://www.hrtw.org

Transitions - Changing Roles for Families

Health & Wellness 101 **The Basics**	**Yes** my child/ youth can do this	I want my child/ youth to do this	I need to learn how to teach my child/ youth	Someone else will have to do this for my child/youth Who?
1. My child/youth understands his/her health care needs, and disability and can explain needs to others.				
2. My child/youth can explain to others how our family's customs and beliefs might affect health care decisions and medical treatments.				
3. My child/youth carries his/her health insurance card with him/her				
4. My child/youth knows his/her health and wellness baseline (pulse, respiration rate, elimination habits)				
5. My child/youth tracks appointments and prescription refills expiration dates				
6. My child/youth call to make his/her own doctor appointments				
7. My child/youth calls in his/her prescriptions refills				
8. Before a doctor's appointment my child/youth prepares written questions to ask.				
9. My child/youth is prepared to see the Doctor by him/her self.				
10. My child/youth carries his/her important health information everyday (i.e.: medical summary, including medical diagnosis, list of medications, allergy info., doctor's / drug store numbers, etc.)				
11. My child/youth helps file medical records and receipts at home				
12. My child/youth pays co-pays for his/her medical visits				
13. My child/youth co-signs the "permission for medical treatment form" (with or without signature stamp, or can direct others to do so)				
14. My child/youth knows his/her symptoms that need quick medical attention.				
15. My child/youth knows what to do if they have a medical emergency.				
16. My child/youth knows how to monitor medical equipment so it's in good working condition (daily and routine maintenance).				
17. My child/youth and I have discussed a plan to be able to continue healthcare insurance after they turn 18.				

HRTW Tool developed by Patti Hackett, Ceci Shapland and Mallory Cyr, 2009.

The HRTW National Resource Center is headquartered at the Maine State Title V CSHN Program and is funded through a cooperative agreement (U39MC06899-01-00) from the Integrated Services Branch, Division of Services for Children with Special Health Needs (DSCSHN) in the Federal Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS). Activities are coordinated through the Center for Self-Determination, Health and Policy at the Maine Support Network. The Center enjoys working partnerships with the Shriners Hospitals for Children and the KY Commission for CSHCN. HRSA/MCHB Project Officer: Lynda Honberg, of the HRSA/MCHB, Rockville, MD.

Information courtesy of Patti Hackett, Healthy and Ready to Work Resource Center http://www.hrtw.org

Finding and Using Adult Health Care

As you grow from childhood into adulthood, you will move from the care of pediatricians into adult or family health care providers. If you move to a new town or change employment, you may also need to find a new doctor.

Before you start looking for a new doctor, think about what you want:

- Is the location of the office important? Will you need help with transportation?
- Do you need an office that is wheelchair accessible or do you need other special assistance in the doctor's office?
- Are office hours convenient? How do you contact the doctor at other times?
- What hospital do you want to use and is this doctor on staff there?
- Do you want someone who will take time with you during the office visit or are you comfortable with seeing someone who is "good in his/her field" but may not have the best bedside manner?
- Is it important that this new doctor is knowledgeable about your special health care needs or do you think you can provide the information or connect the new doctor with those who can provide medical insight?

Ways to look for a new doctor include:

- Ask your current doctor
- Check out the doctor your parents or other family members see
- Call a family support group or adult disability agency and check around.
- Ask adults who have health needs similar to yours for recommendations.
- Refer to your health insurance company booklet of approved providers.
- Ask a Vocational Rehabilitation or Independent Living Center counselor.
- Find a university health center (sometimes there are research studies going on which offer free care).
- Contact your local Medical Society, American Academy of Family Practitioners, or Internal Medicine Society either online or in the Yellow Pages.

Since your wellness depends on the medical services you receive, it is important that you are comfortable talking with your new doctors and feel that he/she understands your concerns. Consider scheduling a "get-acquainted" interview before you make a final choice of a new doctor. You will have to pay for this visit, as it is NOT covered by insurance benefits. An ideal interview time is about 15 to 30 minutes and should not waste your time or the doctor's. The best time to see a new physician is when your health condition is stable so you aren't asking for crisis care while seeing if you can develop a working relationship.

Think about (and write down) questions that are important to you:

- Is the doctor knowledgeable about your health issues and/or willing to learn from you and from previous doctors?
- Do you like the communication style with the doctor and in the office?
- Are you satisfied with office practices and access during an emergency or in urgent situations?
- Do you have access to hospitals and specialists if you need them?

Skills

Doctors who like to care for children are different from doctors who like to care for adults. For this reason, young adults seeking health care need certain skills (with or without additional supports):

- Ability and willingness to tell the doctor about your history, current symptoms, lifestyle, and self-care in just a few minutes (including carrying your own records and a summary of your medical history).
- Ability to ask questions about your condition and how it will affect your school, work, recreation, and social life.
- Ability to tell the doctor about your needs for education, technology, and accommodations and how your condition affects or might be affected by these.
- Willingness to follow medical recommendations that have been mutually developed by you and your doctor.
- More independence in following up with referrals and keeping all agencies informed.
- More involvement in keeping yourself well with diet and weight control, exercise and recreation, following medication, treatment and hygiene regimens, limiting risk-taking behaviors (such as drinking alcohol, smoking, taking non-prescription drugs, or unsafe sexual practices), and getting help when you feel angry, lonely, or sad for long periods.
- Being more aware of your physical and mental symptoms and health needs before you have a serious medical crisis and knowing when to inform your doctor.
- Developing a plan for action for when you need emergency care: when to consult with the doctor, what hospital to report to, what care you want and do not want, and naming someone who can let your wishes be known if you cannot (health care surrogate).
- Understanding how the health care benefits/insurance plan you have works for you: when to call for pre-approval, how to get reimbursements, what services are not covered, and how to file an appeal if you do not agree with decisions from the plan.
- Recognizing that as you become more capable in directing your care that you, not your parents, should make medical appointments, be the most knowledgeable about your health needs, know when to seek guidance in solving problems, and demonstrate that you are capable and competent and ready for adulthood!

Information courtesy of Kentucky Commission for Children with Special Health Care Needs.

Communicating with Doctors and Other Health Care Providers

Talking to doctors and other health care providers can be difficult, overwhelming, and even scary. Here are some tips to help you communicate with your health care providers that were suggested by youth in the "Making Healthy Connections" program:

- Make sure to **ask for a long enough appointment.** Sometimes appointments are rushed. If you know that you will have a lot to talk about with your doctor, ask for an extended appointment.
- **Tell your doctor everything you can about yourself, what you do, and how you feel.** The more information your doctor has, the more helpful he/she can be.
- Bring a **list of questions and concerns.** It's easy to forget things when you're at the doctor's office. A written list of questions, concerns, or other information you want to share with your doctor will help you remember everything.
- **Say what you think** – and be honest.
- Tell the doctor to be honest and tell you everything. **You're entitled to know all** about your condition, treatment, and options available to you.
- **Be assertive**. Be nice, but persistent.
- **Ask questions**. Remember – there is no such thing as a stupid question. If you don't understand an answer to a question, ask your doctor to explain it again until you do.
- **Write down what the doctor says** so that you remember it later.
- **Bring someone with you**, if you prefer. Sometimes it helps to have someone else there for support, to hear what the doctor says, or to ask questions you don't think of.
- Ask your parents to wait outside of the exam room so that you **have time alone to talk with your doctor,** if you want. Sometimes it helps the doctor focus on you and what you have to say. Your parents can come back when you are finished to ask their questions.
- **If you need help, ask for it.**

What do I do when I'm meeting a new doctor?

When visiting a new doctor **ask about his/her background and experience.** Even if you've seen your doctor for a long time it is okay to aks about his/her background and what his/her experience has been. Call back with questions after your appointment. Sometimes questions come up when you get home or maybe you forgot something the doctor said. **It's okay to follow up with more questions.**

Learn about your insurance coverage. What services are covered and what procedures do you have to follow to get those services?

Information courtesy of Kentucky Commission for Children with Special Health Care Needs and Institute for Community Inclusion at Children's Hospital, Boston.

What about health insurance?

It is important to know about health insurance. Health care can be very expensive, and insurance can help cover the cost if you are insured. Health insurance helps you pay for medical care if you have it. It is important to start thinking about your choices for health insurance right now and how they might change as you get older, turn 19, or live on your own.

Knowing the answers to the following questions is the first step in making sure you have the health insurance you need. If you don't know the answers, ask your parents, doctors, or health insurance provider:

- Do I have health insurance?
- Is my health insurance through my parents?
- Who is my health insurance provider?
- What happens when I turn 19, move out, go to school, get married, or get a job?
- Can I lose my health insurance?
- How do I get health insurance?

If you don't have insurance you can get health care at a federally qualified health center. These centers help people who are not insured and charge what you can afford. With the passage of the Affordable Care Act in March 2010, it is important to know the changes coming and when they will affect you.

Do You Qualify for Public Health Insurance?

- **Medicaid/MO HealthNet:** provides health coverage for people of any age with little or no money (low income) as well as people with disabilities who have large medical bills or need a lot of health or personal care services and meet state and federal guidelines. In Missouri, Medicaid is called MO HealthNet. Your income is reviewed yearly to see if you still qualify for coverage.
- **MO HealthNet for Kids:** Medicaid for ages 19 and under.
- **MO HealthNet for Families**: Medicaid for individuals over 19 and families.
- **MO HealthNet for Youth in Foster Care:** Youth transitioning out of foster care have extended coverage through Medicaid through age 21.
- **Ticket to Work:** must be at least 18 and meet income requirements and the definition of a person with a disability or have a "medically improved" disability according to SSI.
- **Medical Assistance:** must meet requirements as Permanently or Totally Disabled (PTD) or Aid to the Blind. If you receive SSI or Social Security based on age or disability you automatically qualify for Medical Assistance.
- **Home & Community Based Services (HCBS) Waivers:** may be available based on your health care need.
- **Missouri Health Insurance Pool (MHIP):** a high-risk pool to provide coverage if you can't get it due to health conditions or lack of availability through employers.
- **Supplementary Security Income (SSI):** If your income goes up and you no longer qualify for SSI, Medicaid may still help based on the cost of your health care.

For more information, visit these links:

http://www.dss.mo.gov/mhd

http://www.thedesk.info/

Private Health Insurance

Keeping your family's insurance:
If you are a full time student you can stay on your parents' coverage if you prove that you are a full-time student. You can ask for full-time status under special circumstances.

Your family pays for COBRA coverage after age-out:
A dependent qualifies for COBRA if coverage is lost under a parent's employer-sponsored insurance (20 or more employees) if:

1. The employee dies
2. The hours of the employee are reduced
3. The parent ends employment for any reason other than gross misconduct
4. The employee becomes enrolled in Medicare.
5. The parents become divorced or legally separated
6. The dependent no longer qualifies as a dependent under the plan

Cobra is temporary (36 months for number 6). Beneficiaries usually pay the entire premium which cannot exceed 102% of the cost of a plan for a similarly situated individual who has not had a qualifying event.

You have a disability, need help with daily living, and can't work:
If you are already on private insurance you can remain covered as long as they carry the same plan and their policy allows you to keep coverage after you turn 18. Apply to continue coverage after you turn 17, with plenty of time before you turn 18.

Getting your own health insurance:
Missouri insurers are allowed to reject your application for coverage based on your health status. You may still qualify for "HIPAA-eligible" coverage if you:

- Had at least 18 months of continuous creditable coverage, the last day of which was under a group plan

AND

- Have exhausted all COBRA continuation coverage which was available to you.

If you have questions concerning eligibility contact the Insurance Consumer Hotline at 1-800-726-7390 or go online for information at http://insurance.mo.gov

Getting and Staying Organized

Paperwork provides a paper trail, so keep your paperwork and keep it organized. Getting organized is essential when taking care of your health care needs and for keeping your own records. Medical documents contain personal information , if you don't need a document any longer be sure to dispose of it properly to protect your identity. Make sure your information is in a safe, yet accessible location.

There are many ways that you can get organized, so find a system that works for you. Some people use the following types of systems:

- Notebooks
- Expanding file folders
- File box
- Plastic tub

You may also want to request a copy of your medical record from specialists each year to make sure that you have everything.

Being organized also helps when you are meeting with doctors. It helps you share your health information and history when you are asked to provide it on paperwork of when you talk to your doctor. A health history is provided in this document for your use.

Health History Summary

As you make the transition from pediatric to adult health care, you will be assuming more responsibility for your health care. When you go to your new adult doctor (or other health care provider), you will be asked about major health events in your life. **Have a parent help you fill out this form** and take it with you when you go to your new adult care doctor (or other health care provider) and you will be prepared for the questions that you will be asked.

How would you describe your overall general health? (Please circle one and add comments if you want to)

Fair Good Excellent

What are your special health care needs? Is there anything in particular that your doctor needs to know about your special needs?

As a child and teenager, what were your major health problems?

What medications are you **currently** taking?

Medications:	What is it taken for?	**How Much? (Dose)**	How Often? (Schedule)

Allergies or adverse reactions to medications

Are there any medications that you have taken that have caused you problems?

Medication	Reasons no longer taking medication

Food or other allergies: (include bee stings)

Food or substance	Reaction and Treatment

Past medical history:

Your birth weight: ________ Were you born early? _____ If so, how many weeks early? _______

Did your mother have any problems with her pregnancy or delivery of you?

Were you hospitalized at the time of your birth? _____ If yes, how many days?____ or weeks?____

What problems did you have at birth?

____

____

____

____

____

____

Please list any serious illnesses you have had and any injuries that included loss of consciousness.

____

____

____

____

Please list hospitalizations and surgeries you have had and include the dates and places.

Personal health history: Have YOU ever had the following:

Condition:	**Yes**	**Age**
Anemia		
Asthma		
Blood Transfusion		
Cancer		
Constipation		
Diabetes		
Ear Infections		
Eating Problems		
Heart Disease		
Hepatitis		
Seizures (Epilepsy)		
Tuberculosis		
Attention Deficit Disorder		

Condition:	**Yes**	**Age**
Depression		
Suicide attempt		
Conduct Disorder		
Anxiety		
Learning Disability		
Developmental Delay		
Eating Disorder		
Other Conditions not Listed:		

If the answer is yes to any of the above conditions please use this space to make any additional comments about the conditions. **For individuals with seizures,** describe the seizures and include how often the seizures occur, how long they last, and when was your last one?

What tests have previously been done for these conditions, what were the results, and where were they done? (MRI? CT? EEG? EKG? Genetic Testing? Blood Tests? Psychological Testing?)

What treatments have been tried for these conditions and what was the most successful?

Are the conditions (please circle one): (the same) (improving) (getting worse)

Resource Information:

School:________________________ Grade in School: ____________

Do you have an Individual Education Plan (IEP)?______________Do you have a 504 plan? ____________

Name of contact person at school____________________Telephone:______________

Do you use Vocational Rehabilitation services? **Contact person at VR**

Recent medical records:

List the name, address, and telephone number of any doctors or other health care provider who have the latest medical records about your health conditions.

Name	Specialty	Address	Telephone #

Other resources:
List the name, address, & telephone number of any other person that has worked with you in regard to your health condition in the past two years (such as a physical therapist, pharmacist, medical supply house, caseworker, school nurse, etc.).

Name	What They Do	Address	Telephone #

Your immunization dates: (Or attach a copy of your immunization record)

DPT/DT	1.	2.	3.	4.	5.
TD	1.	2.	3.	4.	5.
OPV	1.	2.	3.	4.	5.
MMR	1.	2.			
HIB	1.	2.	3.	4.	
Hep B	1.	2.	3.	4.	
Varicella	1.	2.			

Family Health History: Have any of your blood relatives had the following:

Condition:	**Relation**
Anemia	
Breast Cancer	
Cancer (Other)	
Diabetes	
Heart attack	
High Blood Pressure	
High Cholesterol	
Seizures	
Sickle Cell Anemia	
Stroke	
Thyroid Problems	
Tuberculosis	

Condition:	**Relation**
ADD/ADHD	
Alcoholism	
Depression	
Drug Abuse	
Learning Disability	
Manic Depressive	
Suicide	
Schizophrenia	
Other Conditions?	

Comments:

____

____

____

____

____

____

____

____

Insurance Coverage Information:

Insurance	**Policy number**	**Telephone number**
Do you receive social security income (SSI)?	YES	NO
Do you receive medical benefits through the SSI program?	YES	NO

Emergency Contacts:

Name	**Relationship**	**Telephone numbers**
		(W) (H)
		(W) (H)

Activities of Daily Living

	YES	NO
Are you visually impaired?		
Do you wear glasses or contacts?		
Are you deaf or hard of hearing?		
Do you use a hearing aid?		
Do you have any speech problems?		
Do you use sign language?		
Is English your preferred language? If no, what language do you speak?		
Can you walk?		
Do you use a walker?		
Do you use a wheelchair?		
Do you routinely wear medic alert identification?		

What other aids do you use to accomplish daily activities?

Are there any restrictions to your daily activities? (Can you drive an automobile? Do you need a computer to communicate? Etc.)

Your adult doctor will ask you questions in private about your sexuality, about drug and alcohol and cigarette use.

Information courtesy of Diana Patterson and the Adolescent Health Transition Project
http://depts.washington.edu/health

PERSONAL STORIES

This section will provide you with the perspective of parents, family members and those living with the disability or special health care need. Written personal stories are one way of connecting to others who have similar experiences. These stories give you insight on a specific experience including some of the joys and challenges that were experienced as well as suggestions.

Another way of connecting with others is through the Sharing Our Strengths peer support network. SOS provides you with an individualized match specific to what you want. This may include being matched to mentors with a similar disability experience, a mentor located in a similar part of the state or around a specific issue. If you are interested in being matched or in becoming a mentor for someone else, please contact us.

Another Transition, OH NO!!!!!!

Personal Perspective of Lucy, parent of a child with a disability

As I think of the many times I've heard the word "Transition", the hardest one has been the transition of medical care from pediatric to adult. I thought "okay so when Troy grows up and needs to move beyond the care of Children's Mercy how hard can it be?" Well it has been and continues to be a tough issue. First of all, you're being asked to leave all the doctors that have been with you since birth, all those years of knowledge specific to him, those friendships and trusts. I was also naïve to think that finding adult medicine doctors that carry his insurance and willing to take him on as a patient with his pre-existing conditions would be easy. It's actually worse than finding an insurance company to take him with pre-existing conditions.

We have been very fortunate that Children's Mercy's Teen Clinic has been more than willing to work with me while we make this transition in finding a primary care physician (PCP). PCP's are harder to find than specialists, go figure. This process is even harder since we have primary insurance to his Medicaid. If he only had Medicaid it would be easy, we'd go to Truman and be done. However, that's not our case. Having to coordinate the primary insurance with a doctor who also takes Medicaid is a horribly long and involved process. First going through the 300+ pages of doctor listings from the Medicaid website and then matching it up with the insurance's listings. When I find matches, calling to find out that, "no, they won't take your child because of his medical involvement". Really? What happened to the Hippocratic Oath you took to care for those in medical need? My son's diagnosis is nothing earth shattering or contagious and believe me when you meet him you're usually glad you did. Even when I find that perfect doctor, which I'm still searching for, getting his medical records transferred from Children's Mercy could be a nightmare. When I've requested records for specialists in the past it's taken for ever to get things from them. I can only imagine what it's like to get them for a PCP.

All told, I've learned from Troy what to do and not to do as my final child makes the transition from pediatric to adult care. Of course her medical history is not as extensive, but is still involved. So, I have kept more extensive medical records on her and ask for copies of everything. I've done this with Troy to an extent but could have done a better job with his records. I have already started looking for a new PCP instead of waiting until she's 18 and ready to move to college. I'm also getting things in place so when a medical emergency arises I'm not seeking help with people we don't know.

Challenging YES, Impossible NO!!! Take a deep breath and enjoy the ride, remembering all the while who you're doing this for and only the best counts.

FAMILY SUPPORT ADVOCACY & SERVICES

This section will provide you with a listing of agencies focused on areas such as educational, medical care or social services to individuals with developmental disabilities or special health care needs. This includes listings such as state or local agencies, hospitals, clinics or education systems.

Support for Families

Missouri Family-to-Family Resource Center
Housed at the UMKC-Institute for Human Development, UCEDD
215 W. Pershing
Kansas City, MO 64108
Phone: 816.235.1763
Toll Free: 800.444.0821
web: http://www.mofamilytofamily.org

Missouri Family-to-Family is a statewide network of parents, family members, and individuals with disabilities and/or special health care needs providing information and peer support through the MOF2F Disability & Health Information Center and Sharing Our Strengths (SOS). SOS is a statewide support network of parents, family members, individuals with developmental disabilities and/or special healthcare needs, and professionals who are matched with peer mentors to share experiences, offer emotional support, and to network with others. You can request an individual parent to parent or peer support match with another parent or individual who has experienced similar circumstances.

The Family Partnership members include individuals with special health care needs, as well as, parents, family members or legal guardians. The Partnership has three professional Family Partners who share responsibility for each of SHCN's service areas. The Family Partners are parents of special needs individuals served by SHCN. In addition to providing information and resources to local members, they serve as the Partnership's contact person for their designated areas.

Family Partners can be reached through the following agencies:

Special Health Care Needs (SHCN)
Missouri Department of Health and Senior Services
PO Box 570
Jefferson City, MO 65102-0570
Telephone (Toll-free): 800-451-0669
Fax: 573-751-6237 Email: info@dhss.mo.gov

Miller County Health Center
P.O. Box 2
Tuscumbia, MO 65082
Family Partnership Family Partnership
Toll-Free Number
1-866-809-2400, ext. 308

Missouri
Service Systems

The purpose of this section is to provide you with a listing of agencies focused on specific topics. This includes listing such as state or local agencies, hospitals, clinics, or education systems.

Missouri Service System Contacts

- **MO Healthnet (Division of Social Services)**
  Find providers who accept MO Healthnet insurance or get answers about your MO Health net questions.
  (573) 751-3425
  https://dssapp.dss.mo.gov/ProviderList/sprovider.asp

- **Missouri Statewide Independent Living Council**
  To find the Center for Independent Living closest to you, call toll free
  1 (888) 667-2117
  http://www.mosilc.org/CIL.htm

- **DMH Division of Developmental Disabilities**
  For information about getting home and community-based waiver program services in Missouri or to find your local regional office, call toll free
  1 (800) 207-9329
  http://dmh.mo.gov/ddd