

Fact Sheet

Health Care Reform: What's in it for Children and Youth with Special Health Care Needs?

AMCHP's Role

AMCHP supports state maternal and child health (MCH) programs and provides national leadership on issues affecting women and children. We work with partners at the national, state and local levels to expand medical homes, provide and promote family-centered, community-based, coordinated care for children with special health care needs and facilitate the development of community-based systems of services for children and their families.

AMCHP's National Center for Health Reform Implementation provides state maternal and child health (MCH) leaders and their partners with the information, tools and resources to optimize the opportunities presented by the Patient Protection and Affordable Care Act (ACA) for improving services, systems, and health outcomes for MCH populations.

Introduction

Currently, there are major gaps in the health care coverage, financing and delivery system that prevent children and youth with special health care needs (CYSHCN) from accessing health care services or which impose significant financial hardship on their families. Strategies are urgently needed that improve the coverage and financing of care for CYSHCN in four important areas:

- **Covering More Kids:** reducing the number of CYSHCN who do not have public or private insurance coverage,
- **Closing Benefit Gaps:** enhancing benefits for CYSHCN whose health insurance coverage is inadequate to meet their needs,
- **Paying for Additional Services:** increasing 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, and
- **Building Capacity:** promoting stronger, more comprehensive systems of care for CYSHCN.

The recently passed Patient Protection and Affordable Care Act of 2010 (ACA) contains provisions that are designed to improve each of these four areas of need. The law is designed to increase coverage, improve benefits and provide important new insurance protections for all Americans. Many of the law's provisions will impact children, including CYSHCN, and all will be implemented over time. This issue brief offers a concise description of some of the provisions under ACA that directly impact CYSHCN and offers some thoughts about the role of State Title V MCH and CYSHCN programs in realizing their promise.

Prohibits private insurance companies from denying coverage based on pre-existing conditions (Section 2704)

A pre-existing condition is a health care need that was present before a person was issued a particular private insurance policy. Prior to September 23, 2010, insurance companies could legally deny coverage of claims

related to a pre-existing condition or could refuse outright to issue a policy to a person with a pre-existing condition. For families of CYSHCN, this made it difficult to find adequate and affordable coverage for their child's health care needs, kept them from changing jobs if they got their insurance through their employer, and put them at risk for financial hardship and medical debt.

Under the ACA, insurance companies are now prohibited from using pre-existing conditions as a way to limit their financial responsibility to those they insure. This provision went into effect for children under age 19 on September 23, 2010 (six months after the signing of the bill on March 23, 2010). It begins for adults over age 19 on January 1, 2014 and includes a ban on denial of coverage for claims related to a pre-existing condition. This requirement is for both new and existing insurance policies, except for 'grandfathered' individual policies (policies purchased on or before March 23, 2010 directly from the insurer, not through an employer). More narrative information on this provision can be found at: <http://www.healthcare.gov/law/provisions/ChildrensPCIP/childrenspcip.html>. The actual regulations are available online at: <http://edocket.access.gpo.gov/2010/2010-15278.htm>

Establishes a new coverage option for uninsured children and adults with pre-existing conditions (Section 1101)

Under Section 2704, currently uninsured CYSHCN who had previously been denied private coverage due to a pre-existing condition should now be able to access it after September 23, 2010. However, the prohibition against denying coverage based on a pre-existing condition in adults does not become effective until 2014, when the Exchange plans will become operational. The ACA contains a provision that offers an alternative for individuals who have been denied coverage based on a pre-existing condition called the Pre-existing Condition Insurance Plan (PCIP). Each state is required to offer a PCIP program and states were allowed to decide whether they wanted to administer the program themselves (sometimes in coordination with an existing high risk pool) or allow the U.S. Department of Health and Human Services (HHS) to do so. Individuals who are eligible for PCIP must:

- Be uninsured for at least six months;
- Have had a problem accessing coverage or been denied coverage due to a pre-existing condition; and,
- Be a citizen or legal resident of the United States

Eligibility for PCIP is the same in every state, but the program name, premiums, co-pays, deductibles, out-of-pocket limits and application process varies from state-to-state. Benefits include primary and specialty care, hospitalization and prescription drug coverage. Specifics on each state program can be found at:

<http://www.healthcare.gov/law/provisions/preexisting/index.html>

While there is no age or income limit associated with PCIP, this provision is not likely to be a robust option for a large number of CYSHCN. Relatively few CYSHCN are uninsured, in part because the majority have access to employer-sponsored coverage. Disability offers a pathway to Medicaid eligibility in many states and the Children's Health Insurance Program (CHIP) is specifically intended to cover uninsured children, including CYSHCN. For those who qualify, CHIP is an attractive coverage option because of its child-centered benefit package, low cost-sharing and lack of exclusion based on pre-existing conditions. The PCIP, while designed to reduce uninsurance among those with pre-existing conditions, is a less attractive option for CYSHCN than for adults with disabilities and chronic health conditions because it may not include the full array of pediatric benefits, there is no child-only option that only includes pediatric services (and is therefore priced accordingly) and the premiums and cost-sharing are fairly expensive for the scope of benefits provided.

Two requirements for eligibility under a PCIP are particularly problematic. The first is the requirement that an applicant be uninsured for at least six months, putting CYSHCN at risk for adverse health outcomes; a situation which most families will avoid in any way possible. The second is the requirement that applicants must have experienced a problem accessing coverage or were denied coverage due to a pre-existing condition. Proof of this requirement varies from state to state. This may impose an administrative burden on some families. Since better options are available to the majority, only a limited number of CYSHCN and young adults with

special health care needs may benefit from enrollment in a PCIP, including 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.

Removes the annual and lifetime benefit caps for children and adults (Section 2711)

Prior to the passage of ACA, private insurance companies could place annual and lifetime benefit caps on coverage. This practice resulted in children with high medical costs effectively becoming uninsured when they exhausted their benefits and put families at risk for medical debt and financial hardship. The ACA removes annual and lifetime benefit caps for children and adults, thereby helping families of children with high medical costs maintain their private insurance coverage. This provision will roll out over time with the first requirements beginning September 23, 2010. Starting on that date, insurance companies cannot impose lifetime benefit caps in both new and current plans, or a restrictive annual benefit limit on new individual plans, and existing individual and group plans. (In 2014, insurance companies will not be able to impose restrictive annual benefit limits on new group plans.) More information on this provision is available at:

<http://www.healthcare.gov/law/provisions/limits/limits.html>

]. The regulations are available online at:

<http://edocket.access.gpo.gov/2010/2010-15278.htm>

Allows coverage of young adults on their parent's policy (Section 2714)

Young adults currently have the highest rate of uninsurance among all age groups. For those just starting careers and families, the cost of employer-sponsored health insurance can be prohibitive, assuming it is even available to them. In some states, young adults have been able to stay on their parent's health plan but only as long as they are full-time students, single or receive financial support from their parents. This provision allows otherwise independent young adults to receive health care coverage through their parent's plan up until the age of 26. Here are some of the details regarding eligibility for young adults:

- The parent's plan must offer dependent coverage and the parent must enroll in a family or dependent plan;
- Parents must be allowed to enroll in whatever family or dependent coverage is available to them or switch coverage options if they are currently insured;
- Parents can enroll their married adult children under their plan, but not their child's spouse or dependent children;
- This provision applies to individual and group market plans, and includes self-insured plans;
- For grandfathered plans (those group or individual health plans in existence on March 23, 2010), the young adult must not have access to their own employer-sponsored insurance (until January 1st, 2014; then anyone under age 26 regardless of access to their own insurance can be covered under their parent's plan).

While the law did not require insurers to provide young adult coverage until those plan years that began after September 23rd of this year, many major insurance companies, including self-insured plans, offered it voluntarily before then. State Title V MCH and CYSHCN programs will want to encourage families to check with their employer or insurance company to see if their plan is offering early adoption of the young adult coverage provision.

If the parent's insurance company did not offer early adoption, then the provision goes into effect for the plan year beginning after September 23, 2010. The start of plan years can vary by employer and insurer. For example, if a parent's plan year begins January 1st, that is when young adult coverage will be available to them. For more information on the details of this provision, including the tax benefits related to young adult coverage, go to the U.S. Department of Health and Human Services' webpage at:

http://www.hhs.gov/ociio/regulations/adult_child_fact_sheet.html.

The regulations are available at:

<http://www.hhs.gov/ociio/regulations/dependent/index.html>

Requires preventive services as part of coverage and prohibits plans from imposing cost sharing (e.g., co-pays) on preventive care (Section 2714)

Preventive care is as important to CYSHCN as it is to any child. Detecting new or worsening health problems through screening activities and preventing the deterioration of physical or mental health by intervening early are critical to maximizing a child's health and well-being. Under the ACA, new job-related and individual plans with plan or policy years beginning after September 23, 2010 must provide coverage for the following services without cost-sharing, including co-pays, co-insurance and deductibles:

- Preventive care/screening based on Bright Futures, a joint initiative of the American Academy of Pediatrics and the U.S. Department of Health and Human Services (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 Advisory Committee on Immunization Practices at the Centers for Disease Control and Prevention (<http://www.cdc.gov/vaccines/pubs/ACIP-list.htm>)

Grandfathered plans are exempt from this provision.

More information on Section 2714 is available at: <http://www.healthcare.gov/law/provisions/preventive/index.html>. The regulations are available at: <http://www.healthcare.gov/center/regulations/prevention/regs.html>

Medicaid coverage expansions (Sections 2001, 2002 and 2004)

States are required under the ACA to increase their income eligibility for Medicaid to individuals under age 65 whose income is less than 133% of the federal poverty level (FPL) by January 1, 2014 (Section 2001). Children under age six whose family income is up to 133% of the FPL and children ages six to nineteen in families whose income is up to 100% of the FPL are currently income eligible for Medicaid, as required by federal law. All states already cover children through their Medicaid or CHIP programs at higher income levels

than these minimums. As a result, this provision will most likely have the greatest impact on childless adults but there may be some CYSHCN ages six to nineteen whose family income is between 100-133% of the FPL and who did not have previously have access to CHIP. In addition, children already covered by a separate CHIP program whose family income is up to 133% of the FPL will have access to Medicaid coverage, which in many states offers a more robust benefit package and includes the guarantee of Early Periodic Screening Diagnosis and Treatment (EPSDT) as well as lower cost-sharing.

The methodology which will be used for determining income eligibility under this provision is called Modified Adjusted Gross Income (MAGI) (Section 2002). Currently, individual states use their own formula for determining income that involves federal and state disregards as well as asset tests. Using MAGI is a simpler process; it takes the amount of money an individual or family receives on a monthly basis and applies a straight-forward 5% disregard, without asset or resource tests. It will also be used to determine eligibility for coverage subsidies in the Exchange, simplifying eligibility determination between programs. Certain populations are exempted from MAGI being used to determine income eligibility and states will continue to use their current formula for them. Exempted groups include those who are dual-eligible for Medicare and Medicaid, those who are medically needy and those who are eligible for Medicaid because they are eligible for another program, such as Supplemental Security Income (SSI).

While states are required to increase eligibility by January 1, 2014, they are allowed to do so any time before that date through a state plan amendment. States who are currently covering individuals in this expansion category with only state dollars will now be able to draw down the current federal match. They will also have access to the higher federal match which will begin in 2014, so early adopters of expanded coverage are not penalized for having done so. It is uncertain as to whether new states will take advantage of this option to expand coverage during this interim period, as many are facing budget deficits and any increase in state spending is challenging.

Another important Medicaid expansion under the ACA requires states to continue providing Medicaid coverage to children who have aged out of the foster care system

but who are under age 26 (Section 2004). This provision comes into effect on January 1, 2014 and will offer former foster care children continuity in their health care as they transition to adulthood, as well as allowing them access to a source of coverage comparable to or better than that offered to young adults under age 26 who can access their parent's coverage under section 2714.

Maintain current eligibility criteria and enrollment procedures for Medicaid and CHIP – Maintenance of Effort (Section 2001(b))

The “Maintenance of Effort” (MOE) provision requires states to keep the Medicaid and CHIP eligibility criteria and enrollment procedures for children and adults which they had in place on March 23, 2010, the day the ACA was signed. States cannot reduce the income eligibility for these programs, nor can they make it more difficult for families to enroll their eligible children. They can, however, raise the income eligibility and/or make enrollment easier.

Medicaid and CHIP are particularly important to CYSHCN, thanks to the comprehensive set of benefits offered (including EPSDT in Medicaid) and little or no cost-sharing in both programs. The MOE provision prevents states from using changes in eligibility or enrollment to reduce spending in Medicaid or CHIP; those who are either currently eligible or enrolled will remain so. However, there are other mechanisms states can use to reduce public benefit program spending that may have implications for CYSHCN. States can reduce provider payment rates, for example, which may in turn limit access to primary or specialty care. They can also increase cost-sharing for families as long as they stay within the current rules. This provision is currently in effect for children until September 30th 2019 (note it ends for adults on January 1, 2014, when the Exchange plans open).

New coordination between Medicaid, CHIP and the Exchanges in determining eligibility – “No Wrong Door” (Section 1413)

Under the ACA, a single, simplified form will screen all applicants for eligibility in their state's Medicaid and CHIP programs and for premium tax credits through the Exchange. There will be many ways to submit the

application form, including by mail, by telephone, in person or online, and it will not matter whether an application is submitted through Medicaid, CHIP or the Exchange. The law requires states to establish a secure data interface so that information is easily shared between the programs. States are also required to establish a website that allows consumers to compare benefits, premiums and cost-sharing between Medicaid, CHIP and the Exchange. Renewals of existing coverage can also be made online through the data interface when it is operational.

The idea behind this coordinated application process is also known as “no wrong door” and it should minimize the administrative burden families of CYSHCN currently experience when applying to multiple programs, helping them get onto the coverage their children qualify for and stay on it as long as they are eligible. It should also help minimize gaps in coverage as family income or other circumstances change and enrollees move from one program to another, facilitating continuity of care. Families whose individual members qualify for different programs should find it easier to maintain their enrollment and access their various benefits.

The addition of special health care needs screener questions to the streamlined application may benefit CYSHCN. It could help families more effectively access pathways to coverage based on disability, such as the Family Opportunity Act's Medicaid buy-in program or a TEFRA state plan option.

Assistance in navigating the complexities of health care coverage (Section 1002)

Getting, keeping and maximizing health care coverage can be complicated and many people find they need support and assistance in doing so. Beginning this year, \$30 million in grants will be awarded to states through the ACA to create new or strengthen existing health care consumer assistance or ombudsman programs. These consumer assistance programs will help with enrollment in health coverage, provide benefits counseling, educate people on their rights and responsibilities and aid consumers in filing health insurance complaints and appeals.

Benefits counseling is an important activity of many Title V MCH and CYSHCN programs. The state consumer assistance programs should be a helpful, independent

ally in making sure CYSHCN and their families get the coverage they need. In return, Title V MCH and CYSHCN program staff may be able to provide valuable information and education to the consumer assistance programs on the unique needs of this vulnerable population.

Hospice care for children under Medicaid (Section 2302)

Currently, children with life-threatening conditions (those with a medically-certified life expectancy of six months or less) enrolled in Medicaid and CHIP programs operating as Medicaid expansions have access to coverage for hospice care, either as an optional benefit or through application of EPSDT. However, their families must decide to end curative care before they can access hospice services. This sometimes means a curative treatment that has palliative benefits is no longer available. It is also a difficult emotional decision for families, which can limit timely access to helpful services through hospice. Section 2302 of the ACA, also called “Concurrent Care for Children”, allows children to receive both types of care at the same time, including pain and symptom management and family counseling. It went into effect on March 23, 2010. It is hoped that removing the requirement to stop curative care will increase the use of hospice services by terminally ill children and their families.

States with stand-alone CHIP programs can offer hospice care as an optional benefit but if they choose to, they are required to comply with this provision as well.

State Title V MCH Program Role – Looking Towards the Future

It is generally thought that federal health care reform will help reduce the number of uninsured Americans. Strategies for doing so through the ACA include expansion of eligibility for public benefit programs, an individual requirement to obtain and keep coverage and financial assistance through premium subsidies. Whether it will address the important issue of underinsurance for CYSHCN is still unclear. According to the National Survey of Children with Special Health Care Needs, 96.4% of CYSHCN have coverage, either through a private plan, a public benefit program like

Medicaid or CHIP or a combination of the two. However, 33.1% of families say their insurance coverage is inadequate in meeting their child's needs and 18.1% of families say their child's special health care needs have caused them financial problems (see graphics on page 7).

Much remains to be done and clarified by federal regulation. Will the benefits offered through the Exchanges be comprehensive enough to meet the unique needs of CYSHCN? The essential health benefits in the Exchanges beginning in 2014 offer encouraging descriptions of broad coverage areas; however, how these benefits will be defined, operationalized and enforced in practice is unclear and they are not required in all private coverage options. In the past, efforts to expand coverage and reform health care at the state level have demonstrated the necessity of making compromises between the depth of the benefit package while ensuring the affordability of coverage to as many children as possible. The regulations and policies related to the ACA will be debated and clarified on the federal level but they will be put into practice on the state level. With a mandate to provide a foundation for the health and well-being of mothers and children, especially CYSHCN, State Title V MCH and CYSHCN program leadership and expertise in developing and implementing medical home activities, providing care coordination and partnering with family leaders will be essential in assuring that the promise of health care reform is realized for CYSHCN and their families.

Conclusion

While the impact of the law and its implications for CYSHCN in particular will occur over several years, there is much to be celebrated now. As of this year, parents of premature infants will never again have to worry about leaving the NICU with their newborn already having reached their lifetime benefit cap. A child who gets sick or injured will not be denied coverage simply because they have a pre-existing condition. Young adults, the group with the highest rate of uninsurance, will have access to their parent's insurance coverage up until the age of 26. These are important early victories to celebrate as State Title V MCH and CYSHCN leaders, federal and state policymakers, family advocates and their allies prepare for the important work still to come.

Type of Insurance	% of CYSHCN by insurance category
Private insurance only	60.3%
Public insurance only	28.6%
Both public and private	7.5%
Uninsured	3.6%

Citation: The Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. Retrieved 03/22/10 from www.cshcndata.org

National average for currently insured CYSHCN whose insurance is inadequate (according to their families)

33.1%

Citation: The Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. Retrieved 03/22/10 from www.cshcndata.org

Sources and Selected Resources for Further Information

- **Association of Maternal and Child Health Programs.** Additional information covering key aspects of ACA that pertain to maternal and child health populations is available at: <http://www.amchp.org/Advocacy/health-reform/Pages/default.aspx>
- **The Catalyst Center.** The Catalyst Center is funded by the federal Maternal and Child Health Bureau to serve as the national center on improving financing of care for children and youth with special health care needs. The Center creates publications and products, answers technical assistance questions, researches innovative state-based financing strategies, guides stakeholders to outside resources, and connects those interested in working together to address complex health care financing issues. See the “Publications and More” section of the organization’s website at <http://hdwg.org/catalyst/publications> for more resources on health care reform including:
 - [What Do Children with Special Health Care Needs Require from Health Care Reform?](#) (July 2009)
 - [Health Care Reform and Children with Special Health Care Needs: Coverage is Not Enough](#) (July 2009)
 - [The Essential Components of Health Care Reform for Children with Special Health Care Needs](#) (September 2009)
- **Family Voices.** Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities by providing families with tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care. www.familyvoices.org

- **Maternal and Child Health Bureau, Health Resources and Services Administration, HHS.** Information on the Title V Maternal and Child Health Services Block Grant and other related programs and efforts is available at: <http://www.mchb.hrsa.gov/>
- **U.S. Department of Health and Human Services.** The official federal website on the Affordable Care Act from the U.S. Department of Health and Human services is available at: www.healthcare.gov

Acknowledgements

This issue brief was written by Meg Comeau and developed in partnership with the Catalyst Center at the Boston University School of Public Health under cooperative agreement #U41MC13618 from the Maternal and Child Health Bureau, Health Resources and Services Administration, US Department of Health and Human Services.

AMCHP Staff Contact Information

This fact sheet is part of a series of AMCHP tools, documents and resources on implementation of the Affordable Care Act and its impact on maternal and child health populations. For more information, please visit the AMCHP website at: www.amchp.org and/or contact the AMCHP staff listed below. All AMCHP staff can be reached via phone at: (202) 775-0436.

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