The Affordable Care Act Provisions for Children and Youth with Special Health Care Needs (CYSHCN)

by Zobeida Bonilla, MPH, PhD

THE CENTER FOR LEADERSHIP EDUCATION IN MATERNAL & CHILD PUBLIC HEALTH
UNIVERSITY OF MINNESOTA

The Maternal and Child Health Bureau (MCHB) defines the population of children and youth with special health care needs (CYSHCN) as "...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."[1] An estimated 15% of children and youth (birth to 17) in the U.S. have a special health care need.[2] Several provisions of the Affordable Care Act (ACA) will directly affect CYSHCN.

The ACA will provide coverage to CYSHCN that is universal, continuous, adequate, and affordable in four major areas:[3]

- "Covering more children and youth;
- Closing benefits gaps;
- Paying for services that were not covered prior to the ACA; and
- Building capacity in health care systems."[3]

ACA Provisions That Affect CYSHCN

There are several provisions in the ACA that directly affect CYSHCN. The following summarizes ten such provisions, as described by AMCHP[3,4] and the Catalyst Center: [5]

1. ***No denial of coverage by private insurance companies because of pre-existing conditions (Section 2704)***
   Preexisting conditions were barriers to coverage and service gaps for CYSHCN before the implementation of the ACA. Private insurance can no longer deny coverage for pre-existing conditions. This became effective for children up to 19 years of age in September 23, 2010.

2. ***New coverage under the PCIP option of the ACA (Section 1101)***
   Although most children are covered under private insurance, Medicaid, or a combination of both,[2] the new coverage option under the Pre-existing Condition Insurance Plan (PCIP) can benefit some uninsured CYSHCN and young adults. Medicaid and the Children's Health Insurance Program (CHIP) are available to CYSHCN, but this option may be attractive to CYSHCN and young adults who are not eligible for coverage, such as "those who have been uninsured for six months or more, whose countable income is higher than their state's Medicaid or CHIP program eligibility, and/or whose age (over 18) means they are not yet protected by section 2704."[3]

3. ***No annual and lifetime benefit caps (Section 2711)***
   Under the ACA, there are no annual and lifetime benefit caps for children and adults. The first requirements of this provision went into effect on September 23, 2010, which helps families cover the care of children who have high medical costs.

4. ***Young adults covered under parents' policy (Section 2714)***
   The ACA allows coverage of young adults on the parent's policy until the age of 26.

5. ***Required coverage of preventive services (Section 2714)***
   Preventive care and screening, critical to CYSHCN, are required under the ACA with no cost sharing.

6. ***Medicaid coverage expansion (Sections 2001, 2002, 2004)***
   Fifty-two percent of CYSHCN with autism spectrum disorder conditions, and 42% of CYSHCN with other conditions, receive Medicaid/CHIP, either as their sole source of health insurance or as a supplement to their private coverage.[4] While states have the option to NOT expand Medicaid to special populations (i.e., non-disabled, childless, not pregnant adults), there is a mandatory change in Medicaid eligibility of children (younger

than 19 years-old) that will take effect on January 1, 2014 in every state. Income Medicaid eligibility for every child will go up to 133% of the federal poverty level (FPL). Also beginning in 2014: children with family incomes under 133% of the FPL who are receiving CHIP will be moved to Medicaid and will thus have access to Medicaid's Early Periodic Screening Diagnosis and Treatment (EPSDT) Program. This program provides early and periodic screenings to identify and treat any physical, mental, developmental, or other health needs. EPSDT is especially important for CYSHCN who often require specialized health services. EPSDT guarantees that if a child has a medically necessary heath care need, the state's Medicaid program must provide it, even if the service is not included in the state's list of covered benefits.

7. ***Maintenance of Effort (MOE) (Section 2001(b))***
   Under the MOE provisions, states cannot change the income eligibility criteria and enrollment procedures for Medicaid and CHIP that were in place when the ACA went into effect on March 23, 2010.

8. ***Coordinated and simplified application process (Section 1413)***
   New coordination among Medicaid, CHIP and the state and federal Exchanges will facilitate the application process for families through a simpler application process that will screen applicants for "eligibility in their state's Medicaid and CHIP program and for premium tax credits through the Exchange."[3] This coordinated application process is also known as "no wrong door."

9. ***Help navigating the system (Section 1002)***
   ACA grants to the states will create consumer assistance programs that will help everyone (including families with CYSHCN) in navigating the complexities of the system to obtain the care needed. Examples of assistance that these consumer programs can provide include enrollment, benefits counseling, consumer education, and assistance in filing complaints and appeals.

10. ***Hospice care (Section 2302)***
    Effective March 23, 2010, children receiving Medicaid or CHIP hospice benefit "may receive care related to their terminal illness concurrently with hospice care"[6]

The implementation of the ACA has already positively impacted the provision of care for many CYSHCN, expanding coverage, increasing accessibility to needed services, and removing barriers to receive needed care. In the future, we hope that more doors to care will open as the full implementation of the ACA goes into effect advancing the health of *all* children throughout their life cycle.

REFERENCES

1. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. Pediatrics,1998;102(1):137–140.
2. National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Available from: http://www.childhealthdata.org/learn/NS-CSHCN
3. AMCHP. Health Care Reform: What is in it for children and youth with special health care needs? 2010. Available from: http://www.amchp.org/Policy-Advocacy/health-reform/Documents/CYSHCN-ACA-Fact-Sheet.pdf
4. AMCHP. The Affordable Care Act and children and youth with autism spectrum disorder and other developmental disabilities [Fact Sheet]. 2012. Available from: http://www.amchp.org/Policy-Advocacy/health-reform/resources/Documents/ACA_AutismFactSheet_5-3-12.pdf
5. Catalyst Center. The Affordable Care Act: A side-by-side comparison of major provisions and the implications for children and youth with special health care needs. 2011. Available from: http://hdwg.org/sites/default/files/ACAsidebyside-catalystctr.pdf
6. Lindley LC, Edwards S, Bruce DJ. Factors influencing the implementation of health care reform: An examination of the concurrent care for children provision. Am J Hosp Pall Medicine July 18, 2013 [epub ahead of print].

Zobeida Bonilla is an Assistant Professor in the Division of Epidemiology & Community Health, School of Public Health, University of Minnesota.

Funding for the Center:, US-DHHS/HRSA/Maternal and Child Health Bureau T76-MC00005 (Hellerstedt, PI)
Facebook: www.facebook.com/pages/Maternal-and-Child-Health-University-of-Minnesota/103274476412772
Twitter: UMN_MCH
Listserv: To subscribe to this list, send an email to: listserv@lists.umn.edu. Leave the subject line blank. In the body of the text write: sub cyfhealth YOUR FIRST AND LAST NAME (example: sub cyfhealth Mary Jones). You will receive an email asking you to confirm your request.