



UNIVERSAL AND CONTINUOUS COVERAGE







ADEQUATE COVERAGE







AFFORDABLE COVERAGE





The Affordable Care Act

A side-by-side comparison of major provisions and the implications for children and youth with special health care needs

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INTRODUCTION

Children and youth with special health care needs (CYSHCN) require health care coverage that is **universal and continuous, adequate** and **affordable**. However, there are major gaps in the current system of health care coverage and financing that cause significant problems for CYSHCN in accessing care and financial hardship for their families. According to the National Survey of Children with Special Health Care Needs, over a third of insured families report their child's coverage is inadequate to pay for the services they need and 18% say their child's health condition has caused their family financial problems.¹ In 2008, over 20,000 health insurance policies in the individual market were denied to children based on pre-existing conditions, and over 18,000 were issued but had restrictions on covered benefits for the same reason.²

The Patient Protection and Affordable Care Act (ACA), signed into law on March 23, 2010, offers opportunities to close these gaps for CYSHCN. This brief offers a concise description of many of the provisions in the ACA along with a side-by-side analysis of their implications for CYSHCN.

Who are children and youth with special health care needs (CYSHCN)?

According to the federal Maternal and Child Health Bureau, CYSHCN have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and also require health and related services of a type or amount far greater than required by children generally.³ The National Survey of CSHCN reports that there are 10.2 million CYSHCN or 13.8% of the U.S. population under age 17.⁴

¹U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2005–2006*. Rockville, Maryland: U.S. Department of Health and Human Services, 2008.

²America's Health Insurance Plans' Center for Policy and Research. *Individual Health Insurance, 2009: A Comprehensive Survey of Premiums, Availability and Benefits.* Washington, DC, October 2009. Retrieved online 2/2/11 from http://www.ahipresearch.org/pdfs/ 2009IndividualMarketSurveyFinalReport.pdf ³McPherson, M, et al. *A new definition of children with special health care needs.* Elk Grove Village, IL: Pediatrics, 1998,102: 137-140

⁴U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2005–2006*. Rockville, Maryland: U.S. Department of Health and Human Services, 2008.



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PROVISIONS RELATED TO UNIVERSAL AND CONTINUOUS COVERAGE

Affordable Care Act Provision	Details	Implications
Pre-existing conditions Section 1201/2704*	This provision prohibits private insurance companies from denying or limiting coverage to children un- der age 19 based on a pre-existing condition.	This provision will affect thousands of CYSHCN. In 2008 more than 20,000 applications for children's coverage were denied due to pre-existing conditions.
Effective plan/policy years begin- ning after September 23, 2010	Grandfathered individual plans are exempt.	
Pre-existing Condition Insurance Plans (PCIP) Section 1101 Effective July 1, 2010	 A new coverage option for uninsured youth and adults with preexisting conditions. To be eligible for coverage a person must: Be uninsured for at least six months. Have had a problem getting insurance due to a pre-existing condition 	This is a transitional benefit avail- able through Jan. 1, 2014 when the ban on pre-existing condition exclusions or limits goes into ef- fect for adults.
Extension of coverage for young adults on their parent's policy to age 26 Section 1001/2714* Effective plan/policy years begin- ning after September 23, 2010	 Eligibility: The parent must be enrolled in a family or dependent plan (rather than an individual plan). Parents must be allowed to switch coverage from an individual to a family plan if available. Includes self-insured plans. In grandfathered plans, the young adult must not have access to their own employer-sponsored insurance (until January 2014, then the provision applies to anyone under age 26). 	A major benefit for CYSHCN tran- sitioning from pediatric to adult health care systems who are not eligible for Medicaid. This will not help some CYSHCN if insurance companies continue to deny policies or limit benefits based on a pre-existing condi- tion until January 1, 2014, when Section 2704 goes into effect for adults.

PROVISIONS RELATED TO UNIVERSAL AND CONTINUOUS COVERAGE (cont.)		
Affordable Care Act Provision	Details Implications	
Extension of Medicaid coverage for former foster children to age 26 Section 2004 Effective January 1, 2014.	States must continue providing Medicaid coverage to children who have aged out of the foster care system but who are under age 26.	A major benefit for CYSHCN in the foster care system transitioning from pediatric to adult health care systems.
Coverage rescission Effective plan/policy years begin- ning after September 23, 2010	Insurance companies cannot drop coverage because of a mistake or inadvertent omission on an ap- plication. This provision applies to all health plans, including grand- fathered plans, except in cases of fraud.	Previously insurers could drop cov- erage after a costly episode of care by finding a mistake on the ap- plication. This could be retroactive to the beginning of the policy and create major financial hardship.
Guaranteed issue and guaranteed renewal Sections 1201/2702 and 2703* Effective January 1, 2014	A new policy must be issued and an existing policy must be renewed for anyone who meets the criteria for coverage, regardless of health status, age, gender, etc., except in cases of fraud. Grandfathered individual and group plans are exempt.	This prohibits denial of coverage or non-renewal of coverage based on health status or high utilization of health care services.
Individual mandate to obtain coverage Section 1501 Effective January 1, 2014	 Individuals must have qualified health coverage to avoid penal- ties under the individual mandate. Coverage that is considered "quali- fied" includes: A government-sponsored health plan such as Medicare, Med- icaid, the Children's Health Insurance Program (CHIP) or TRICARE Employer-based coverage, a plan that an individual or family receives through an employer, including through the Exchanges Individual coverage, a plan pur- chased in the individual insur- ance market, including through the Exchanges. 	The requirement for individual coverage helps spread the risk of insurance across the population. Without this requirement, there is concern that only those with known health care needs would purchase coverage, resulting in higher than expected costs for health plans participating in the Exchanges and threatening their financial stability.
Maintenance of Effort for Medicaid and CHIP Section 2001(b) Effective March 23, 2010	States cannot reduce eligibility levels or make enrollment/renewal more difficult for children in Med- icaid or CHIP through Sept. 20, 2019. They <i>can</i> expand eligibility.	This protection preserves the prog- ress made by states in expanding coverage for children over the past decade and more.

PROVISIONS RELATED TO UNIVERSAL AND CONTINUOUS COVERAGE (cont.)		
Affordable Care Act Provision	Details	Implications
Eligibility simplification Section 2002 Effective January 1, 2014	State-determined income criteria for Medicaid and CHIP are re- placed with a national standard: the Modified Adjusted Gross Income (MAGI). A standard 5% of income will be disregarded. This income standard will also be used as the test for subsidized coverage in the Exchanges.	Pros: This will level the playing field across states in terms of eligibility for public coverage, and will facilitate transitions between Medicaid, CHIP and the Exchange plans. Cons: CYSHCN who are eligible for Medicaid based on criteria other than income (for example, through a waiver, buy-in program, spend-down, etc.) may get lost in the effort to streamline eligibility systems.
Coordination between Medicaid, CHIP and the Exchanges in determining eligibility Section 1413 Effective January 1, 2014	A single, simplified form will screen all applicants for eligibility in the Medicaid and CHIP pro- grams and for premium tax credits through the Exchanges and then refer applicants to the program for which they qualify.	This is important because chil- dren's eligibility for different programs may fluctuate due to changes in their parents' income and employment status. An im- portant refinement to this provision for CYSHCN would be to include disability determination in the eligibility screening process, since disability is a pathway to many public benefit programs.



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PROVISIONS RELATED TO ADEQUATE COVERAGE

Affordable Care Act Provision	Details	Implications
Essential benefits Section 1302	 Health plans must cover these "essential benefits:" Ambulatory patient services Emergency services Hospitalization Laboratory services Maternity and newborn care Pediatric services, including oral and vision care Preventative and wellness services, and chronic disease management Rehabilitative and habilitative services and devices Prescription drugs Mental health and substance abuse services Grandfathered individual and group plans are exempt. 	Many of these benefits are vitally important to CYSHCN and some are not currently covered in many private sector plans. The exact definition, duration and scope of benefits in each of these broad categories is yet to be deter- mined by the U.S. Department of Health and Human Services.
Removal of annual and lifetime benefit caps for children and adults Section 1001/2711* Effective September 23, 2010 for lifetime benefit caps and annual benefit caps under \$750,000 Effective January 1, 2014 for no annual benefit caps	Insurance companies cannot impose a lifetime benefit cap or an annual benefit cap of less than \$750,000. In 2014, no restric- tive annual benefit caps will be allowed. Individuals who were previously disenrolled from a plan because they met their lifetime limit are allowed to re-enroll if they are still eligible. Applies to self- funded plans. Grandfathered individual plans are exempt.	A step in the right direction for CYSHCN, but a potential missed opportunity to reduce underinsur- ance. Insurers can still cap benefits themselves (20 physical therapy sessions per calendar year, for example)

PROVISIONS RELATED TO ADEQUATE COVERAGE (cont.)			
Affordable Care Act Provision	Details	Implications	
Medicaid coverage expansion up to 133% of the federal poverty level (FPL) Section 2004 Effective January 1, 2014	Medicaid eligibility will be ex- panded to anyone whose income is under 133% of the FPL, in- cluding low-income youth with special health care needs as they transition to young adulthood, regardless of family or disability status. Children in families with income under 133% of FPL who are enrolled in CHIP will switch to Medicaid coverage.	In states where CHIP is operated separately from Medicaid, CYSHCN who are now eligible for Medicaid will gain access to Medicaid's more generous coverage under Early Periodic Screening, Diagnosis, and Treatment (EPSDT).	
Changes in hospice care for children enrolled in Medicaid Section 2302 Effective March 23, 2010	This provision allows both cura- tive and hospice care, also called concurrent care, to be offered at the same time.	Previously, families had to de- cide to end curative care for their children enrolled in Medicaid (and some CHIP programs) before they could access hospice benefits. Now families do not need to ter- minate curative care to receive the supports provided under hospice.	
Health homes for chronic conditions Section 2703 Effective January 1, 2011	States can receive a higher federal match for their Medicaid expenses if they amend their state plans to cover health home services such as care coordination, health promotion, patient and family sup- port and referrals to community and social services. Health home enrollees must have one or more selected chronic conditions such as mental illness, substance use disorders, asthma, diabetes, heart disease, or being overweight.	Currently, this provision appears to be more focused on adults with chronic illnesses. However, there is no age limit specified within it and the Secretary of the U.S. Department of Health and Human Services (HHS) may add to the list of chronic conditions that qualify individuals for health homes.	
Medicaid primary care rate increases Section 1202 of the Health Care and Education Reconciliation Act (H.R. 4872)	The ACA provides enhanced Med- icaid payments for primary care services, including those provided by pediatricians, of no less than 100% of the Medicare rate.	This increase is intended to im- prove the participation of primary care providers in Medicaid, thus expanding access to care.	
Effective 2013 and 2014			



PROVISIONS RELATED TO AFFORDABLE COVERAGE

Affordable Care Act Provision	Details	Implications	
Premium Tax Credits Section 1401 Effective January 1, 2014	Families with incomes up to 400% of the FPL are eligible for premium tax credits on a sliding-fee scale when they purchase coverage through the Exchanges.	A three-person fam \$24,000/year (just of the FPL) can buy policy costing \$11, tax credit is \$10,70 cost of the policy \$ their income.	over 133% y an insurance 500. Their 68, making the
Cost-sharing subsidies	Families with incomes under	Cost-Sharing	Subsidies
Section 1402	250% of the FPL are eligible for cost-sharing subsidies that reduce the cost of copayments, coinsur-	Family Income	Plan-Covered Expenses
	ance and deductibles on a sliding-	Up to 150% FPL	94%
	fee scale. They must purchase a "silver" category of coverage, meaning that the plan covers, on average, 70% of the costs of care	151 - 200% FPL	87%
		201 - 250% FPL	73%
Effective January 1, 2014	and the member pays the rest.		
Limits on out-of-pocket expenditures Section 1402	ocket expendituresOut-of-pocket expenditures are limited to \$11,900 in 2010 dol- lars (subject to change each year) for family coverage.In addition, families with incomes under 400% of FPL who purchase silver plans under the Exchanges will have additional limits on their out-of-pocket expenditures.	Out-of-Pocket Limits in Silver Exchange Plans	
		Family Income	Out-of-Pocket Limit
		Up to 200% FPL	\$3,927
		201 - 300% FPL	\$5,950
		301 - 400% FPL	\$7,973
Effective January 1, 2014	Grandfathered individual and group plans are exempt.		

PROVISIONS RELATED TO AFFORDABLE COVERAGE (cont.)		
Affordable Care Act Provision	Details	Implications
Help in understanding costs and coverage Section 1311 Effective January 1, 2014	Exchanges must provide a calcula- tor to help individuals determine the value of any credits or sub- sidies and the ultimate cost of coverage	This calculator will enable com- parisons of both the benefits and cost of coverage across plans.
Well-child visits and preventive services without cost sharing as part of coverage Section 1001/2713*	 New plans must cover the following without cost sharing (e.g., copays): Preventive care/screening based on Bright Futures, (http://www.brightfutures.org) Additional preventive care/screening based on the U.S. Preventive Services Task Force (http://www.ahrq.gov/clinic/tfchildcat.htm) Immunizations recommended by the Centers for Disease Control and Prevention (http://www.cdc.gov/vaccines/pubs/ACIP-list.htm) 	This provision is designed to improve the affordability of preven- tive care and promote its use.
Effective September 23, 2010 for new plans	Grandfathered individual and group plans are exempt.	





ADDITIONAL PROVISIONS OF INTEREST

Continued funding for state-based Family-to-Family Health Information Centers (F2F HICs)

Section 5507

The ACA provided \$5 million to continue funding for the Family-to-Family Health Information Centers in each state and the District of Columbia. These additional funds are authorized through 2012 and are administered by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services.

Led and staffed by experienced family members of CYSHCN, these centers provide an important resource for help in navigating the state-specific system of coverage and health care financing by providing outreach, peer support, and benefits counseling.

Creation of the Center for Medicare and Medicaid Innovation

Section 3021

Established under the ACA, the new Center for Medicare and Medicaid Innovation (CMI) will focus on identifying and testing ways to enhance health care quality, improve the health outcomes of individuals and communities and reduce costs through improvements. A total of \$10 billion dollars has been appropriated to CMI between 2011 and 2019, with at least \$25 million designated each year for the design, implementation and evaluation of models that achieve these goals.



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A FEW DEFINITIONS

What is a plan/policy year?

While a few of the provisions in the ACA went into effect immediately, most are scheduled to roll out over time and become "effective" on a variety of dates. September 23, 2010 is an effective date that appears frequently in the initial set of provisions; it is six months to the day following the signing of the health care reform bill into law. However, the majority of provisions associated with that date do not go into effective precisely on September 23; they go into effect when an individual's plan or policy year begins after that date. For example, if your plan year begins on June 1, provisions that go into effect for plan or policy years beginning after September 23, 2010 will not take effect until June 1, 2011, when your new plan year begins.

What's the difference between a plan and a policy year?

Plans cover people in large groups, such as those who work for the same employer. Plans tend to renew at the same time each year for the whole group they cover, regardless of when an individual person enrolls. Policies cover individuals or individual families, and they can renew at various times, depending on when the policy was purchased and what was written into it with regard to the renewal date. An awareness of which provisions actually go into effect when will be important for analyzing the impact of the ACA on CYSHCN over time, monitoring compliance, advocating effectively for improvements to the law and providing accurate benefits counseling to families.

What is a grandfathered plan?

Plans in the individual and group markets that were in effect on March 23, 2010, the day the ACA was signed into law, are called grandfathered plans and they are "frozen in time" or exempt from many, but not all, of the provisions in the ACA as long as they keep their grandfathered status. Grandfathered status was a compromise implemented in an effort to reassure those who did not want to change anything about their existing coverage. A plan can lose its grandfathered status and become subject to ACA provisions by making major changes, such as significantly raising premiums or reducing benefits. For details on what constitutes "significant" changes, see the federal Departments of Treasury, Labor and Health and Human Services' interim final regulations at: http://frwebgate.access.gpo.gov/ cgi-bin/getdoc.cgi?dbname=2010_ register&docid=DOCID:fr17jn10-25.pdf

Grandfathering has important implications for CYSHCN. It is estimated that approximately 80% of people with employer-sponsored insurance will be in grandfathered plans in 2011. Because the majority of CYSHCN currently get their health care coverage from employer-sponsored insurance that will be grandfathered or from self-insured plans, many ACA provisions will not apply to them. An awareness of which provisions have grandfathering exemptions associated with them will be important for analyzing the impact of the ACA on CYSHCN over time, monitoring compliance, advocating effectively for improvements to the law and providing accurate benefits counseling to families.



CONCLUSION

While there is much to celebrate in the passage of the ACA, the work in ensuring that CYSHCN have access to coverage that is universal and continuous, adequate and affordable is not yet done. There are several provisions, particularly in the area of consumer protection, that hold significant potential for meeting this goal. However, there are also some limitations, primarily in the exemption of large-group, grandfathered and self-funded plans (where the majority of CYSHCN get their coverage) from the Essential Benefits requirement. In addition, the ACA was designed with the primary goal of expanding coverage for the general population. Whether it will also have a positive impact on reducing underinsurance for CYSHCN, the challenge the majority of them face, is still unknown.

As the federal regulations, guidance and clarifications to this historical legislation are being developed and written and amendments to the ACA to improve gaps in it for CYSHCN are possible, state agency staff and policymakers, child health advocates, clinicians, families and others interested in the health and well-being of children in general and CYSHCN in particular must be well informed about the details of the various provisions and the opportunities and limitations of each. Only then can we be best prepared to effectively ensure that CYSHCN have access to coverage for the care they deserve so that they can learn, play and grow to their fullest potential.



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SOURCES AND SELECTED RESOURCES

The Patient Protection and Affordable Care Act of 2010 (Public Law 111-148)

http://www.healthcare.gov/center/authorities/ patient_protection_affordable_care_act_as_passed.pdf This URL brings the user to the full text of the ACA legislation.

The Catalyst Center at the Boston University **School of Public Health**

The Catalyst Center is funded by the federal Maternal and Child Health Bureau, Health Resources and Services Administration, Department of Health and Human Services to serve as the national center on improving financing of care for children and youth with special health care needs. We create publications and products, answer technical-assistance questions, research innovative state-based financing strategies, guide stakeholders to outside resources, and connect those interested in working together to address complex health care financing issues. See the "Publications and More" section of our website at http://hdwg.org/catalyst/publications for more resources on health care reform, including:

- Presentation: National Health Care Reform: What Does it Mean to Massachusetts Children with Special *Health Care Needs?* (October, 2010)
- Fact Sheet: Health Care Reform: What's in it for Children and Youth with Special Health Care Needs? (A joint publication of Catalyst Center and Association of Maternal and Child Health Programs) (October, 2010)
- Presentation: Essential Elements of Health Care Reform for CYSHCN: Looking to the Future: Opportunities and Challenges in Health Reform for MCH (October, 2010)

- Policy Paper: The Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for State Policymakers (A publication by the National Academy for State Health Policy (NASHP, http://www.nashp.org) for the Catalyst Center) (January 2011)
- Archived Webcast: The Affordable Care Act and Children with Special Health Care Needs (associated with the above NASHP publication) (January 2011)

In addition to these materials, the Catalyst Center Week in Review offers a compilation of media items related to coverage and financing of care for CYSHCN in general and ACA news in particular. Our monthly e-newsletter, Catalyst Center Coverage, features more in-depth news and analysis, links to resources and original articles on related topics of interest. Sign up to receive both by providing your e-mail in the field in the upper right corner of our homepage at:

http://www.catalystctr.org

Maternal and Child Health Bureau, Health **Resources and Services Administration, U.S. Department of Health and Human Services** Information on the Title V Maternal and Child Health Services Block Grant and other related programs and efforts is at: http://www.mchb.hrsa.gov

The Family-to-Family Health Information Centers (F2F HICs)

Led and staffed by experienced family members of CYSHCN, the F2F HICs are an important resource for help in navigating the complex system of coverage and financing in each state and the District of Columbia. For more information or to find the F2F HIC in a specific state please visit the Family Voices website:

http://www.familyvoices.org/page?id=0034

Association of Maternal and Child Health Programs

Additional information covering key aspects of the ACA that pertain to maternal and child health populations is at: http://www.amchp.org/Advocacy/healthreform/Pages/default.aspx

www.healthcare.gov

The official federal website on the Affordable Care Act from the U.S. Department of Health and Human Services includes easy-to-read descriptions of specific provisions related to the ACA, along with a helpful glossary of related terms and links to other federal resources.

Georgetown Center for Children and Families: Health Reform Implementation Center

Friendly and accessible expert policy analysis and opinion, written with a specific focus on topics important to children, families and those who care about them. Sign up for CCF's *"Say Abh!"* blog to keep up-to-date on the latest developments in health care reform implementation for kids. http://ccf.georgetown.edu/index/hcr

InsureKidsNow.gov

To find state-specific information about Medicaid and CHIP programs, use the map at : http://www.InsureKidsNow.gov/state/

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