

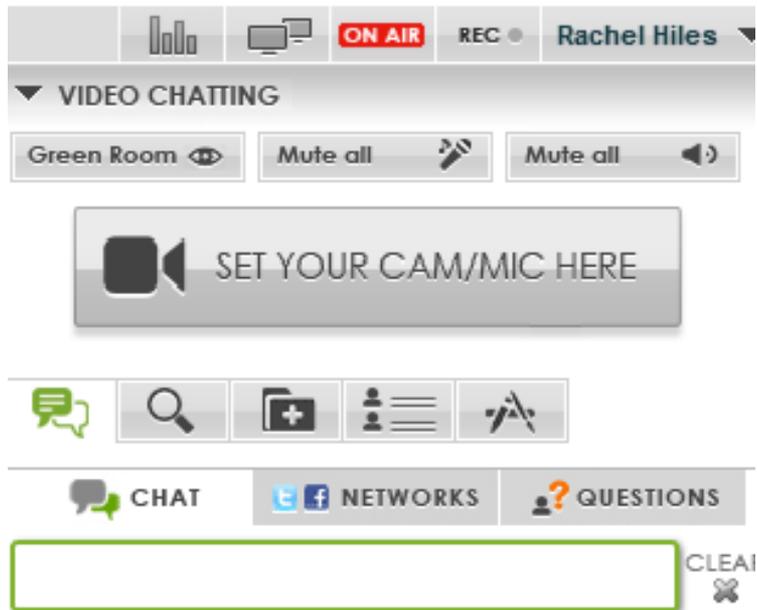
BROWN BAG LUNCH WEBINAR

July 27, 2011

Surviving the Transition to Adult Medical Care



How to Participate



CHAT – To communicate with the hosts or the other participants, you can type your comments in the CHAT area below

NETWORKS – To share this webinar on Facebook or Twitter, you can click your favorite one and invite people to join in!

QUESTIONS – If at any time you have a question, you can type it in this box and we will answer it when questions are taken



How to Participate



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Surviving the Transition to Adult Health Care

Missouri Family-to-Family Resource Center
University of Missouri-Kansas City
Institute for Human Development, UCEDD



Goals

- Talk about medical transition and how to plan for the future.
- Listen to a personal story about medical transition
- Talk about the roles everyone should play in medical transition.
- Talk about ways of “organizing” your medical history and documents.



Medical Transition

Medical transition is when a child/youth is moving from pediatrics to adult health care

The University of Illinois at Chicago <http://internet.dsc.uic.edu/forms/psu/o592.pdf>



Why is Medical Transition important?

Because Health Affects Everything!

- Employment
- Housing
- School
- Community Living
- Recreation
- Inclusive opportunities



Source: Cyr, M., Shapland, C. & Hackett, P. (2010). What's Health Got To Do with Transition: EVERYTHING!
(<http://www.hrtw.org/hrtwu/presentations.html>)



Why is Medical Transition important?

- Adult needs and requirements differ from those of children
- Medical needs differ (e.g., need to monitor blood pressure, cholesterol, etc.)
- Developmental needs differ (e.g., marriage, independent living)
- Psychosocial (e.g., work, etc)
- Relieve Stress



Pediatric VS. Adult Care

Pediatric

- Focus on family
- Nurtures and provides emotional support
- Doctors work as a team
- Parents provide consent
- Flexible

Adult

- Focus on individual
- Focus on specific need
- Doctors don't work together – a doctor for each need
- Patient provides consent



The Pros of Adult Care

- Promotes independent living / self-determination
- Grows/Develops system of support
- Allows individual to receive necessary adult care
 - Screening and treatment of adult health problems
 - Reproductive health care
 - Specialists in treatment for adults with SHCN
 - Access to adult inpatient services and specialists



Self-Determination in Health Care

Definition of Self-Determination:

- *“...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” (Wehmeyer, 1996).*



Self-Determination in Health Care

Why Self-Determination?

- It has been shown to improve Quality of Life.
- A healthy lifestyle requires skills & knowledge linked to health.
- Parents/Guardian may not always be there.



What youth are saying is important to them

- What to do in an emergency?
- How to get health insurance?
- What could happen if my condition gets worse?
- Learning to stay healthy.



PACER Survey – over 1300 YSHCN (1997)
The National Youth Leadership Network Survey (2001)



Ben's Medical Transition

- A little about Ben
- Medical issues going into adulthood
- What we worried about
- What we did/do
- Things Ben did/does to prepare



Role of youth in medical transition

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

SOURCE: http://depts.washington.edu/healthtr/powerpoint/transitiontalk_files/frame.htm



Role of parent in medical transition

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

SOURCE: http://depts.washington.edu/healthtr/powerpoint/transitiontalk_files/frame.htm



Parent and youth together in medical transition

- Develop a health record
- Teach/re-teach about the health condition at appropriate level
- Begin talking about the future (college, work, etc.) and how their SHCN effects their ability to achieve those goals
- Make a plan (think in 5 year segments)
- Discuss how to pay for health care/what insurance is available



Role of pediatrician in medical transition

- Continue to manage health care needs
- Encourage youth to cosign and become involved in the health care process
- Help the youth to understand what the physician and medical staff do
- Encourage family to visit and ‘interview’ adult physicians and staff to transfer care
- Provide health record to new provider and give youth a copy (1-2 page transition summary)

SOURCE: http://depts.washington.edu/healthtr/powerpoint/transitiontalk_files/frame.htm



Teens and Young Adults with SHCN/disability should:

Understand their own condition and the 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 should I 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 for now because I have a disability and I 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."

Guardianship or not?

Things to think about

- 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 issue you are concerned with?
- If guardianship seems like the only option, consider Limited Guardianship (for only the areas needed)



Some alternatives to guardianship that might help with 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 Youth Can Start Working On

- Know Doctors names
- Greet Doctors and medical professionals at appointments (ie- “Hello Dr. Yankem”)
- Tell the doctor/nurse what is wrong/why they are there
- Give basic demographics (name, birthdate, address, etc.)
- Give as much medical history as they are able
- Know and relay disability/special healthcare need information (it’s okay to have a “cheat sheet”)
- Carry and present insurance card



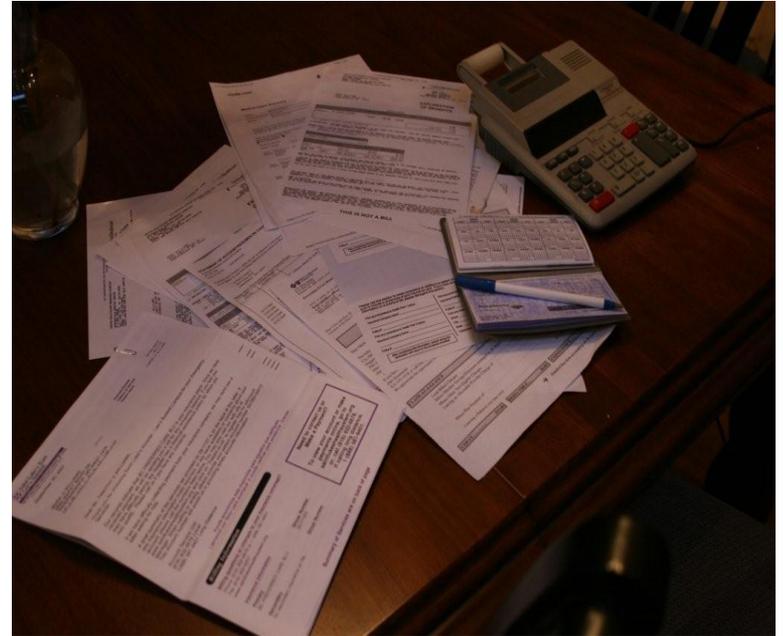
More things to work on

- Present co-pay (ie- pay with their own debit card)
- Know the names of prescriptions
- Call in Rx refills
- Learn about choice (of doctors, providers, hospitals, etc.)
- Prepare for Doctor visit: list 5 questions
- Insurance information – what insurance company, how much is co-pay, etc.
- Learn other benefits that affect healthcare: SSI, Medicaid/Medicare, VR



Options for financing health care

- Extend parent's insurance coverage (short-term solution)
- Insurance through employer (best solution)
- Medicaid/MO HealthNet
- MO HealthNet for Kids
- Home & Community Based Services (HCBS)
- Waivers
- Missouri Health Insurance Pool
- Supplementary Security Income (SSI)



Tips for identifying and working with insurance companies

- List your health care needs
- Check with your provider to make sure they accept your plan or if there are out of network benefits
- Make sure your doctors/specialists are on their provider list
- Know what type of plan you have and read it carefully
- Stay positive



Tips for organizing health documents and medical history

- Paperwork provides a paper trail; Keep it and keep it organized.
- Create a notebook/use an expanding folder, file box, or tub; Use a system that works for you.
- Request a copy of your child's medical records from each specialist annually for continuity.
- Make sure your information is in a safe, yet accessible location.



Be prepared.....transition takes time.

Start small, start slow, start NOW.



Reference/Resources

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Questions?????



Survey

Please take the time to visit our surveymonkey evaluation of this webinar and tell us what you thought!

<http://surveymonkey.com/bbmt>



Special Thanks

- MODHSS Bureau of Special Healthcare Needs
- Miller County Health Department
- Missouri Planning Council for Developmental Disabilities
- DMH Regional Offices and Family Support Coordinators



Next Month's Webinar

MO Guardianship: Understanding Your Options & Alternatives

August 24, 2011 at 12:00pm

- Have you gotten "the letter" from your child's school saying you should file for guardianship?
- Do you want to explore the options and alternatives to traditional guardianship?



For more information

Contact the

Missouri Family-to-Family Resource Center

800-444-0821

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