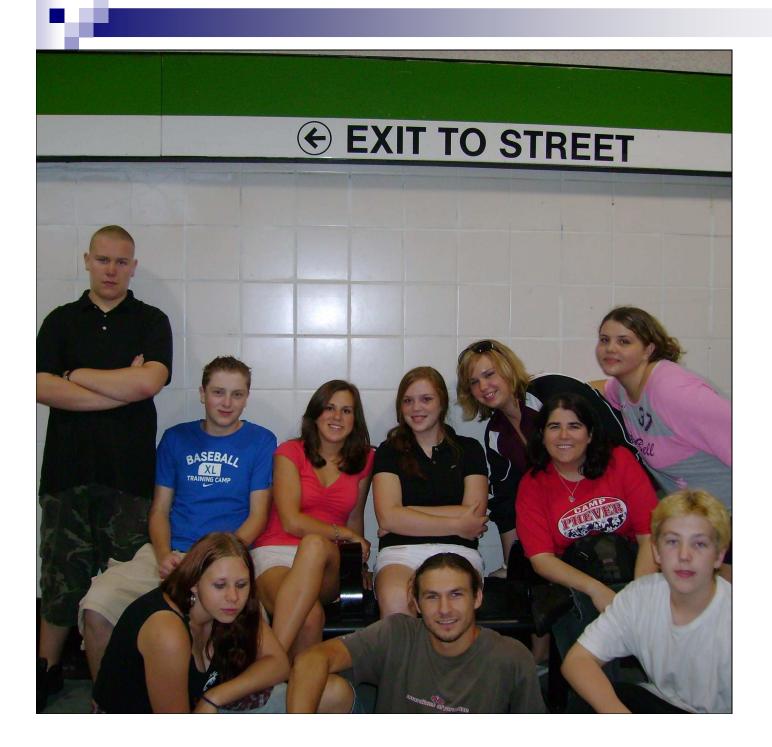
# TRANSITION: PSYCHOSOCIAL CONSIDERATIONS

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## CONSENSUS STATEMENT

- The goal of transition in health care for young adults with special health care needs is to maximize lifelong functioning and potential through the provision of highquality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.
- American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine. Published in Pediatrics, 2002; 110:1304-6



### COMING OF AGE



## EXTENT OF THE PROBLEM

- Estimated # adults with PKU (ages 21-45 years): 8,400 (based on 350 per year)
- Estimated 10% lost to follow-up \*
- Adult metabolic clinics in United States:
  - None in 1998
  - □ Maybe 3 now − Seattle, Atlanta, Boston

\*Hanley WB. Eur J Obstet Gynecol Reprod Biol. 2008; 137:131-135.





## METABOLIC DISORDER (PKU)— A good example of the challenge

 Critical need for adult medical care related to the disorder (Bone Density Problems, Psychiatric Disorders, Reproductive Care)

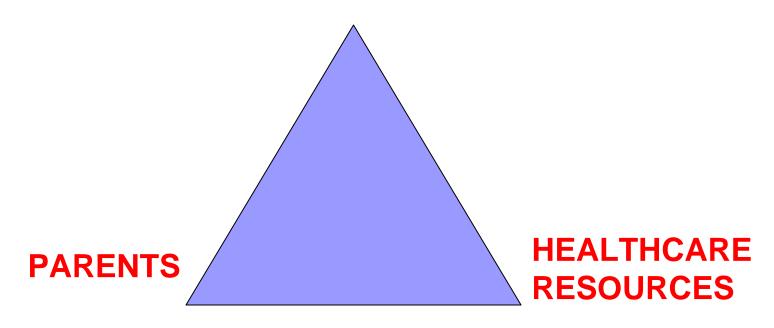
 Critical lack of adult metabolic specialists (Few places to "transition to")





### DEAL WITH THE CHALLENGE

#### **YOUTH AND ADULTS**





### PSYCHOSOCIAL PERSPECTIVE

- PSYCHOLOGICAL FACTORS
  - DEVELOPMENTAL STAGES
  - IMPACT OF THE MEDICAL CONDITION
  - □ PRINCIPLES OF BEHAVIOR
- SOCIAL FACTORS
  - □ ENVIRONMENTAL CONTEXT



### THIS IS IMPORTANT BECAUSE:

Transition requires changes in behavior



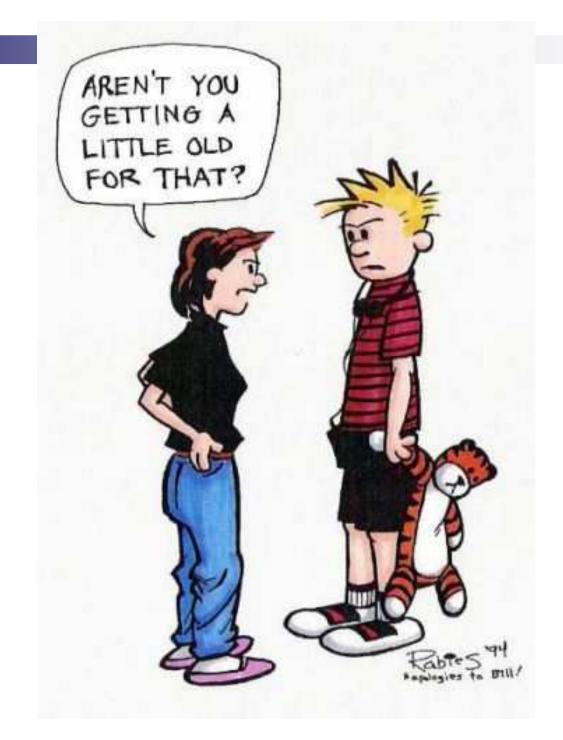
 Transition requires an understanding of the barriers to making these changes



## PSYCHOLOGICAL ISSUES FOR YOUTH AND ADULTS

- Impact of the metabolic condition
  - Executive Functioning Deficits (Planning, organization, memory)
  - Slower processing of information
  - Depression
  - Low motivation
  - □ Dependency on parents







## OTHER ISSUES

- Moved from childhood home
- No longer follow dietary treatment
- Lost to follow-up
- No affordable insurance
- Transportation difficulties
- Can't take time off from work
- Prefer "old" healthcare providers



## MOTIVATING FACTORS

- Fulfill expectations of parents and others
- Better health and functioning
- Treatment more manageable



As long as it's a whiz kid."



## ISSUES FOR PARENTS

- Difficulties letting go
- Preference for "old" healthcare providers
- Lingering psychological issues (guilt, resentment, loss, raison d'etre)
- Feelings of responsibility (recognize child's limitations)
- Lack of information



## MOTIVATING FACTORS

- Offspring will function better
- Parents will be less responsible for the care of their offspring



## INFRASTRUCTURE ISSUES

- Difficulties identifying population to be served
- Lack of trained providers (clinics & medical homes)
- Need for a multi-disciplinary clinical team
- Lack of incentives (reimbursement for providers)
- Need for coordination of Public Health Departments and Clinical Providers
- Few financial resources for Public Health



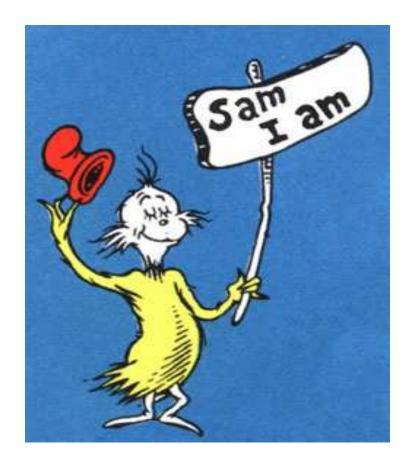
## MOTIVATING FACTORS

- Save money
- Reduce burden on metabolic centers
- Make money
- Achieve institutional mission



#### **RECOMMENDATIONS: YOUTH & ADULTS**





## POSITIVE ATTITUDES

## MANAGEABILITY

Finkelson L, Bailey I, Waisbren SE. J Inherit Metab Dls. 2001; 24: 515-516.



PKU CAMP AT THE SOUTH SHORE YMCA CAMP ON CAPE COD



## ASSESS SAM AND BEYOND

- Assess cognitive skills and emotional wellbeing (refer for counseling if needed)
- Assess skills for independence (provide education if needed)



## Write summary of health history

#### PKU HEALTH HISTORY

- Newborn screening level or level off diet
- ☐ Genotype (Type of PKU)
- □ On/off diet (since when)
- Current medical formula (Dosage)
- □ Current medications (Dosage)
- Last PHE level
- Learning disabilities
- Mental health history
- ☐ General health history
- □ Significant illness/hospitalizations/surgery



### INCLUDE SPECIFIC GUIDELINES

- PKU is associated with depression, anxiety, agoraphobia. Before treating with psychotropic medication, consider issue of elevated phenylalanine levels. These medications don't work if PHE levels are high.
- Low bone density may be associated with dietary restrictions in PKU. Consider this history when evaluating osteoporosis.
- Maternal PKU requires strict metabolic control prior to pregnancy. When issues of infertility arise, consider the difficulties of diet when deciding how long to wait before treating.



## **Establish Transition Plan**

- Timing: preliminary steps (knowledge, insurance, self-help skills)
- Who (primary care, specialty clinic, general clinic)
- Where (at college, near home)
- When
- Coordination with current healthcare providers

## PKU WALLET CARD

Primary Care Doctor:	Phone Number:	Personal Medical Information of:
Metabolic Clinic Physician:	Phone Number:	
		Date of Birth:
Dietician:	Phone Number:	
		My Phone Numbers:
Other Provider:	Phone Number:	

Blood Type:	Current Medications:	Health Insurance Info:
I have:	Name of Special Formula:	
Classic PKU		Pharmacy Phone Number:
Atypical PKU	Prescription:	
Mild PKU		Contact in Emergency:
Mild Hyperphenylalaninemia	Allergies:	



## RECOMMENDATIONS FOR PARENTS

- Assess readiness to foster transition to adult care
- Assess SAM
- Provide education and information

### Checklist for Parents

As a parent, your goal should be to slowly end your job as a direct care provider. Find out how you could help make your teen more responsible for his/her health!

- 1. Does your teen know about PKU and its consequences?
- 2. Does your teen know about PKU treatment?
- 3. Does your teen see his/her doctor while you wait in the waiting room?
- 4. Does your teen keep you informed about what challenges he/she has regarding metabolic control?





"Don't call me a teenager. From now on, I want to be referred to as a pre-adult."



## LOW-COST INFRASTRUCTURE RECOMMENDATIONS

- Word-of-mouth identification of responsive primary care providers:
  - □ The Primary Care Provider Booth
  - Survey of current patients
  - □ Survey of metabolic specialists
- Contact recommended providers to establish them as referral source



## MEDICAL HOME BY DEFAULT

- Send individual health history to primary care
- Send emergency protocols to primary care
- Invite to conferences
- Call periodically
- Include on list of "Recommended medical homes" (with permission, of course)



## Partner with industry

- Support for conferences
- Reproduction of educational materials
- Information on new therapies
- Surveys



## DESIGNATE TRANSITION NAVIGATOR

- Person responsible for answering questions from patients, families, metabolic centers, and medical homes
- Social worker, genetic counselor, nurse, psychologist
- Can be housed at public health department, metabolic center, or adult clinic



### EXISTING RESOURCES

- WEBSITES
- ORGANIZATIONS
- MATERIALS
- CONFERENCES



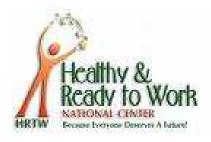
## MAJOR INITIATIVES

Genetic Alliance



Jacksonville Health and Transition Services JaxHATS

Healthy and Ready to Work (HRTW)



Institute for Child Health Policy



## Genetic and NBS Collaboratives



## National Metabolic and Genetic Conditions Transition Work Group

■Region 2 (NYMAC): Developed main website (www.wadsworth.org/newborn/nymac/index

For minutes, drafts, and internal business of work group go to:

www. westernstatesgenetics.org/transitionwg/index (username: kids2adults; password: success2008)



## ADULT METABOLIC CLINIC BRIGHAM & WOMEN'S HOSP.

- Key to success: Adult geneticist, genetic counselor, hospital support
- Challenges:
  - Credentialing of pediatric providers to go to Brigham & Women's for first transition visit
  - Training of nutritionists at Brigham & Women's



www.newenglandconsortium.org/toolkit

- Also in book form:
- My PKU Toolkit: A Transition Guide to Adult PKU Management (Available from Applied Nutrition)



## SUMMARY

- Transition is a 3-part process: patients, families and infrastructure
- A psychosocial perspective takes into account factors related to behavioral change: SAM (Social support, Positive Attitudes and Manageability)
- With creativity and use of existing resources, improvements in transition to adult care are possible.



## The Bottom Line

- All parties must feel some ownership (some incentive) to become involved in creating a program for transition to adult care.
- Larry Summers said it well:



## "NO ONE EVER WASHES THEIR RENTAL CAR!"

