

WISHES: Working Initiative for Special Health Education Services

*Transitioning Youth with Special Needs from
Pediatric to Adult Health Care*

Kitty O'Hare, MD & Manisha S. Patel, MD

Opening Doors for Youth

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Bios and Disclosures

- ◆ Dr. Kitty O'Hare
 - 2008 graduate, UPenn-CHOP Internal Medicine-Pediatrics residency
 - Instructor in Internal Medicine and Pediatrics, Children's Hospital Boston
 - Frances.Ohare@childrens.harvard.edu

- ◆ Dr. Manisha S. Patel
 - 2008 graduate, UPenn-CHOP Internal Medicine-Pediatrics residency
 - Fellow in Pediatric Cardiology, Children's Healthcare of Atlanta
 - mcschanbhag@yahoo.com

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Who are Youth with Special Health Care Needs (YSHCN)?

- ◆ Those with an increased risk of chronic physical, developmental or emotional conditions
- ◆ 15% of children less than 18 years old have special health care needs
- ◆ **Every year 500,000 YSHCN will turn 18 years of age.**

What is Transition?

“...the purposeful, planned movement of adolescents and young adults... from child-centered to adult-oriented health care system.”

A Consensus Statement On Health Care Transitions For Young Adults With Special Health Care Needs. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine, 2002.

“...a purposeful, planned movement of youth with special health care needs from pediatric to adult care.”

Transition from child-centered to adult health-care systems for adolescent with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adolesc Health. 1993; 14:570-576.

Goals of Transition

Provide care that is patient-centered, age and developmentally appropriate

Enhance a sense of control and interdependence in health care

Promote skills in communication, decision-making, self-care, and self-advocacy

American Academy of Pediatrics. Committee on Children with Disabilities and Committee on Adolescence. Transition of care provided for adolescents with special health care needs. Pediatrics 1996, 98 1203- 1206

2002 AAP, AFP, and ACP-ASIM Consensus Statement

- ◆ Create a written health care transition plan by age 14
- ◆ Identify a health care provider to coordinate the transition
- ◆ ***Train primary care providers in transition services***
- ◆ Maintain up-to-date, portable accessible medical summaries
- ◆ Ensure affordable continuous health insurance coverage for all CSHCN throughout adolescence and adulthood

What do YSHCN want?

- ◆ Jobs and training
- ◆ Independent Living Skills
- ◆ Guidance for postsecondary education
- ◆ Involved in decision-making
- ◆ Given options of care with rationale for each option
- ◆ Early transition with adequate communication between providers

Goals of WISHES: Educate...Educate...Facilitate!

- 1) Create and administer a health care curriculum pertinent to Youth with Special Health Care Needs (YSHCN)
- 2) Train Med-Peds residents as providers for YSHCN, and educate health care professionals on the importance of transition
- 3) Facilitate the transition of YSHCN from pediatric to adult medical providers

Goal #1: Educate YSHCN

◆ Examples

- Transition binder for Sickle Cell patients
- Conferences for adolescents with Congenital Heart Disease
- Presentations to special-needs adolescent fellowship groups
- School-based Healthy Choices seminar
- Occupational readiness program

Sickle Cell Anemia Transition Binder

- ◆ Self Advocacy Tips
- ◆ Portable Health Care Summary
- ◆ Basic Medical Information on Sickle Cell
- ◆ Local/National Resources List
- ◆ Medical Information Card

Sickle Cell Medical Info Card

Name: _____ DOB: _____

Emergency Contact: _____

Primary Hematologist: _____

Allergies: _____

Type of Sickle Cell Disease: _____

Baseline HgB: _____ Baseline Retic.: _____

Baseline pulse Ox: _____

Current Medications: _____

VOE Pain Medications: _____ (initialed by MD, RN)

Previous Complications: _____

Transfusion: Monthly As Needed Hx of Transfusion Reaction?

Surgeries: _____

Other Health Care Providers: _____

Healthy Choices Seminar and Occupational Readiness

- ◆ A health curriculum was designed for the Widener School, a Philadelphia public school for children with developmental disabilities.
- ◆ Presentations were multi-sensory to address barriers of deafness, blindness, and mutism.
- ◆ Selected students later participated in a job training program at Children's Hospital of Philadelphia. A multi-disciplinary team coordinated physical therapy, occupational therapy, speech, and neuropsychological evaluations.

Goal #2: Educate Health Care Providers

- ◆ Transition presentations
 - Disease-specific lectures to categorical residents and students
 - Monthly conference series for Med-Peds residents
 - Medical school advocacy seminar
 - Grand Rounds presentations on healthy transitions
 - Presentations to non-physician health care professionals
 - Leadership Education in Neurodevelopmental Disabilities (LEND) program

- ◆ Clinical experiences
 - Resident electives in Adult Congenital Heart Disease, Cystic Fibrosis, Oncology Survivorship, Genetics and Metabolism

- ◆ Resident-led advocacy projects

Goal #3: Facilitate Transitions

- ◆ Med-Peds residents serving as entry point to adult primary care
- ◆ Barriers to transition- survey of young adults with Congenital Heart Disease
- ◆ Barriers to transition- survey of Internal Medicine and Pediatrics residents

Resident Survey

- ◆ Anonymous internet survey
 - 109 residents from the Hospital of the University of Pennsylvania and Children's Hospital of Philadelphia
- ◆ 78% believed there is an absolute age by which patients should be transitioned
- ◆ 38.5% reported attending a lecture or other training session in transition
- ◆ 91.7% reported “sufficient” or “very sufficient” training in Asthma. In contrast to training in other childhood-onset chronic illness:
 - 66.6% for Sickle Cell Disease
 - 52.4% for Cystic Fibrosis
 - 26.8% for Congenital Heart Disease
 - 25% for Down Syndrome
 - 17.6% for Autism
 - 13.7% for Spina Bifida

Bottom Line

- ◆ Pediatricians are not being trained to transition their patients
- ◆ Internists are not being trained to receive patients with chronic childhood illness
- ◆ **Training in Health Care Transitions for Childhood-Onset Chronic Illness should be mandated for all Internal Medicine and Pediatrics residency programs**

Keys to Successful Transition Training

- ◆ Work with others! (Multidisciplinary)
- ◆ Work everywhere! (Multifacility)
- ◆ Educate everyone! (Providers and Patients)
- ◆ Create venues such that all interested parties can participate

Healthy Transitions Resources:

HRTW National Resources Center -
<http://www.hrtw.org>

National Center on Medical Home Initiatives -
<http://www.medicalhomeinfo.org>

Adolescent Health - Transition Project
<http://depts.washington.edu/healthtr/index.html>

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