



Advocates for Justice and Education, Inc.

The Parent Training and Information Center for the District of Columbia

How Health Care Reform Affects Children and Youth with Special Health Care Needs

The Patient Protection and Affordable Care Act of 2010 (ACA) offers many children with special health care needs (CYSHCN) an increase in affordability and adequate healthcare coverage to address issues of access and gaps in services to children and families. According to the 2005-2006 National Survey of Children with Special Health Care Needs, over a third of insured families reported that their child's coverage was inadequate to pay for the services they needed and 18% expressed that their child's health condition has caused their family financial problems.¹ In 2009-2010, the same survey results reported that 65% of insured families of CYSHCN expressed that their insurance was inadequate to meet their child's needs; and 21% expressed that their child's health condition has caused their family financial problems. With the passing of the ACA, more children and families will receive proper care.

The Association of Maternal & Child Health Programs (AMCHP) has identified the following areas that will be improved for CYSHCN under the ACA:

- **Coverage for More Kids:** The ACA will reduce the number of CYSHCN who do not have public or private insurance.
- **Closing Benefit Gaps:** Will enhance the benefits for CYSHCN whose health insurance coverage is adequate to meet their needs.
- **Paying for Additional Services:** Will increase the options available to finance care coordination, respite care, home modifications and other wrap-around services for CYSHCN (critical supports that are not typically covered by insurance).
- **Building Capacity:** Will promote stronger, more comprehensive systems of care for CYSHCN.

Below, is a description of some of the provisions in the ACA along with an explanation of their benefits for CYSHCN:

ACA Provision	Benefit for CYSHCN
Added coverage for pre-existing conditions	Prohibits private insurance companies from denying coverage based on pre-existing conditions. CYSHCN with pre-existing conditions can receive the care they need through their insurance.
Removes the annual and lifetime benefit caps for children and adults	Insurers cannot place annual or lifetime benefit cap of less than \$750,000. However, insurers can still cap benefits themselves (e.g., 18 speech therapy sessions per calendar year).
Allows coverage of young adults on their parent's policy	Young adults up to age 26 are able to remain on their parents insurance. Major benefit for CYSHCN transitioning from pediatric to adult health care systems.
Coverage of Essential Benefits	Health Plans must cover these essential benefits that

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Children with Special Needs, need Parents with Special Skills!

	are important to the health of CYSHCN: prescription drugs, maternal and newborn care, hospitalization, pediatric services (including vision and oral care), emergency services, ambulatory patient services, laboratory services, preventative and wellness services, and chronic disease management; mental health and substance abuse services, and rehabilitative services and devices.
Medicaid coverage expansions	<p>Medicaid eligibility will be expanded to anyone whose income is under 133% of the federal poverty level (FPL), including low-income youth with special health care needs as they transition to young adulthood, regardless of family or disability status.</p> <p>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).</p> <p>Under the ACA states are required to provide Medicaid coverage to CYSHCN who have aged out foster care system.</p>
New coordination between Medicaid, CHIP and the Exchanges in determining eligibility	States will create a simplified form to screen applicants for eligibility of Medicaid, CHIP, or through the state insurance Exchange. This will ensure faster eligibility, referral to program they qualify for and quicker access to receive services.
Assistance in navigating the complexities of health care coverage	States will create new or strengthen existing health care consumer assistant programs. These programs will help consumers enroll in health coverage, provide benefits counseling, educate people on their rights and responsibilities and helped consumers file complaints and appeals.
Hospice care for children under Medicaid	Both curative and hospice care, also called concurrent care, is now offered at the same time. Previously, families had to decide 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 terminate curative care to receive the supports provided under hospice.

Resources:

District of Columbia Health Benefit Exchange Authority: www.hbx.dc.gov or call (202) 715-7576.
 D.C. Health Link Online Insurance Marketplace: www.dchealthlink.com or call (855) 532-5465.

¹ Data Resource Center for Child and Adolescent Health. National Survey of Children with Special Health Care Needs. <http://www.childhealthdata.org/learn/NS-CSHCN>