"Taking the Next Step:
Transitions in Care/Transitions
in Life"
Midwest Region NMPRA
MEETING
Saturday, May 12, 2012
Pritzker School of Medicine

Sponsored by ICAAP, the Comer Classic Fund, the Kovler Diabetes Center, University of Chicago Med-Peds Residency and NMPRA.

### SCHEDULE FOR THE DAY

- 7:00-7:50: Welcome, Registration and Continental Breakfast. Completion of Transition Care Survey (Lobby)
- CME and nursing credits: Must fill out forms before you leave today.
- 8:00-9:00: The A,B,C's of Caring for Youth and Young Adults with Special Health Care Needs (Room 109)
- 9:00-9:50: KEYNOTE SPEAKER: Jeffrey Arnett, PhD: Emerging Adulthood (Room 109)

- 9:50–10:05: Break for Viewing Posters,
   Questions
- 10:05-11:15: Transition Care Models/ Programs in Progress (Room 109)
- o 11:15-11:20: Break for posters/ questions
- 11:20-12:20: ICAAP Presentation. Moderated Panel Presentation by Two Recently Transitioned Young Adults with Special Heath Care Needs (Room 109)
- o 12:20-1:00: Lunch

1:00-1:45: Break-out Sessions for Transition Care

Subspecialty Groups (adult and pediatric): (Room 218)

Generalist Groups (adult and pediatric); (Room 202)

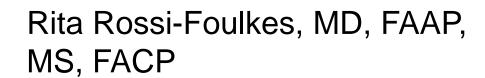
Patient Small Group: Question and Answer with the patients from the morning session (Room LL109)

- 1:45-2:00: Break /Poster Viewing
- 2:00-2:45: ICAAP Presentation on Transition Tools (Room 109)
- 2:45-3:00: NMPRA President, Winning Poster presentation, CME and Conference Forms (Room 109)
- This concludes CME portion of the event. NMPRA specific presentations will continue through afternoon for Meds-Peds Program Directors, students, residents and fellows.

- 3:00-3:40: Break-out sessions for NMPRAspecific sessions
- Program Director and Resident Panel: For students interested in MedPeds (Room 218)
- Fellowship Panel: For MedPeds residents applying or interested in applying for fellowships (Room 202)
- 3:40: Adjourn. Hand in CME forms and Conference Evaluation



# A,B,C's of Transition Care: Introduction and Overview



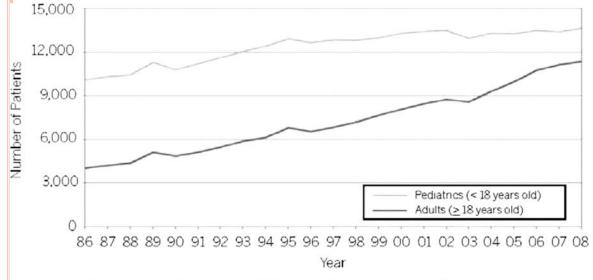
Midwest Region NMPRA Meeting: May 12, 2012

### TRANSITION CARE

- <u>Definition</u>: the movement from adolescence to adulthood
  - Home
  - Health care
  - Education
  - Community
- So... how does this change if you have a patient with:
  - Developmental disability?
  - Intellectual disability?
  - Chronic medical conditions?

### THE SCOPE OF THE PROBLEM:

- 500,000 youth in the US with special health-care needs graduate to adulthood yearly
  - YSHCN account for 13% of all youth but 70% of medical expenditures



2008.

Trends in number of

patients with CF, 1986-

**Tuchman L K et al. Pediatrics** 2010;125:566-573

The number of adults with CF has steadily increased over the past decade.

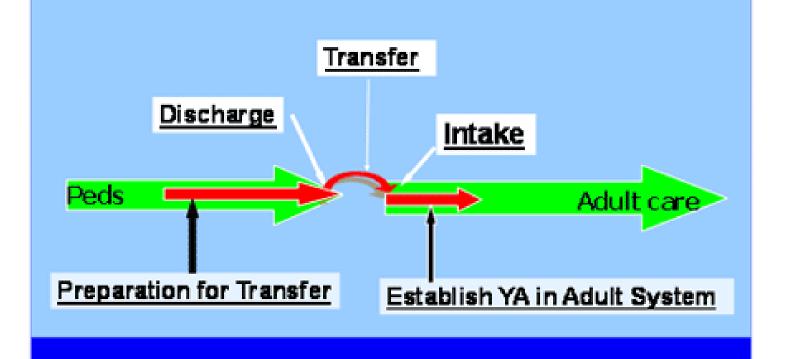
The number of children has remained relatively stable.

# SUPPORTING THE HEALTH CARE TRANSITION FROM ADOLESCENCE TO ADULTHOOD IN THE MEDICAL HOME: AAP, AAFP, ACOP: JULY, 2011



- Ensure that all young people who have special health-care needs have an identified health-care professional who attends to the unique challenges of transition and assumes responsibility for current health care, care coordination, and future health-care planning.
- 2. Identify core knowledge and skills required to provide developmentally appropriate health-care transition services to young people who have special health-care needs and make them part of training requirements for residents and physicians.
- 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 with the young person and family which should contain what services needed, who will provide them, how they will be financed.
- 5. Apply the same guidelines for primary and preventive care for all adolescents and young adults.
- 6. Ensure affordable, continuous health insurance coverage for all young people who have special health-care needs throughout adolescence and adulthood.

# HCT Process for AYA with Chronic Conditions and Disabilities



# BARRIERS TO SUCCESSFUL TRANSITION

- Medical competency
- Family involvement
- Psychosocial needs
- System issues
- Maturity/autonomy
- Transition coordination

- Internist feel uncomfortable with childhood conditions
- Family-centered care to Patient-centered care
- Social work
  - Insurance, guardianship, day programs, respite
- Pediatricians & families uncomfortable transitioning
- No set transition plans/ guidelines

Peter, N. et al. Transition from Pediatric to Adult Care: Internists' Perspectives. Pediatrics 2009, 123 (2); 417-23.

### SO WHAT CAN WE DO ABOUT IT?

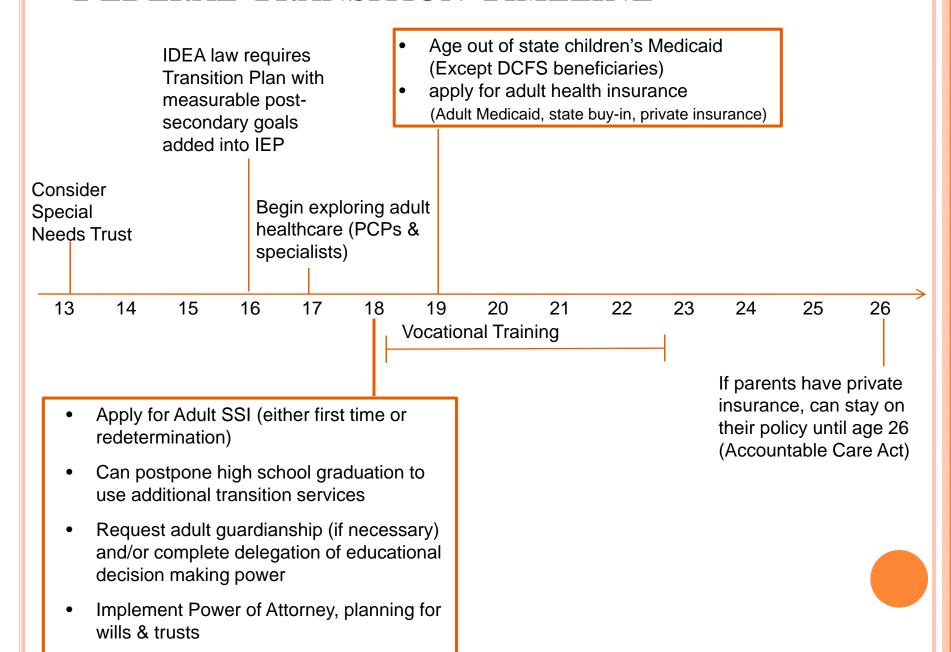
Patient and family education

Successful transition

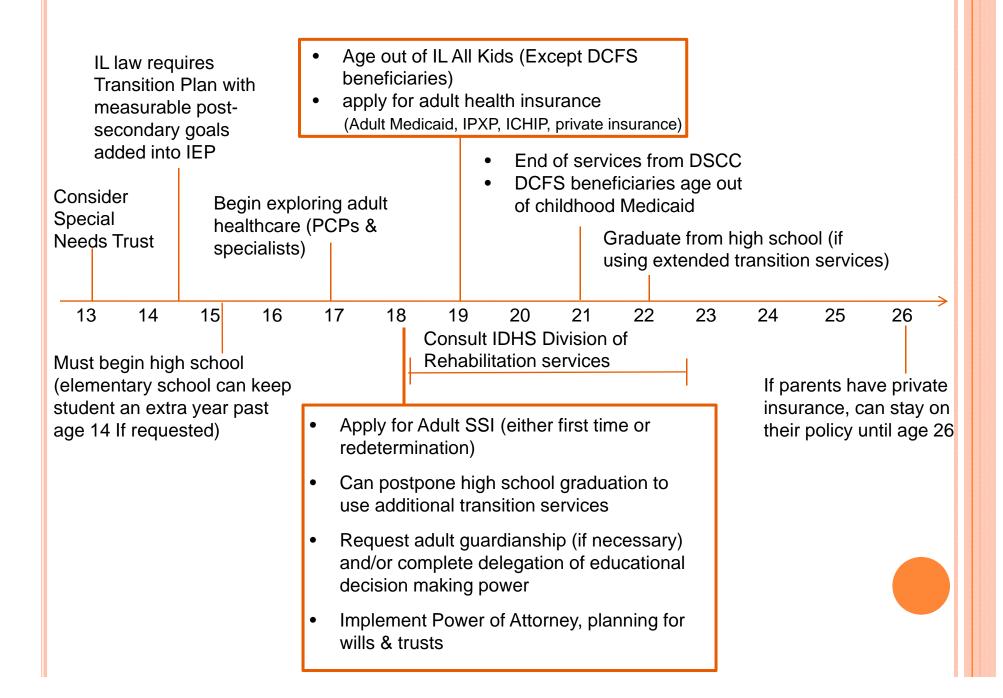
Patient autonomy

Finding adult medical providers
•Subspecialists
•Primary care/medical homes

### FEDERAL TRANSITION TIMELINE



#### IL TRANSITION TIMELINE



RESOURCES

Got Transition <a href="http://www.gottransition.org">http://www.gottransition.org</a>	Wisconsin Transitions <a href="http://www.waisman.wisc.edu/cedd/products.php/">http://www.waisman.wisc.edu/cedd/products.php/</a>
University of Chicago Transition Care <a href="http://transitioncare.uchicago.edu/">http://transitioncare.uchicago.edu/</a>	State Transitions <a href="http://ncset.edu/stateresources/resources/.asp">http://ncset.edu/stateresources/resources/.asp</a>
Transitions In Care-Transitions in Life Midwest Region NMPRA Meeting Website <a href="http://www.transitionsincaremidwest.com/">http://www.transitionsincaremidwest.com/</a>	Children with Special Health Care Needs In Illinois the Division of Specialized Care for Children 800-322-3722 http://www.uic.edu/hsc/dscc
Adolescent health transition project at the University of Washington 206-685-1358 <a href="http://depts.washington.edu/healthtr/">http://depts.washington.edu/healthtr/</a>	National Dissemination Center for Children and Youth with Disabilities 800-695-0285 http://www.nichcy.org/
ICAAP http://illinoisaap.org/	Family resources center on disability 312-939-3513 http://www.fred.org/contaact
Healthy Transitions <a href="http://healthytransitionsny.org/">http://healthytransitionsny.org/</a>	Family Matters Parent Training and Info Center 866-436-7842 http://www.fmptic.org
State Transitions <a href="http://ncset.edu/stateresources/resources/.asp">http://ncset.edu/stateresources/resources/.asp</a>	Illinois network of centers for independent living 800-587-1227 <a href="http://www.incil.org/">http://www.incil.org/</a>
Medical Home <a href="http://www.medicalhomeinfo.org/state">http://www.medicalhomeinfo.org/state</a> pages/	The Arc 301-565-3842 http://www.thearc.org
Healthcare Transitions Florida <a href="http://hctransitions.ichp.ufl.edu/about.php">http://hctransitions.ichp.ufl.edu/about.php</a>	Life Center at RIC www.lifecenter.ric.org

# RESOURCES

Health and Disability Advocates <a href="http://www.hdadvocates.org/">http://www.hdadvocates.org/</a>	Illnois Assistive Technology Porgram 800-852-5110 http://www.iltech.org
FloridaHats <a href="http://www.floridahats.org/">http://www.floridahats.org/</a>	Job accommodation network www.jan.wvu.edu
Disability.gov  http://www.disability.gov/	Healthy and Ready to Work National Center <a href="http://www.hrtw.org/">http://www.hrtw.org/</a>
Cornucopia of Disability http://codi.buffalo.edu/	Health Benefits for workers with disabilities 800-226-0768 www.hbwdillinois.com/
Physician Parent <a href="http://physicianparent.org/">http://physicianparent.org/</a>	SSI for children 700-7272-1213 http://www.ssa.gov/pubs/10026.html
SSDI for disabled adult 800-772-1213 http://www.ssa.gob/pubs/10026.html#older-children	Division of Rehabilitation Services 800-226-6154 http://www.dhs.state.il.us/org/
SSI the work site 800-772-1213 http://www.socialsecurity.gov/work/index.html	Illnois state board of education 312-814-2220 http://www.isbe.state.il.us/
Illinois Provider Resources <a href="http://www.illinoisproviderdirectory.com/">http://www.illinoisproviderdirectory.com/</a>	Family Voices  www.familyvoices.org/about/board
www.hctransitions.org/	Children's Memorial www.childrensmemorial.org/professioals/chronic-illness- transition.aspx (providers) http://www.childrensmemorial.org/parents/transitioning-to-adult- care.aspx (parents and families)

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- o <sup>3</sup>Harvey, Pinzon J. Care of Adolescents with Chronic Conditions. Paediatr Child Health 2006; 11: 43-8.
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