



Institute for Human Development

Partnerships for Effective Social Change

UMKC Institute for Human Development

A University Center for Excellence in Developmental Disabilities

**30 Years of Building University and Community
Partnerships for Effective Social Change**

Transition to Adult Health Care

George S. Gotto, Ph.D.

Research Associate

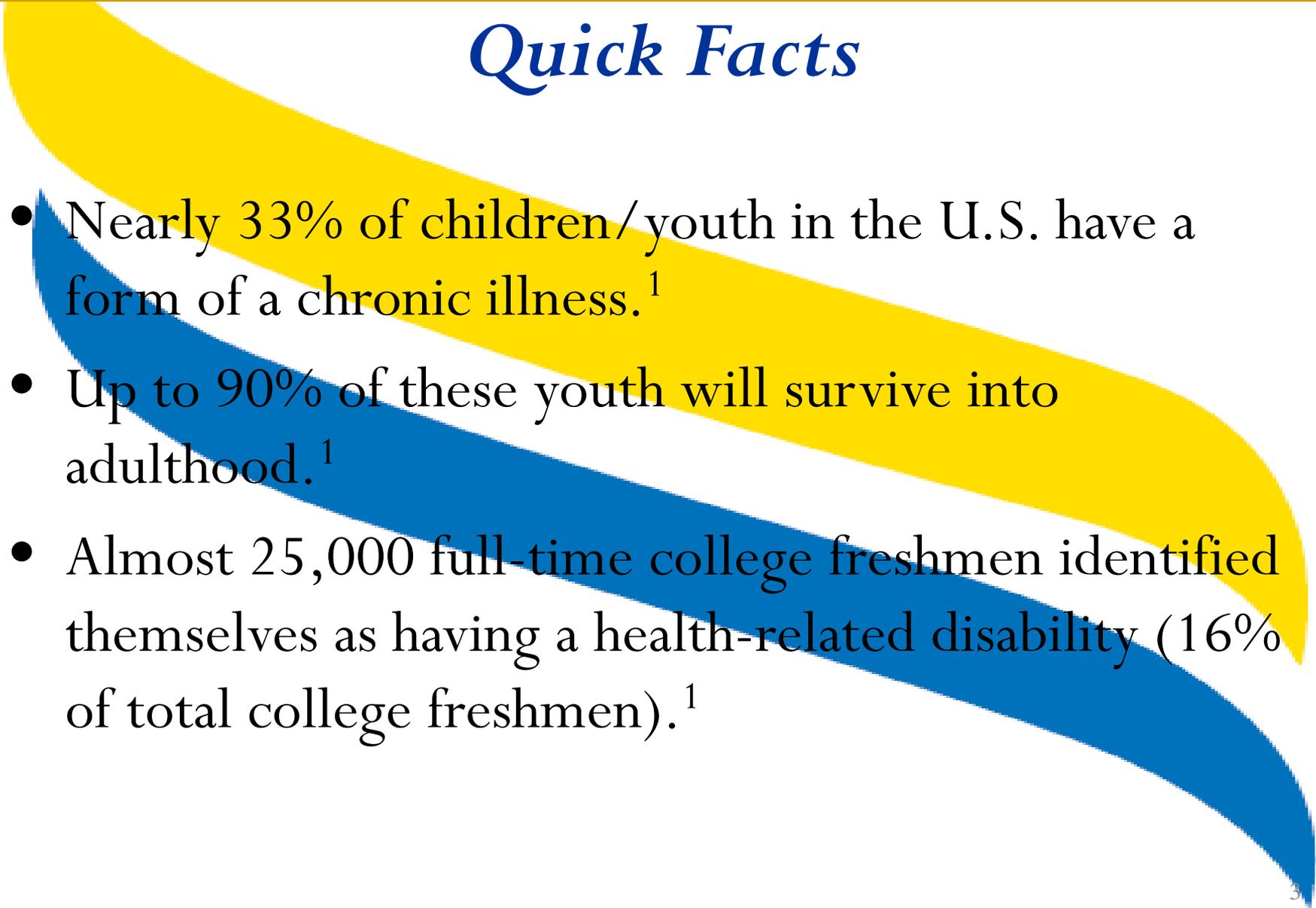
Jenny Hatfield-Callen, BS CIRS

Research Associate and Parent

816.235.1700

800.444.0821

www.ihd.umkc.edu



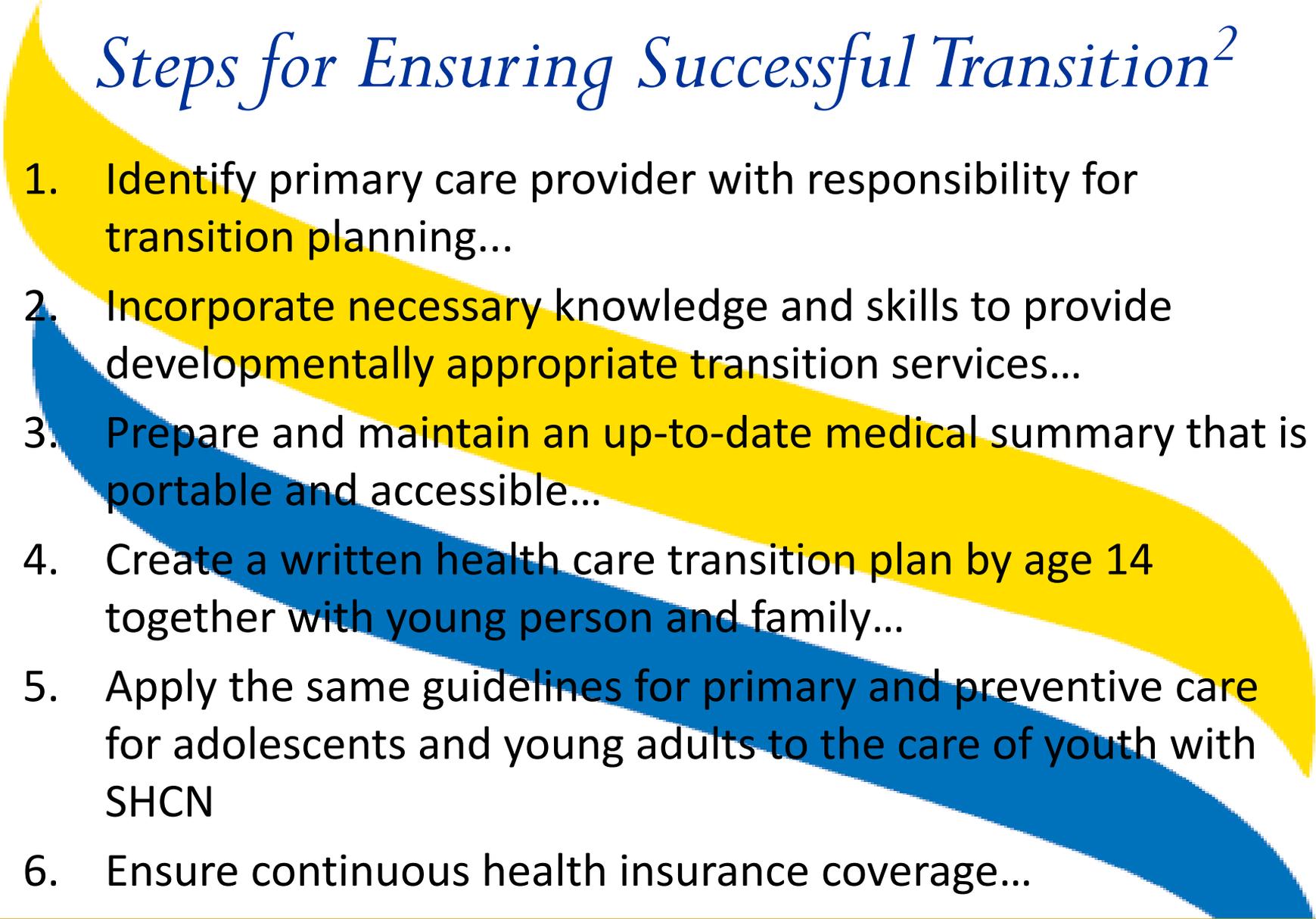
Quick Facts

- Nearly 33% of children/youth in the U.S. have a form of a chronic illness.¹
- Up to 90% of these youth will survive into adulthood.¹
- Almost 25,000 full-time college freshmen identified themselves as having a health-related disability (16% of total college freshmen).¹

Transition to Adult Care

- To make transition a smooth process young people need assistance over a period of time to assume their new role as informed health care consumer
- The move from pediatric to Adult Care can be a traumatic experience – parents and youth more often than not feel completely unprepared.

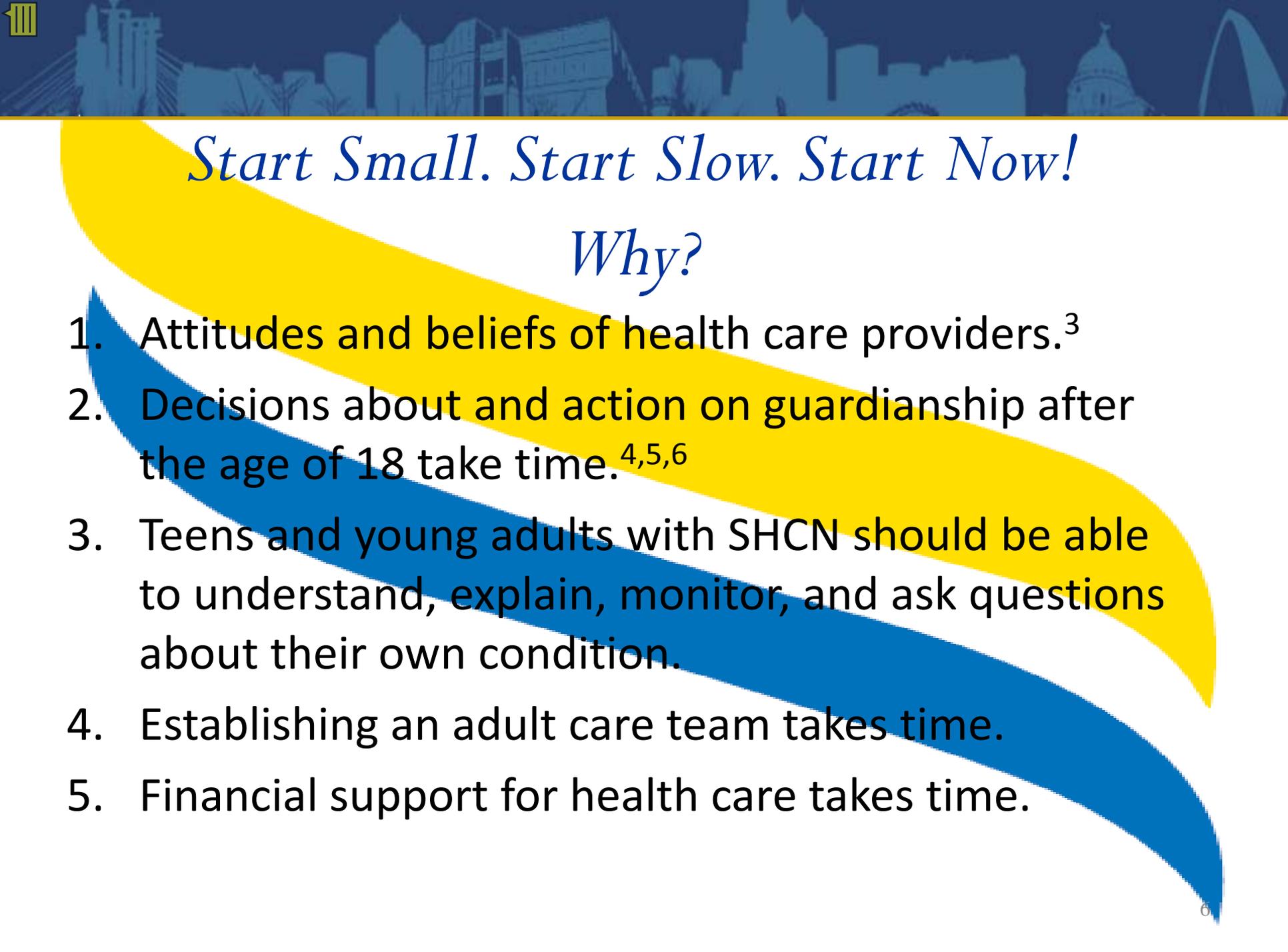




Steps for Ensuring Successful Transition²

1. Identify primary care provider with responsibility for transition planning...
2. Incorporate necessary knowledge and skills to provide developmentally appropriate transition services...
3. Prepare and maintain an up-to-date medical summary that is portable and accessible...
4. Create a written health care transition plan by age 14 together with young person and family...
5. Apply the same guidelines for primary and preventive care for adolescents and young adults to the care of youth with SHCN
6. Ensure continuous health insurance coverage...

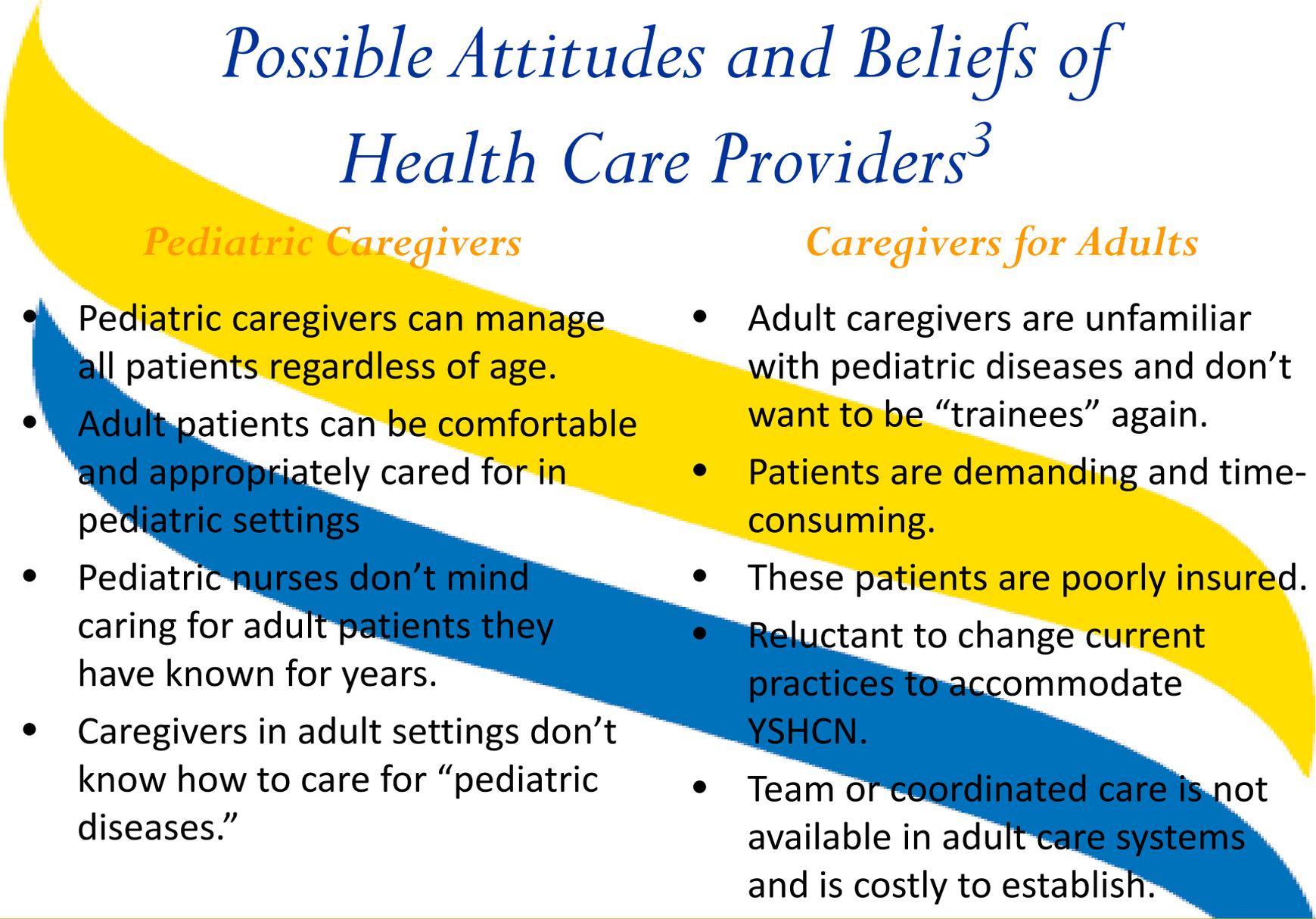




Start Small. Start Slow. Start Now!

Why?

1. Attitudes and beliefs of health care providers.³
2. Decisions about and action on guardianship after the age of 18 take time.^{4,5,6}
3. Teens and young adults with SHCN should be able to understand, explain, monitor, and ask questions about their own condition.
4. Establishing an adult care team takes time.
5. Financial support for health care takes time.



Possible Attitudes and Beliefs of Health Care Providers³

Pediatric Caregivers

- Pediatric caregivers can manage all patients regardless of age.
- Adult patients can be comfortable and appropriately cared for in pediatric settings
- Pediatric nurses don't mind caring for adult patients they have known for years.
- Caregivers in adult settings don't know how to care for "pediatric diseases."

Caregivers for Adults

- Adult caregivers are unfamiliar with pediatric diseases and don't want to be "trainees" again.
 - Patients are demanding and time-consuming.
 - These patients are poorly insured.
 - Reluctant to change current practices to accommodate YSHCN.
 - Team or coordinated care is not available in adult care systems and is costly to establish.
- 



The Future Sneaks Up on You

In Missouri Legal Adulthood begins at 18

- Vote;
- Get married;
- Make a will;
- Make a contract (rent an apartment, buy a car, take out a loan);
- Make independent decisions free from parental control; and
- Give or refuse consent for medical treatment;



Teens and Young Adults with SHCN¹

Should be able to	Example
Understand their own condition and the treatment or intervention needed.	<i>“I have cerebral palsy because I lost oxygen at birth...I need help with...”</i>
Explain their condition and needed treatment or intervention to others.	<i>“I am on three medications for spasticity.”</i>
Monitor their health status on an ongoing basis.	<i>“I use my communication device to let others know how I am feeling.”</i>
Ask for guidance from their pediatric health care providers on how and when to make the move from pediatrics to adult care.	<i>“I’m going to ask my pediatrician when should I start seeing a family practice doctor for my general care instead of a pediatrician.”</i>
Learn about the systems that will apply to them as adults	<i>“I have applied for medical assistance through Social Security for now because I have a disability and I need to be able to get medial care”</i>
Identify formal and informal advocacy services and supports they may need.	<i>“I ask my parents for advice because they have known my medical care the longest.”</i>



Adult Health Care Team³

(using cystic fibrosis as an example)

Team Members	Responsibilities
Physician	Provide medical services on inpatient and outpatient basis; serve as medical director of team; fiscal administrator; liaison with pediatric physicians; representative and advocate within the hospital and departmental administrative systems.
Nurse Coordinator	Provide direct care; take patient calls and act as a resource for patients; provide education and consultation to in-patient nursing staff; facilitate communication among team members.
Social Worker	Complete psychosocial assessment and identify problem areas needing intervention; Provide counseling and other interventions to aid in adjustment to transition; Communicate plan with team both verbally and in writing.
Dietician	Nutritional assessments and recommendation for nutritional needs; set up appropriate meal pattern; provide consultation to team members on nutritional issues; communicate diet plan to team.
Physical Therapist	Deal with inpatient equipment needs; develop rehabilitation plan; Assess motion, strength, posture, etc.; provide physical therapy consultation to the team.



Financing Adult Health Care

- Extend Parent's Insurance coverage (short-term solution)
- Insurance through an employer (best solution)
- Community Health Center
- Medicaid^{8,9}
- Other?



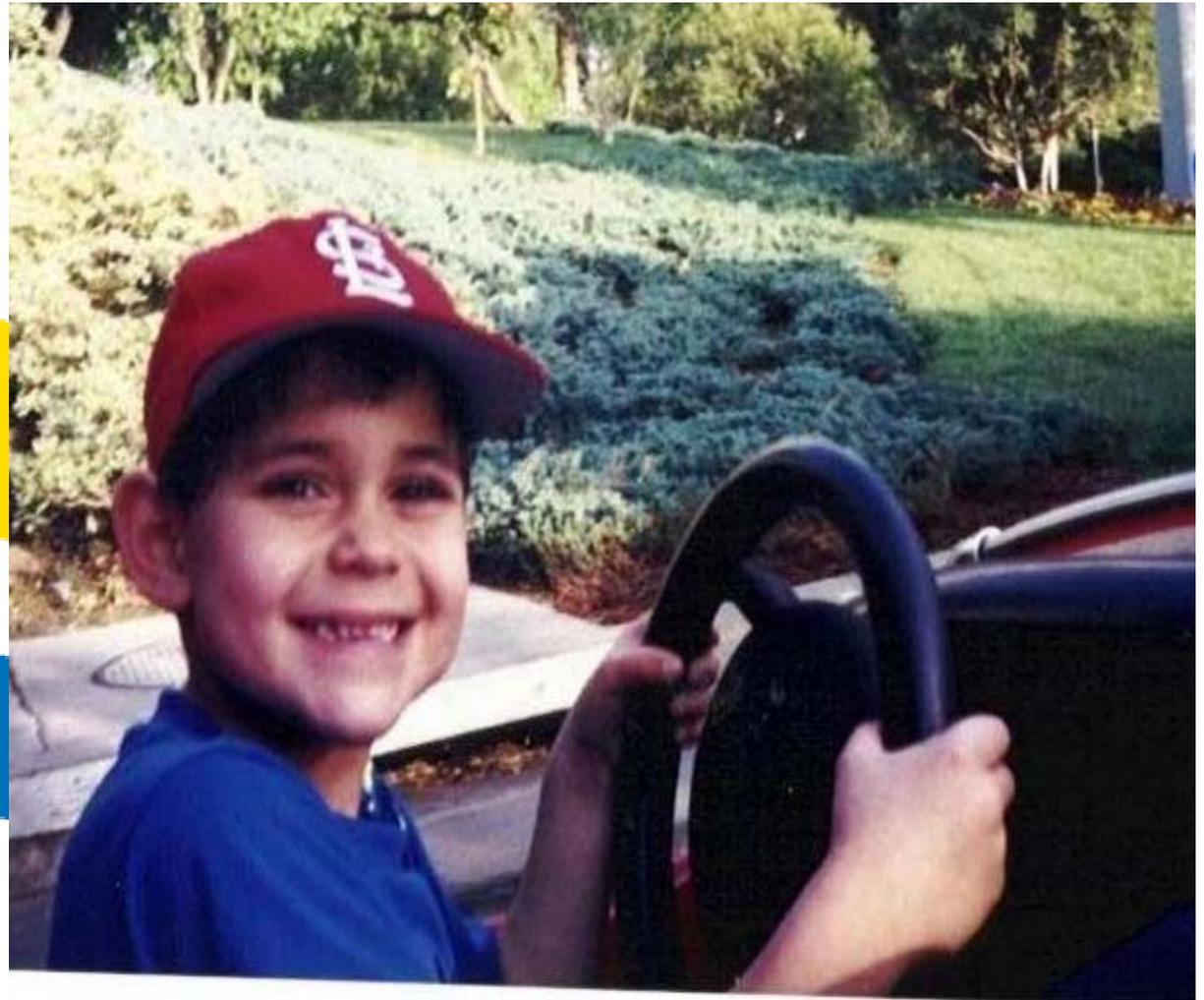


Transition to Adult Life

- Over 22 years of experience in the disability field
- Talk to many parents about issues with their children when it comes to the transition from Childhood to Teen Years to Adult life
- Researched issues surrounding transition for many families, teachers, school counselors, service coordinators, social workers, etc.
- And, I am Joe's mom....

Joseph's Story

- Adopted @ 4 days old by a couple in their 30's unable to have children
- Birth mother young and unable to rear him
- Unknown to the adoptive parents at the time, birth mom involved with alcohol during pregnancy



Joe's Diagnosis

- Age 4—ADD/ADHD—added medication (Ritalin—later Concerta) at age 6 to help him cope at school—we did not medicate outside of school from the initial decision to medicate—
- Age 11—FAE—Fetal Alcohol Effect now called ARND—Alcohol Related Neurological Disabilities
- Age 12—Dysgraphia, a learning disability
- Age 21—Traumatic Brain Injury related to an MVA

- Life with Joe as we moved toward Adult Life:
- Joe said at his first educational transition (IEP) that he was interested in serving in the military—we visited with the Air Force ROTC program in our district, but, Joe didn't like the idea
- Not giving up, we found information about the US Naval Sea Cadet Program, found the Unit in our area, and Joe became involved, serving 4.5 years as a Sea Cadet, and rising to the rank of Lead Petty Officer



Medical Transition

- We were lucky enough for Mom to have health insurance, and, since Joe was still a minor, all Joe's medical care issues received his Mom's touch, except:
 1. It was a struggle to get him to cooperate with almost any medical visit if he felt that needles or "talking a long time" would be involved.
 2. At age 15— On his birthday, Joe removed himself from medication, as it interfered with his future plans—from that point on we coped with his disability w/o assistance from medication! I agreed to this because:
 - a. He had shown a strong commitment to his future plans
 - b. We created a way to closely monitor his "activities" via the IEP
 - c. There was no risk to his physical health
 - d. For the duration of his time on ADD medication we had used meds for school purposes only—no medication on weekends, summers or school breaks—he had opportunities to learn internal control.
 - e. Issue of size, reach, and propriety

- This was a very rewarding day!
- One of Joe's mentors that helped tutor him through the studies in piloting a private aircraft talked to a friend who owned a trainer plane.
- Joe got to go up in the plane and "hands on" put his studies to use.....



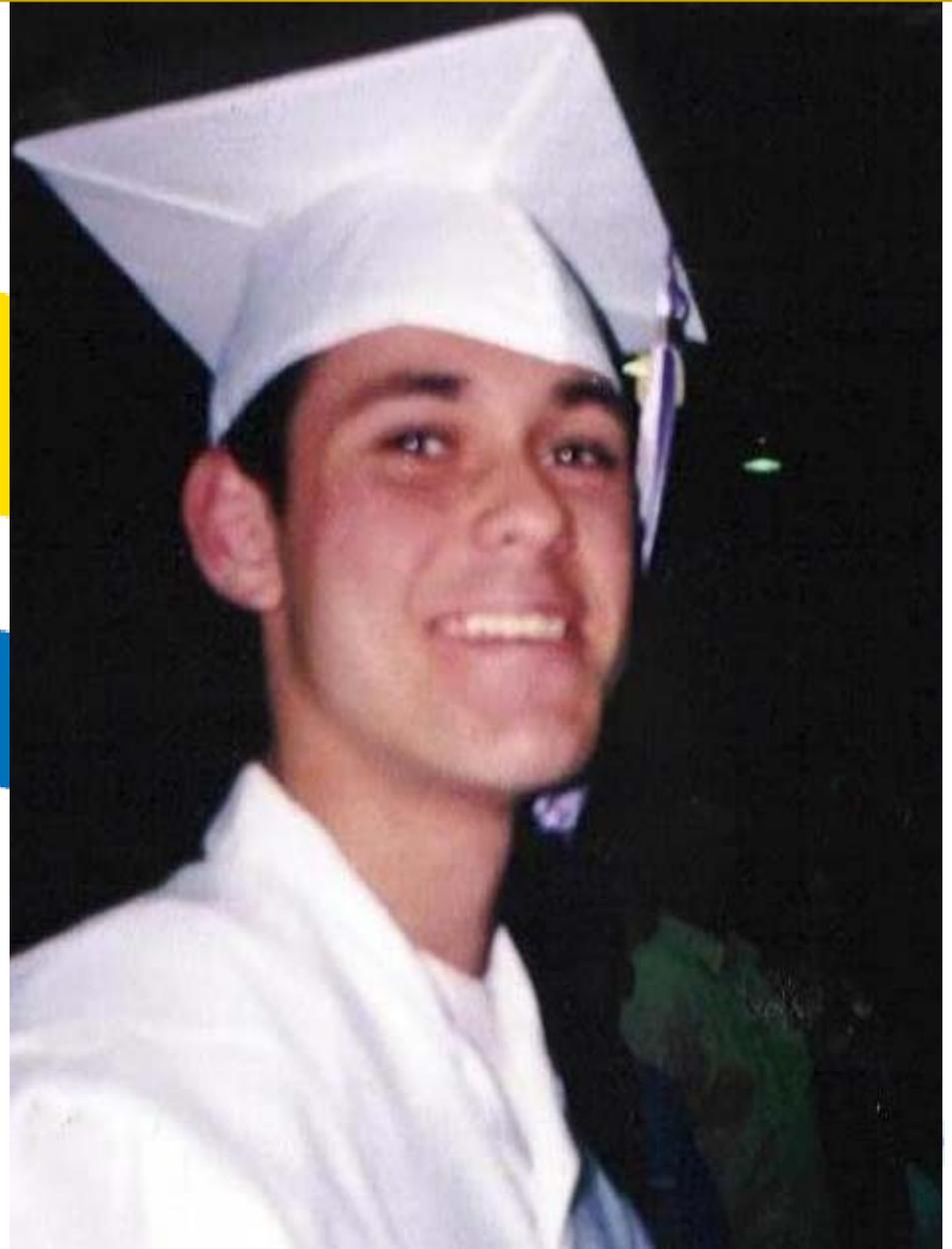
He took outside classes that related to his interests, including classes in piloting a private aircraft thru BSA



Graduation!!!

A Banner Day!

May 17, 2005



And Medically, what did we do?

- Joe was able to stay on my health insurance because he was 18 at the time of graduation.
- Joe was working a part-time job in retail, but, because of his employment status, insurance was not offered.
- There were no medical issues for the next 61 days, as Joe's employment status would change on July 27, 2005. On that day, his world changed....



- Joseph trained at Great Lakes Naval Training Center in Chicago, IL, where he served as a Recruit Chief Petty Officer.
- On October 10, 2005, Joseph reported to NDW Anacostia Annex in Washington D.C., where he began serving with the **United States Navy Ceremonial Guard**. He served in B squad of the Ceremonial Guard where he was a part of the “firing team” that does 21 gun salutes at Naval Funerals and burials at Arlington National Cemetery . He also served at Presidential ceremonial activities.



Seaman Joseph S. Reed, USN

What else has happened?

- Joe has been through many trials and travails in life since joining the Navy in 2005. But, through it all he has prevailed. 2008 was a very difficult year for us all.
- In August 2008, Joe was in transit to Great Lakes Naval Training Center, via home in KC (Mom's storage facility for his worldly belongings!) He was involved in a roll-over accident in his brand new truck. The vehicle rolled 4 times at 74 mph. Joseph sustained a C-4 vertebrae fracture, a mild TBI, a collapsed lung, and numerous cuts, scrapes and bruises. He spent 6 days in the Trauma Unit at University Hospital in Columbia, MO and 3 weeks on convalescence leave with Mom. Joe was 21 when the accident occurred.

What Mom Learned....

- I had to prove my relationship with Joe to get access to him in the hospital—that was new!
- Joe had to sign a consent form for me to act in his behalf, medically, during his hospitalization.
- After his release, however, I had to advise his Tri-Care Insurance Coordinator that she had to talk to him about his medical issues or obtain his consent before talking to me. Why?

Today.....

- Joe is back with the US Navy , and is stationed at Great Lakes Naval Training Center near Chicago. He is attending Gunner's Mate (GM) and Advanced Technical Training (ATT) Schools, and passed ATT in early March 2009 .

He is struggling with schooling, as it is harder for him to retain information, due to the TBI, and since the accident he has frequent bouts with neck pain and migraine headaches. Also, due to the accident, he had needed to undergo physical therapy and strength conditioning to rebuild his body.

Joe was declared “fit for duty” in late March 2009.



What Mom has learned...

- Joe will always call me when he doesn't feel well.
- Joe does not always do what he needs to do, preventatively, to stay healthy
- Joe will not call at opportune hours when he doesn't feel well

Example: It is 11:30 pm on a Thursday evening, Joe has called, he has neck pain that radiates down into his shoulder and into his head—he also has a migraine headache. He calls to ask, “Should I go to the hospital off base?”

I have also learned:

- I cannot force Joseph to change his lifestyle to better meet his medical needs
- I can only ask questions, provide suggestions, and discover the outcome
- This is the time for the “over 18 Mommy Mantra”
“It’s his life, not mine; It’s his life, not mine; It’s his life, not mine.”

I would be happy to “Talk Medical Transition” with you...

- 800-444-0821—Always leave me a message!!!
- 816-235-1763---In the Greater KC area-still leave a message!
- moddrc@umkc.edu
- hatfieldcallenj@umkc.edu



References

1. Gillman, D. & Schlicht, B. (2005, January). Transition to Adult Health Care: A training guide in two parts. Madison: Waisman Center, University of Wisconsin—Madison, University Center for Excellence in Developmental Disabilities.
2. American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine (2002). A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs. *Pediatrics*, 110, 6:1304-1306.
3. Bronheim, S., Fiel, S., Schidlow, D., MaGrab, P., Boczar, K., & Dillon, C. (undated). *Crossings: A manual for transition of chronically ill youth to adult health care*. Prepared under Grant #SPC-945-713 for the Bureau of Maternal and Child Health, Anne Keller, M.D.; Pennsylvania Department of health, Principal Investigator; in collaboration with St. Christophers Hospital for Children, Temple University Hospital and Georgetown University Child Development Center.
4. "Guardianship of Adults: A decision-making guide for family members, friends and advocates," a handbook by Roy Froemming, J.D., and Betsy Abramson, J.D. It is available from the Department of health and Family Services. Division of Supportive Living, ATTN: Publications Order, One West Wilson St., P.O. Box 7851, Madison, WI 53707-7851. Include the publication number (PSL-460), your name, address and a phone number in case of questions.
5. "Guardians and Conservators Under Missouri Law." The Missouri Bar. <http://www.mobar.org/16f9d7f8-dd52-44f3-89e7-32de079a8d66.aspx>
6. "A Basic Guide for Understanding Guardianship and Conservatorship in Missouri" Available from Missouri Protection and Advocacy Services, 925 South Country Club Drive, Jefferson City, Missouri 65109, 1-800-392-8667 or in Kansas City call 816-756-1001.
7. "Medical Home." American Academy of Pediatrics. <http://www.aap.org/healthtopics/medicalhome.cfm>
8. Barker, M.R. (2007, Winter). *Missouri Medicaid Basics*. Saint Louis: Missouri Foundation for Health. Available online at www.mffh.org. Additional copies are available by calling MFH toll free at 800-655-5560.
9. Williams, B. & Tolbert, J. (2007, January). *Aging Out of EPSDT: Issues for Young Adults with Disabilities*. Issue Paper, Kaiser Commission on Medicaid and the Underinsured. Washington, DC: Kaiser Family Foundation.