

Physician-Parent Caregivers PPC

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Physician-Parent Caregivers

If Physicians Cannot Secure Safe, Quality Health Care for their children, what happens to non-medical parents?

- ◆ Grassroots
- ◆ Voluntary
- ◆ Charitable

...Funded by Passion

Physician-Parent Caregivers

💧 **Mission**

To empower all Children & Young Adults with Chronic Medical Conditions and Disabilities, and their families, to obtain Quality Health Care by building on the unique perspectives of Physician-Parents.

Physician-Parent Caregivers

💧 **Vision**

For all Children & Young Adults with Chronic Medical Conditions & Disabilities to receive optimal health care so they can develop into independent young adults and live life to the fullest extent possible in families that continue to flourish.

Physician-Parent Caregivers

Organizational Map:

- ◆ Board
- ◆ Physician-Parent Panel
- ◆ Physician Panel
- ◆ Policy Committee
- ◆ Council of Advisors
- ◆ Young Adult Panel

Physician-Parent Caregivers

Pro-Bono Partners:

- ◆ Tristar Technology Group
- ◆ Sonnenschein, Nath and Rosenthal, LLP
- ◆ Winston Churchill High School
- ◆ M2 Health Care Consulting
- ◆ Amplify Public Affairs

Physician-Parent Caregivers

Timeline

- ◆ Exploratory and Research Phase
- ◆ Medical Homes Analysis - Maryland Medical Homes
- ◆ Health Care Transition in Maryland
- ◆ Overlaps and Gaps
- ◆ Local Situation ← National Direction

Physician-Parent Caregivers

Timeline

- ◆ PPC Policy Brief
- ◆ White Paper: Enhancing Health Care Transition for Youth and Young Adults Living with Chronic Medical Conditions and Disabilities: Suggestions for Reform.
- ◆ Coalition for Young Adults Living with Chronic Medical Conditions and Disabilities (CMCD)

Coalition for Youth and Young Adults with CMCD

- ◆ Allergy & Asthma Network Mothers of Asthmatics
- ◆ American Academy of Developmental Medicine and Dentistry
- ◆ Association of University Centers on Disabilities
- ◆ Autism Society of America
- ◆ Genetic Alliance

Coalition for Youth and Young Adults with CMCD

- ◆ National Down Syndrome Society
- ◆ Physician-Parent Caregivers
- ◆ Renal Support Network
- ◆ Special Olympics
- ◆ University of North Carolina Transition Clinic

Emerging Problem: Emerging Adults

Today, most children survive child-onset illnesses

- ◆ More disability
- ◆ Living into adulthood

Nation: unprepared for emerging young adults

- ◆ Every year, 600,000 young people with CMCD enter adulthood

Source: University of Florida Health Sciences Center. Culture Clash: Kids With Chronic Illness Face Difficult Transition To Adult Care. Science Daily. March 2, 2005. Available online at: <http://www.sciencedaily.com/releases/2005/02/050224124046.htm>

Emerging Problem: Emerging Adults

Percentage of People with CMCD by Age

| Age | Percentage |
|-------------------------------------|----------------|
| Children up to 5 years old | 8% |
| Youth 12-17 years old | 16% |
| Young adults 18-30 years old | Unknown |
| Adults 18-64 years old | 45% |

Source: The National Survey of Children with Special Health Care Needs Chartbook. 2005–2006. U.S. Health and Human Services
Anderson G, Horvath J. The Growing Burden of Chronic Disease in America. *Public Health Reports*. 2004;119(3):263-70.

Youth & Young Adults with CMCD

Extrapolation

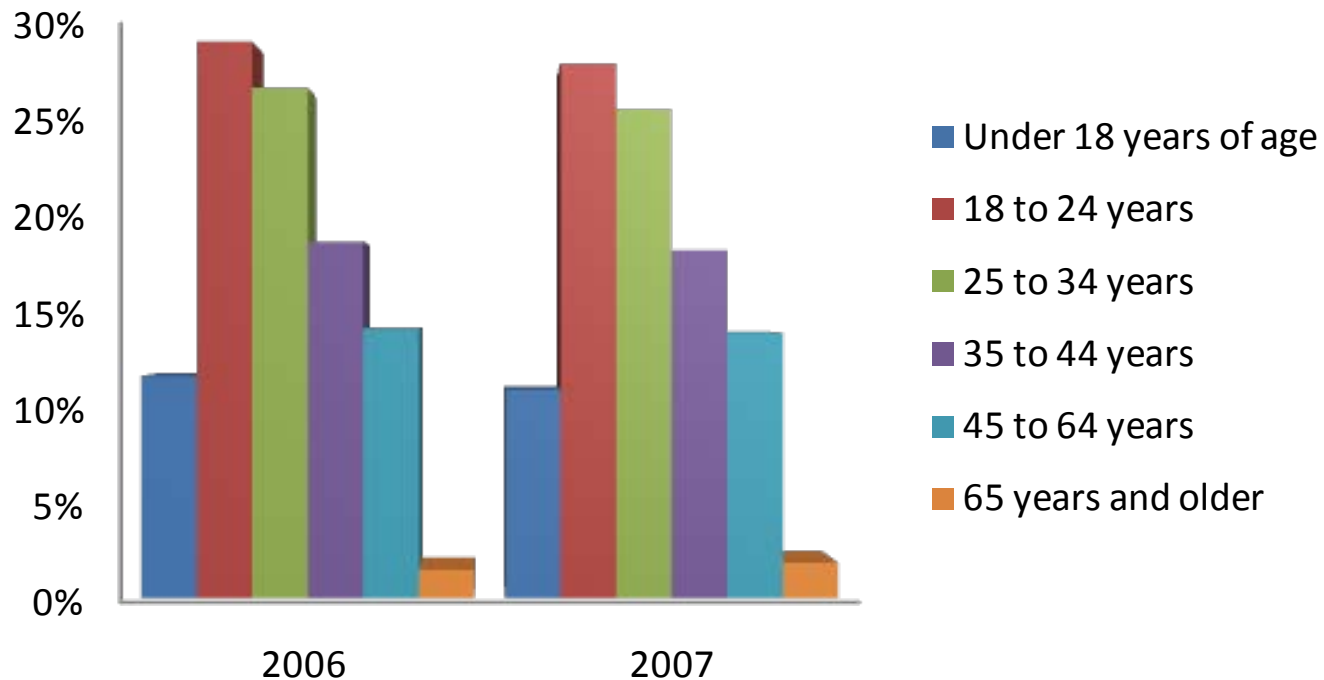
| Age | Prevalence |
|---|---------------------|
| Youth 12-17 years old | 4.3 million |
| Young Adults 18-24 years old | 4.5 million |
| Young Adults 25-30 years old | 4 million |
| Youth and Young Adults 12-30 years old | 12.8 million |

Source: U.S. Census Bureau. Population Division: 2008. Available at <http://www.census.gov/popest/national/asrh/NC-EST2008-sa.html>

Child and Adolescent Health Measurement Initiative. Who are Children with Special Health Care Needs? Data Resource Center for Child and Adolescent Health. Available online at <http://nschdata.org/viewdocument.aspx?item=256>

Transitioning to Adult Insurance

Percent Uninsured by Age Group



Source: U.S. Census Bureau. Income, Poverty, and Health Insurance Coverage in the United States: 2007. Issued August 2008.

What are Young Adults with CMCD Doing?

| Activity | Percentage |
|-----------------------|------------|
| Going to school | 9% |
| Working | 45% |
| Keeping house | 6% |
| Something else | 39% |

Source: Callahan TS, Cooper W. Access to Health Care for Young Adults With Disabling Chronic Conditions. *Archives of Pediatric and Adolescent Medicine*. 2006;160(2):178-82. Available online at <http://archpedi.ama-assn.org/cgi/content/full/160/2/178>

How are Young Adults with CMCD Living?

- ◆ Young Adults with CMCD are 3 times more likely than their healthy peers to earn under \$15,000 a year.

Source: White P, Hackett P. Pearls for Transitioning Youth with Special Health Care Needs from Pediatrics to Adult Health Care. Healthy and Ready to Work National Resource Center. Power Point Presentation, June 2007
<http://www.hrtw.org/rtwu/presentations>.

Transition to Adulthood

...a significant change or set of changes in a person's life circumstances during a relatively limited time period rather than over the life span.....Over a life span, a person will typically experience many transitions, with the transition to adult life being one of the most momentous.

Source: Institute of Medicine. *The Future of Disability in America*. Washington, DC: National Academy Press, 2007. Available online at http://www.nap.edu/catalog.php?record_id=11898

Components of Transition

- ◆ Work
- ◆ Transportation
- ◆ Independent Living
- ◆ Post-Secondary Education/Vocational Training
- ◆ Health

Health Care Transition

- ◆ Health care transition is the deliberate process of moving seamlessly from child-oriented health care to adult-oriented health care.
- ◆ An integral aspect includes the ability to be the leader in one's own health management.

Status of Health Care Transition

◆ 2001 Consensus Statement

American Academy of Pediatrics,
American Academy of Family Physicians,
American College of Physicians-American
Society of Internal Medicine.

Source: American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs. Pediatrics 2002 110: 1304-1306. Available online at:<http://aappolicy.aappublications.org/cgi/reprint/pediatrics;110/6/S1/1304.pdf>

Status of Health Care Transition

Consensus statement calls upon all physicians who treat young people with CMCD to:

- Understand the rationale for transition from child-oriented to adult-oriented health care;
- Have the knowledge and skills to facilitate that process; and
- Know if, how, and when transfer of care is indicated.

Status of Health Care Transition

Healthy People 2010 set a goal for all young people with ongoing health care needs to receive the services necessary for and have a plan to guide their health care transition.

- ◆ Only 16% of youth with CMCD have a plan to transition to adult health care

Source: Scal P, Ireland M. Addressing Transition to Adult Health Care for Adolescents with Special Health Care Needs. *Pediatrics*. 2005;115(6):1607-12.

Status of Health Care Transition

- About 54% of young adults with CMCD lack a usual source of care
- Over two-thirds delay or miss needed care due to cost.

Source: Callahan TS, Cooper W. Access to Health Care for Young Adults With Disabling Chronic Conditions. *Archives of Pediatric and Adolescent Medicine*. 2006;160. (2):178-82.

Available online at <http://archpedi.ama-assn.org/cgi/content/full/160/2/178>

Reiss J, Gibson R. Health Care Transition: Destinations Unknown. *Pediatrics*. 2002;110(6 P 2):1307-14. Available online at

<http://pediatrics.aappublications.org/cgi/content/full/110/6/S1/1307>

Status of Health Care Transition

- ◆ Today, many Young Adults with CMCD struggle to find adult physicians who are willing and able to care for their child-onset conditions and disabilities.

Source: Reiss J, Gibson R, Walker L. Health Care Transition: Youth, Family, and Provider Perspectives. *Pediatrics* 2005;115(1):112-20. Available online at <http://www.pediatrics.org/cgi/content/full/115/1/112>

Disproportionate Costs

- ◆ Cost of treating and caring for children with CMCD is three times higher.
- ◆ In Medicaid, youth with disabilities account for less than 10% of recipients, but nearly 30% of costs.

Source: Damiano, PC, Momany, ET, Tyler, MC Penziner AJ, Lobas JG. Cost of Outpatient Medical Care for Children and Youth With Special Health Care Needs: Investigating the Impact of the Medical Home. *Pediatrics*. 2006;118(4):e1187-e1194
U.S. Government Accounting Office. Children with Disabilities: Medicaid Can Offer Important Benefits and Services. GAO/T-HEHS-00-152. July 2000

Reform Recommendations

- ◆ Change Insurance Rules
- ◆ Reimbursement
- ◆ Expand and Train the Workforce
- ◆ Data Collection and Analytic Activities
- ◆ Streamline and Simplify Public Programs
 - ◆ Interagency Coordinating Council

Health Care Reform

What about young people with CMCD??

Baucus Bill: Young Invincibles

Final Senate Bill: One-line provision

- ◆ 24/7 support and services for transitional needs from adolescence to adulthood

PPC's Goal: Raise Awareness



Policymakers



General Public

Contact Information

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