



The Affordable Care Act and Children with Special Health Care Needs:

An Analysis and Steps for State Policymakers



In Memoriam

“Let us remember as each of us makes decisions that will affect children—whether we are parents, educators, health professionals, or government officials—it is our duty to consider if that decision either affirms or denies a child’s most basic human rights.”

Polly Arango, 1942-2010

Founding Executive Director of Family Voices

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C E N T E R



IMPROVING FINANCING OF CARE
for Children & Youth
WITH SPECIAL HEALTH CARE NEEDS

About the Catalyst Center

The Catalyst Center is a national center located at the Boston University School of Public Health and funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration to improve coverage and financing of care for Children and Youth with Special Health Care Needs (CYSHCN). The Catalyst Center works with states and stakeholder groups to cover more kids, close benefit gaps, pay for additional services and build capacity.

<http://www.catalystctr.org>

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“In a decent society, there are certain obligations that are not subject to trade-offs or negotiations and health care for our children is one of those obligations.”

– President Barack Obama

INTRODUCTION

Purpose

What does a state policymaker say when the mother of a child with cystic fibrosis or the father of a child with autism asks “what does national health care reform mean for my child?” How can policymakers respond when asked whether the new national law means that children with special health care needs will have insurance coverage for the services they need, at a price families can afford? There are approximately 10.2 million children with special health care needs in this country, with a wide array of diagnoses. The answers to questions families ask about health reform will depend heavily on choices that states make in the context of federal guidance. This paper analyzes the opportunities and challenges in state implementation of the Affordable Care Act (ACA) in relation to children with special health care needs (CSHCN)¹ and their families, and suggests some steps states can take to make sure ACA coverage works for this vulnerable population.

The answers to questions families ask about health reform will depend heavily on choices that states make in the context of federal guidance.

Approximately one of every seven children under 18 years of age, or 14 percent of children in the United States, has a special health care need.¹ Children with special health care needs 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.² This definition encompasses a wide range of conditions across every demographic group, although there is a link between poverty and special needs. With advances in medical treatment, children with some of the most complex conditions are now surviving well into adulthood, so that transition from child to adult coverage systems has become a critical issue.

¹ Children with special health care needs (CSHCN) are often referenced as children *and youth* with special health care needs (CYSHCN) to highlight the unique physical and developmental needs of adolescents. In this document, we use CSHCN for simplicity’s sake but adolescents with special health care needs are understood to be part of the population under discussion.

Children and youth with special health care needs face challenges in terms of three critical components of coverage: 1) universality and continuity; 2) adequacy; and 3) affordability.³

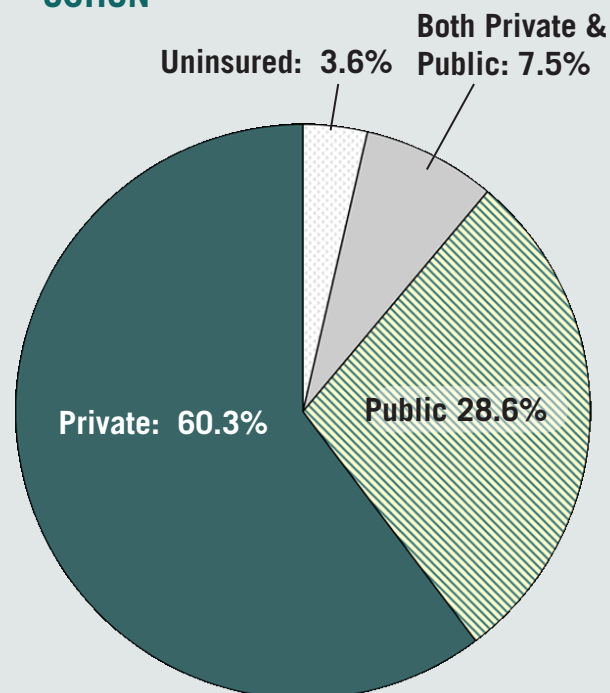
CSHCN-Specific Needs for Universal, Continuous Coverage

Although the vast majority of CSHCN have health care coverage (96.4 percent), continuity of coverage is a substantial issue, with over 900,000 (12 percent) of CSHCN uninsured at some point in 2005.⁴ While one-third of these CSHCN (3.6 percent) had no insurance at all during the year, two-thirds experienced gaps in coverage, either because they lost eligibility for Medicaid or the Children's Health Insurance Program (CHIP) or their parents lost or changed their jobs.⁵ By definition, CSHCN utilize the health care system to a greater extent than other children and have conditions that require ongoing care; gaps in coverage for any amount of time can seriously compromise their health and well-being.

CSHCN-Specific Needs for Adequate Coverage

While having access to coverage is foundational, a more critical issue for CSHCN is ensuring that coverage is adequate for the level and scope of care required. Over 33 percent of families of CSHCN report their health coverage is inadequate in regard to whether their children can see the providers they need, whether needed benefits are covered, and whether uncovered costs are reasonable.⁶ The proportion of families whose children's coverage is inadequate is even higher for specific diagnoses. For example, over 40 percent of families of children with mental health concerns as well as families of children with epilepsy report their coverage is inadequate.⁷ Therefore, while most CSHCN have insurance coverage, many have inadequate coverage because of non-covered benefits, limitations in duration and scope, and annual or lifetime limits, resulting in excessive out of pocket expenses or children not receiving the care they need. Exclusions for pre-existing conditions and limited access to essential providers also have contributed to the inadequacy of coverage for CSHCN.

Insurance Coverage for CSHCN, from the 2005 National Survey of CSHCN



Source: National Survey of Children with Special Health Care Needs
<http://www.cshcndata.org>

This paper provides an in-depth analysis of the Affordable Care Act and steps policymakers can take to better achieve three major coverage goals for children with special health care needs: universal, continuous coverage, adequate coverage, and affordable coverage.

CSHCN-Specific Needs for Affordable Coverage

Over 60 percent of CSHCN have private health insurance⁸ and the affordability of this coverage is a serious issue for families, particularly since CSHCN utilize services at a higher rate than typically developing children.⁹ Expenditures by payers for the care of CSHCN are approximately three times higher than for other children, accounting for about 42 percent of all medical care costs for all children. Premiums, copayments, deductibles and uncovered medical and support service expenses mount up quickly for families of CSHCN. This burden intensifies for nearly a quarter of parents or guardians who must cut back on their employment to care for their child, resulting not only in reduced income, but potentially loss of employer sponsored coverage. While 18 percent of all CSHCN families report that taking care of their child has created financial hardship, the burden can be even higher for children with specific conditions.¹⁰ For example, approximately 40 percent of families of children with autism reported that taking care of their CSHCN created financial problems for the family. Over half of these families have family members who had to cut back or stop working so they could take care of their child.¹¹

Implementation of the ACA

The ACA provides states with tools that can be utilized to better achieve continuous, adequate and affordable coverage for CSHCN. These tools include major structural changes in the individual and group health insurance markets, establishment of health insurance Exchanges, as well as changes in the Medicaid and CHIP programs. To advance a range of health care system improvements, the ACA also provides for grants, demonstration authorities, and other funding opportunities to develop and support state and

community innovations, some of which could help address the needs of CSHCN.

Against the promises of the ACA are a host of questions about statutory interpretation that still need to be addressed in federal guidance. The ACA contains a substantial number of requirements that the Secretary of the Department of Health and Human Services (HHS) is required to act on by issuing regulations or requests for grant proposals, or by conducting studies or providing technical assistance, all of which are important to effective implementation of the law.

In addition to the need for federal guidance and support, states face additional challenges. Implementation and enforcement falls mostly to states, and realizing the reforms envisioned in the ACA will require planning, organization, and change. These reforms also will absorb a large share of the planning and administrative costs at a time when most state budgets are under severe strain and staffing has been significantly reduced in many states. This combination of limited financial and human capital may make it very difficult to devote the resources necessary for effective ACA implementation. Despite these challenges, states are working hard to deploy the resources they do have and make the best decisions they can to achieve the law's intents and promise.

How the law is interpreted and how well implementation challenges are addressed will shape how well the legislation fulfills its promise, especially for CSHCN, a particularly vulnerable population. CSHCN can serve as a litmus test for the effectiveness of the ACA in meeting the needs of children in general; as high utilizers of health care services, they essentially serve as the “canary in the coal mine”.

Overview of the Paper

This paper reviews and analyzes key provisions of the ACA relevant for CSHCN and discusses opportunities and challenges. Its purpose is to inform state policymakers' decisions in implementing the law and realizing its promise for children and youth with special health care needs.

The paper examines ACA provisions that can contribute to achieving the three major coverage goals for CSHCN: universal, continuous coverage; adequate coverage; and affordable coverage. For each of these three areas, the paper reviews ACA provisions that are particularly relevant to CSHCN – first those related to the private insurance market and Exchanges, and then those related to the major public coverage programs for children: Medicaid and CHIP. Following each set of reviews, the paper analyzes the opportunities and challenges presented by the ACA in addressing specific concerns related to CSHCN. The paper concludes with steps that state policymakers can take to utilize the opportunities in the ACA to better achieve coverage goals for children and youth with special health care needs.

This paper reviews and analyzes key provisions of the Affordable Care Act for children with special health care needs, with the goal of informing state policymakers decisions in implementing the law.



Universal, Continuous Coverage

ACA PROVISIONS CONTRIBUTING TO **UNIVERSAL, CONTINUOUS COVERAGE OF CSHCN**

“Gaps in coverage can result in decreased access to care, increased unmet need, and fragmentation of care.”

Source: Mayer, M L, Skinner, A C, Slivkin, R T, Unmet Need for Routine and Speciality Care: Data from the National Survey of Children with Special Health Care Needs, Pediatrics, February 2004

When fully implemented, the ACA will result in coverage for an estimated 32 million more individuals, about 16 million through Medicaid expansion, and the remainder through reforms in and subsidies for private insurance. While the Medicaid expansion is targeted primarily to adults, the private insurance provisions in particular should promote increased coverage for children and youth with special health care needs, and these provisions are addressed first in this and other sections of this paper. Medicaid and CHIP provisions should sustain current coverage for children, including those with special health care needs, as well as promote greater continuity of coverage, which is particularly critical to CSHCN. This first section of the paper reviews ACA provisions promoting increased and more continuous coverage through the private insurance market and new Exchanges established by the law, as well as through Medicaid and CHIP. This review of ACA private and public coverage provisions is followed by a discussion of the specific opportunities and challenges in these provisions for improving the extent and continuity of coverage for CSHCN.

Private Pathways to Coverage—the Private Insurance Market and the Exchanges

Over 60 percent of CSHCN currently receive their health insurance coverage through the private market. The ACA creates the potential for increasing coverage of children through the private market, and perhaps most importantly, for ensuring the continuity of coverage so critical for CSHCN. The ACA contains provisions both to achieve important reforms in the individual and group insurance markets, and to increase access to private coverage by creating the American Health Benefit Exchanges.

The insurance market reforms affecting access and continuity of coverage include prohibitions on pre-existing condition exclusions, guaranteed issue and renewal of policies, and extension of dependent coverage up to age 26. However, most of the ACA's provisions do not apply to all insurance plans; "grandfathered" plans and plans that are self-insured by employers are exempt from certain requirements. Grandfathered plans are individual and group health plans in effect when the ACA was enacted on March 23, 2010. Group plans include both insured and self-insured health plans. Considering that 80 percent of parents with employer-sponsored insurance are likely to be in grandfathered health plans in 2011,¹² the impact of the exemptions is profound. Interim final rules issued by the Departments of Treasury, Labor, and Health and Human Services define the parameters for changes that plans can implement and still retain grandfathered status. It is difficult to predict what decisions plans will make over time to retain this designation. The Departments' analysis provides a mid-range estimate that 66 percent of small-employer plans and 45 percent of large-employer plans will relinquish their grandfathered status by 2013. The Departments also estimate that in any given year, 40 to 67 percent of individual policies will be terminated and their grandfathered status relinquished, with individuals replacing this coverage with new individual or employer-sponsored policies.¹³

Further complicating these distinctions, self-insured plans, in which the risk is assumed by the employer, also are exempt from some of the ACA's requirements. A majority of individuals with private insurance coverage are enrolled in self-insured plans, predominantly those provided by large firms. Thus, many families with CSHCN whose health coverage is grandfathered or self-insured will find that some of the provisions in the ACA designed to improve coverage are not in effect for them, at least not in the initial years post enactment. However, many of the reforms most relevant to privately-insured CSHCN are applicable to all types of plans. These provisions make structural changes in the private market, potentially opening doors to coverage that previously were closed for some CSHCN, and reducing gaps in coverage. Selected private coverage provisions of the ACA that are particularly important to CSHCN follow.

ACA Private Insurance Provisions Relevant to CSHCN

Effective September 23, 2010

Applicable to All Plans (New and Grandfathered Group and Individual Plans)

- Prohibition on health coverage rescissions
- Prohibition on lifetime limits on essential benefits
- Extension of dependent coverage up to age 26 if not eligible for employment-based benefits

Applicable to New and Grandfathered Group Plans, but not Grandfathered Individual Plans

- Prohibition on pre-existing condition exclusions for children under age 19
- Prohibition on annual limits for essential benefits (effective on date of plan renewal)

Effective January 1, 2014

Applicable to all New and Grandfathered Group and Individual Plans

- Extension of dependent coverage up to age 26, regardless of whether eligible for employment-based benefits
- Prohibition on excessively long waiting periods.

Not Applicable to Grandfathered Group Plans and Individual Coverage

- Guaranteed issue of coverage
- Guaranteed renewability of coverage
- Prohibition of discrimination against beneficiaries based on health status
- Requirement to provide essential health benefits

Not Applicable to New Self-Insured Plans

- Guaranteed issue of coverage
- Guaranteed renewability of coverage
- Requirement to provide essential health benefits

Effective in 2010, children cannot be denied enrollment or coverage of specific benefits because of a pre-existing condition.

Pre-existing Condition Exclusions

Effective in 2010 and applicable to all new and grandfathered group plans and all new individual plans, children cannot be denied enrollment or coverage of specific benefits because of a pre-existing condition. This means that regardless of whether medical advice was offered, a diagnosis given, or treatment provided for any pre-existing health condition prior to the date of enrollment, children up to age 19 cannot be denied enrollment or coverage. Children who previously were denied coverage because of a pre-existing condition can reapply and will be accepted for coverage. This provision is likely to affect thousands of CSHCN. In 2008 more than 20,000 applications for children's health insurance coverage were denied altogether due to pre-existing conditions and another 18,000 policies were offered that excluded coverage for certain conditions.¹⁴

Dependent Coverage

Children and youth up to age 26 who are not eligible for employment-based benefits are allowed to remain on their parent's policy when a group health plan or health issuer offers coverage that includes dependent coverage, effective 2010. This is a very important benefit that facilitates CSHCN transition from the pediatric to adult health care system. Its impact will be further bolstered in 2014 when the prohibition on denying coverage for pre-existing conditions goes into effect for applicants over age 19, and dependents can remain on their parent's policy irrespective of their eligibility for employment based coverage.

Coverage Rescission

Health insurers can no longer rescind coverage, regardless of the cost or amount of services used. In the past, insurers have utilized even minor omissions about conditions on applications to void policies. Policies have been voided from their date of issue, making the policyholder liable for all expenses incurred since the policy's inception. When such rescission has occurred, it often follows a hospitalization or costly episode of care. Effective 2010, rescission can now occur only in the case of intentional misrepresentation or fraud.

Guaranteed Issue

Every employer and individual that requests enrollment in health coverage must be accepted during an open or special enrollment period, effective 2014. Issuers also are required to renew health coverage, regardless of health status, utilization of services, or any other factor, thereby ensuring continuity of coverage. Fraud is the only exception to this requirement.

Waiting Periods

Group health plans and issuers in the individual and group markets cannot impose a waiting period longer than 90 days, effective 2014. Waiting periods are the time spans that must pass before coverage becomes effective for otherwise eligible individuals. Individuals cannot use health benefits or have claims paid on their behalf during this period.

Exchanges

Exchanges will be available in 2014 to small employers and families and individuals who do not have access to affordable employer-sponsored coverage. They will offer one-stop comparison shopping and a conduit both for obtaining health insurance and for applying for public subsidies. They are intended to make health insurance coverage more accessible to those who have faced challenges in obtaining coverage in the past, including CSHCN. Subsidies for coverage, in the form of premium tax credits and reduced cost-sharing, will be available exclusively to individuals who receive their coverage through the Exchange.

All of the insurance reforms discussed above are applicable to plans that will be offered through the new insurance Exchanges established at state, regional or national levels. Grandfathered plans and self-insured plans cannot be offered through the Exchanges.

Exchanges are intended to make health insurance coverage more accessible to those who have faced challenges in obtaining affordable coverage in the past, including children with special health care needs.

Discussion: Opportunities and Challenges in the ACA for Promoting Universal, Continuous Coverage for CSHCN through the Private Insurance Market and the Exchanges

The ACA's provisions for private insurance market reform and the establishment of Exchanges hold much promise for improving coverage for CSHCN. However, exemptions to the reforms and initial reactions of insurers to the provisions that are effective immediately highlight the challenges in making sure the reforms work for CSHCN.

Impact of Insurance Market Reforms

While exemptions for grandfathered and self-insured plans significantly dilute the impact of insurance market reforms for CSHCN, the restructuring of coverage is still profound. The reforms promote early and continuous

coverage that can be retained, regardless of the amount of services used by children. Exchanges provide an important avenue for coverage, including subsidies for the cost of coverage for families who previously were excluded or priced out of the market because of a child's pre-existing condition, health status, or high utilization of services.

Child-Only Policies at Risk

Concerns by insurers about possible adverse selection still may make securing coverage for CSHCN in the private insurance market problematic for some families. Families that seek coverage through the individual market may

find that child-only policies are no longer available. A number of major insurers have announced that they will drop child-only policies due to the requirement to cover children with pre-existing conditions. These insurers express concern that without the mandate to buy coverage that will become effective in 2014, families may wait until their children are sick before purchasing coverage, preventing the insurers from spreading risk. Several state insurance commissioners have taken action to require that child-only policies continue to be issued.¹⁵

The interim final rule on pre-existing conditions was issued by the Department of Health and Human Services (DHHS) on July 30, 2010, with questions and answers provided on September 24, 2010. In addressing insurers' concerns, DHHS said that enrollment can be restricted to specific open-enrollment periods, if allowed under state law. Further, insurers can decide on the frequency of open-enrollment periods, unless state law dictates otherwise. DHHS notes that this practice will be monitored by federal and state governments and further guidance will be issued on open-enrollment periods if it appears that their use is limiting children's access to coverage.¹⁶

A number of major insurers have announced that they will drop child-only policies due to the requirement to cover children with pre-existing conditions. Several state insurance commissioners have taken action to require that child-only policies continue to be issued.

Public Program Pathways to Coverage— Medicaid and CHIP

In 2006, more than one out of every four CSHCN relied on public programs for health care coverage – primarily Medicaid or CHIP.¹⁷ Both offer no or reduced cost sharing as well as benefits tailored to the needs of children. Medicaid also is required to ensure that children receive necessary services to prevent, ameliorate or treat conditions and to promote development, through its Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit. Compared to private coverage and to most of the CHIP programs which are

separate from Medicaid, EPSDT provides the most comprehensive coverage for services that meet the needs of CSHCN. Additionally, cost sharing generally is prohibited in Medicaid for children with the lowest incomes, and for those who are in foster care or who are buying into Medicaid under the Family Opportunity Act¹.

While CHIP's capped funding does not provide the same guarantee of coverage as Medicaid, the 2009 CHIP program reauthorization substantially increased funding to enable states to expand coverage to reach more uninsured children, and also required oral health benefits and parity when mental health services are included. State CHIP benefit packages must meet defined national benchmarks, and must cover preventive services for children. Early evaluations of CHIP found improved access, continuity and quality of care for children, and reduced unmet needs, although CSHCN still had more unmet needs than children without special needs.¹⁸ Thus, while not guaranteeing the same coverage as Medicaid in all states, all CHIP programs provide coverage that is tailored to meet the basic needs of children. Of the seven million children enrolled in CHIP, a significant proportion (17 percent to 25 percent in studies done from 1999 to 2002) are estimated to be CSHCN.¹⁹

Therefore, maintaining and extending strong public coverage options for children is especially important for CSHCN. The ACA contains a number of provisions to strengthen public coverage programs, particularly in covering uninsured adults, but also in making improvements relevant to children, including CSHCN. A review of these provisions follows.

Compared to private coverage and to most of the CHIP programs which are separate from Medicaid, the Early and Periodic Screening, Diagnosis and Treatment program (EPSDT) provides the most comprehensive coverage for services that meet the needs of CSHCN.

Medicaid and CHIP Outreach and Enrollment

The ACA requires state Medicaid programs, as a condition of receiving federal matching funds, to conduct outreach and enrollment efforts to vulnerable populations, specifically including CSHCN. Additionally, \$140 million is provided for grants through both this law and CHIP reauthorization for targeted outreach and enrollment efforts to children eligible for Medicaid and CHIP. These grants also are to focus on program retention. Assisting eligible families to retain coverage is very important for all children, but particularly critical for CSHCN.

¹ The Family Opportunity Act, a section of the Deficit Reduction Act of 2005, allows states the option of creating a Medicaid buy-in program for children who meet the disability criteria for Supplemental Security Income (SSI) and whose family income is less than 300% of the Federal Poverty Level. Eligible uninsured children can access Medicaid as their only source of health coverage, while children with private insurance can access Medicaid benefits as supplemental coverage.

Family-to-Family Health Information Centers

In recognition of the pivotal role CSHCN families perform in arranging and coordinating medical and support services for their children, the ACA provides \$5 million to continue funding Family-to-Family Health Information Centers in each state and D.C. Led and staffed by experienced family members of CSHCN, these centers promote a model for effective collaboration between families and the system of care for CSHCN by providing outreach, peer support, and benefits counseling to assist in securing necessary health care coverage and services. The funds are authorized through federal fiscal year 2012, and are administered by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA).

The federal law creates a major simplification in Medicaid and CHIP eligibility by replacing state-determined income criteria with a national standard known as modified adjusted gross income, or MAGI.

Eligibility Simplification

The federal law creates a major simplification in Medicaid and CHIP eligibility by replacing state-determined income criteria with a national standard known as modified adjusted gross income, or MAGI. This simplification, effective in 2014, meshes with the income test for subsidies in the Exchanges, so it will be universally applicable across programs and will ease transitions of individuals from one program to another. States will no longer establish their own rules for disregarding certain types or amounts of income in the eligibility determination; instead a standard five percent of income will be disregarded. The transition to MAGI raises a large number of complicated interpretation and implementation questions in relation to timing and sources for verifying income, determining household size, determining eligibility for new and previously eligible groups, and other very specific issues. Federal guidance in this area is not expected until early 2011.

Maintenance of Eligibility

The ACA also establishes eligibility maintenance of effort (MOE) for children in Medicaid and CHIP through September 30, 2019. The MOE provision for children in Medicaid and CHIP means that states cannot reduce eligibility levels or adopt restrictive eligibility procedures that would make enrollment or renewal more difficult for children without risking loss of federal Medicaid matching funds. This protection preserves the progress made by states in expanding coverage for children over the past decade and more.

CHIP Reauthorized with Increased Federal Match

Authorization of the CHIP program was extended through 2019, accompanied by a 23 percent increase in federal match in 2015. CHIP funding also was extended through 2015, which should ensure that eligible children can continue to be covered during the start-up of Exchanges, and potentially beyond, depending on Congressional action. CHIP's continued availability may be particularly important if Exchange plans fail to provide benefits and cost sharing that are at least comparable to CHIP.

Coordination of Eligibility Determination

States are required to provide seamless coordination and transition among programs to ensure continuous coverage and avoid breaks in coverage, which is particularly important for CSHCN. This coordination is not just between Medicaid and CHIP, but also with the Exchanges in regard to eligibility for a subsidy. Individuals seeking coverage through Medicaid, CHIP or an Exchange will be screened for eligibility for all programs without having to submit additional materials or undergo multiple eligibility determinations. This is particularly important as children's eligibility for different programs may fluctuate due to changes in their parents' income and employment status.

To ensure there is “no wrong door,” a single, streamlined application form will be created that can be submitted to any federally supported program online, in person, by mail or by phone. Additionally, states are required to establish a Medicaid and CHIP enrollment website that is connected to an Exchange. Electronic interfaces and data matches with existing databases and other programs will be used to verify eligibility at enrollment and renewal.

The Affordable Care Act extended CHIP through 2019 with an enhanced federal match starting in 2015. This should ensure that eligible children can continue to be covered during the start-up of Exchanges, and potentially beyond, depending on Congressional action.

Discussion: Opportunities and Challenges in the ACA for Promoting Universal, Continuous Coverage of CSHCN through Medicaid and CHIP

The maintenance of Medicaid and CHIP coverage is important to the many CSHCN eligible for these programs under state eligibility levels in place when the ACA was enacted; CHIP eligibility levels ranged between 160 percent and 400 percent of the Federal Poverty Level (FPL), with 37 states with income eligibility levels over 200 percent of the FPL. The requirements for a seamless system provide an opportunity to create a family-centered application and enrollment process, even if parents and children qualify for different sources of coverage. While the simplifications and improvements in eligibility offer generally good news for all families, they pose a few risks for CSHCN as discussed below.

The maintenance of Medicaid and CHIP coverage is important to the many children with special health care needs eligible for these programs under the relatively generous state eligibility levels in place when the Affordable Care Act was enacted.

Improved Enrollment and Retention

ACA outreach, eligibility, enrollment and renewal reforms and resources generally should benefit all children, including CSHCN. States have learned a great deal about effective outreach, enrollment and retention of children eligible for coverage over a decade of experience in administering the CHIP program, including the lesson that simplifying processes is much easier when eligibility rules are simplified. The vast simplification of eligibility determination and redetermination processes provided through the ACA, especially harnessed with other outreach and enrollment strategies, promise improved enrollment, retention and continuity of coverage. With the majority of CSHCN receiving some or all of their health care coverage through private insurance, states must pay close attention not only to enrollment and retention in public programs, but also in the Exchange and beyond.

Possible Issues with Eligibility Based on Factors Other Than Income

There is some risk that the use of MAGI will disadvantage certain groups of CSHCN. While MAGI should greatly simplify and streamline eligibility determinations for those whose eligibility is based on adjusted gross income, those who qualify under other Medicaid eligibility categories, such as children served by the foster care system and those who receive Supplemental Security Income (SSI) based on disability, will need to have eligibility determination processes that take additional criteria into account. Children with special

health care needs qualifying under home and community-based waiver programs where parental income is waived, such as “Katie Beckett” or TEFRA (Tax Equity and Fiscal Responsibility Act of 1982) state plan option for children who qualify for an institutional level of care but are cared for at home, will need enrollment processes that address their categories of need. With states focused on how to radically streamline systems, CSHCN could be at a disadvantage if new systems fail to include effective methods for considering factors other than income as eligibility criteria for coverage. New eligibility determination processes and systems will need to build in mechanisms such as screener questions to make sure children are directed to the coverage that best meets their needs.

Holding Children’s Coverage Harmless

Depending on the amount of disregards a state currently applies to a family’s income in determining eligibility, the shift to MAGI in 2014 may result in some children exceeding the income guidelines for their state when they previously would have qualified for public coverage. Disregards that states are currently required to use could lower a family’s effective income level by as much as 30 percent and many states have expanded disregards to be even more generous. Recognizing that MAGI may result in some children losing eligibility for Medicaid, the ACA requires states to ensure that the new upper income levels and methods for establishing eligibility will not result in children who would have been eligible for Medicaid in March 2010 losing eligibility later on. While the intent is to hold children’s coverage harmless, the details of federal guidance and state implementation will be important to achieving this intent.

Recognizing that MAGI may result in some children losing eligibility for Medicaid, the ACA requires states to ensure that the new upper income levels and methods for establishing eligibility will not result in children who would have been eligible for Medicaid in March 2010 losing eligibility later on.



Adequate Coverage

ACA PROVISIONS CONTRIBUTING TO ADEQUATE COVERAGE OF CSHCN

“Over a third of families of children with special health care needs report their insurance is inadequate.”

Source: National Survey of Children with Special Health Care Needs
www.cshcndata.org

While most CSHCN had health insurance prior to national health care reform, their coverage often was not adequate to meet their needs. Coverage for necessary diagnostic testing, specialty care, dental services, durable medical supplies, prescription drugs, physical, communication and occupational therapies, and supportive services are critical for CSHCN. The ACA creates some new benefit mandates that are important for CSHCN, especially for those with private coverage.

The Private Insurance Market and the Exchanges

The ACA includes a critically important provision establishing a federal standard for benefits in the private market, as well as a method for assuring at least CHIP comparable coverage in Exchange plans. These provisions are described here.

Federal Standard for Essential Health Benefits

The ACA provides a new way of thinking about what constitutes basic necessary health care coverage. Effective January 1, 2014, coverage provided by non-grandfathered individual and small employer group plans, whether they are outside or within the Exchanges, must include essential health benefits, which will be defined by the Secretary of HHS. The scope of benefits in each category must be equivalent to that provided under a typical employer

plan. The categories of required benefits include:

- Ambulatory patient services;
- Emergency services and hospitalization;
- Laboratory services;
- Maternity and newborn care;
- Rehabilitative and habilitative services and devices;
- Pediatric services, including oral and vision care;
- Preventive and wellness services and chronic disease management;
- Prescription drugs;
- Mental health and substance abuse disorder services, including behavioral health.

Mental health, dental and habilitative services typically have not been standard benefits in private plans, so including these categories in the definition of essential benefits constitutes a significant paradigm shift that is particularly important for CSHCN. While mental health and substance abuse treatment benefits have been more commonly included in private plans than dental or habilitative services, these benefits often have been limited. The Secretary of HHS must define these benefit categories by 2014. The Secretary is instructed to take into account the health care needs of diverse populations, including children, persons with disabilities, and other groups; a provision of particular importance to CSHCN. States and health plans also can add benefits to the standard package, although they must bear the additional costs.

To reinforce the importance of these essential benefits, protections were put in place by the law to ensure that annual or lifetime limits cannot be placed on them effective in 2010.²⁰ Individuals who were previously disenrolled from a plan because they met their lifetime limit will be given the opportunity to reenroll if they are otherwise still eligible. Additional clarification will be required from the Secretary on how these protections will be applied in grandfathered plans and self-insured plans, since the restriction on these limits is based on essential health benefits, but the requirement to provide these benefits does not apply to these types of plans.

Certification of Exchange Plans Comparable to CHIP

The ACA requires the Secretary to certify which plans in each Exchange have benefits and cost-sharing provisions comparable to CHIP by April 2015. In most states, certification will mean that plans provide a scope of benefits and cost sharing that are more generous than standard private insurance policies.

The Affordable Care Act provides a new way of thinking about what constitutes basic necessary health care coverage.

In at least 11 of the 40 state CHIP programs that are separate from Medicaid, the CHIP programs have benefit packages that are the same as for these states' Medicaid programs, although we do not know if the EPSDT guarantee of treatment operates in the same way for CHIP.²¹ A 2009 actuarial study found that the median CHIP plan covers 100 percent of the costs of covered services for children under 175 percent of the FPL, and 98 percent of the costs for those under 225 percent of the FPL.²² Although uncertified plans can still be offered by the Exchanges, the certification will provide families with important information about the scope of coverage.

Discussion: Opportunities and Challenges in the ACA in Promoting Adequate Coverage for CSHCN through the Private Insurance Market and Exchanges

The opportunities for adequate coverage for children with special health care needs are substantially limited since the essential health benefits do not apply to grandfathered and self-insured plans, which is where the majority of children with special health care needs receive their coverage.

The provisions regarding essential benefits in the ACA provide important, if limited, advantages for CSHCN, as discussed below.

Essential Health Benefits Address Children's Needs

In defining the essential benefits, the Secretary is instructed to ensure that the scope of benefits is equivalent to those provided under a typical employer plan. Although private employer coverage definitions might be a bit restrictive related to children's needs, the Act includes several essential benefit categories geared specifically toward children, such as newborn care, pediatric services, oral and vision care and preventive care. While there is great opportunity in defining essential health benefits to ensure adequate coverage for CSHCN, the risk exists that by basing the definition on typical employer-sponsored coverage, benefits will be narrowly defined, resulting in benefit packages that do not adequately address the needs of CSHCN. The opportunities for adequate coverage for CSHCN also are substantially limited since the essential health benefits do not apply to grandfathered and self-insured plans.

CHIP-Comparable Certification Provides Limited Tool

Although the requirement for federal comparability certification does not require plans to provide at least CHIP-equivalent benefits and cost sharing for children, at minimum, it provides a tool for families to use in

comparing children's coverage in Exchange plans, which in turn could serve as an incentive for plans to enhance benefits for children. Whether states or Congress will take any other actions in future to address the consequences of this certification remains to be seen.

Benefit Packages Can Be Enhanced

The ability of plans and states to add benefits provides states an opportunity to ensure that covered benefits meet the specific needs of CSHCN, provided that funding options can be developed either to incentivize plans to add benefits through performance-related payment methodologies, or by directly covering the cost of the additional services. Providing benefits that CSHCN need can generate cost savings. For example, the Robert Wood Johnson Foundation (RWJF) funded integrated systems of care in Medicaid managed care through the Improving Asthma Care for Children (IACC) projects.

These projects had compelling results in cost savings while improving asthma symptoms. At the Affinity Health Plan in the Bronx, New York, for example, inpatient utilization of services declined threefold, while pediatric emergency room visits dropped by more than 400 percent, and every dollar invested in the project generated \$10 in cost savings in childhood asthma care and \$3 in cost savings across the entire health plan.²³ The possibility of generating savings by providing quality care could serve as a strong incentive for plans to provide additional services in their plans.

While the Affordable Care Act does not focus extensively on changes in benefits for children enrolled in Medicaid or CHIP, a number of provisions will affect positively the benefits that children receive.

Medicaid and CHIP

While the ACA does not focus extensively on changes in benefits for children enrolled in Medicaid or CHIP, a number of provisions will affect positively the benefits that children receive. Additionally, the Act includes a number of provisions aimed at increasing the capacity and coordination of the system of services available to those enrolled in Medicaid, many of which will be particularly beneficial to CSHCN. Highlights of these provisions follow the discussion of Medicaid and CHIP benefit opportunities.

Children Moving to Medicaid Obtain EPSDT

As of January 1, 2014, all children with family income up to 133 percent of the FPL will be enrolled in Medicaid. In the 20 states (Alabama, Arizona, California, Colorado, Delaware, Florida, Georgia, Kansas, Mississippi, Nevada, New York, North Carolina, North Dakota, Oregon, Pennsylvania, Tennessee, Texas, Utah, West Virginia and Wyoming) where Medicaid eligibility for older children has remained at the mandatory minimum of

**As of January 1, 2014,
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100 percent, this will result in children and youth ages six to 19 moving from CHIP to Medicaid. Children in this eligibility category will be entitled to Medicaid coverage, including EPSDT benefits and other Medicaid guarantees, a positive step for CSHCN. Increasing the numbers of children with EPSDT will help assure that children, especially CSHCN, can access quality care that promotes health and development. A taskforce of experts convened by the Center for Health Care Strategies to examine ways to modernize EPSDT encouraged consistent use of the federal MCH definition of CSHCN (children 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) “because it focuses on developmental risk rather than specific underlying diagnosis, thereby aligning with current concepts of pediatric practice and ensuring that coverage is extended regardless of the nature of the underlying diagnosis.”²⁴

Coverage for Concurrent Treatment in Hospice Care

Prior to March 23, 2010, 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 had access to coverage for hospice care, either as an optional benefit or through application of EPSDT. However, their families had to decide to end curative care before they could access hospice benefits. This provision in the ACA allows both curative and palliative care, also called concurrent care, to be offered at the same time. A life expectancy of six months or less is still required in order for hospice services to be covered.

Clarification of Medicaid Medical Assistance

Clarification of the role of Medicaid medical assistance underscores the importance of providing services, not just financing. The legislation redefines “medical assistance” as including the provision of services and not just payment, which was the previous definition of the term. This provision was effective upon enactment of the law.

Health (Medical) Homes for Specific Chronic Conditions

Beginning January 1, 2011 the ACA gives states the option of receiving an enhanced federal match if they amend their Medicaid state plans to fund health home services such as care coordination, comprehensive case management, health promotion, transitional care, patient and family support, referral to community and social services, and use of health information

technology to link services. While the ACA uses the term “health home”, this model of care has its origins in the pediatric medical home model. The National Center for Medical Home Implementation (www.medicalhome.org) at the American Academy of Pediatrics offers a comprehensive array of resources to interested providers, policymakers and families. While not specific to children, the health home option under the ACA could be beneficial to CSHCN who qualify, since a health home would facilitate access to a multi-disciplinary array of medical care, behavioral care and community-based services, based upon the needs of the child. According to the ACA, eligible health home participants must have: 1) at least two selected chronic conditions; or 2) one selected chronic condition and be at risk for another one; or 3) have a serious and persistent mental health condition. Qualifying chronic conditions include a mental health condition, a substance use disorder, asthma, diabetes, heart disease, or being overweight, as evidenced by a Body Mass Index over 25. The Secretary may specify additional chronic conditions that would qualify individuals to receive health home services.

Beginning January 1, 2011, the ACA gives states the option of receiving an enhanced federal match if they amend their Medicaid state plans to fund medical home services.

Medicaid Innovation

The ACA established a new broad-based demonstration authority to be carried out by the Center for Medicare and Medicaid Innovation (CMMI) within the Centers for Medicare and Medicaid Services (CMS). CMMI is charged with testing innovative payment and delivery system models related to Medicare, Medicaid and CHIP that improve quality while controlling costs. The law lists an expansive set of potential program models as examples of ones that could be tested, along with any other demonstrations CMMI may develop. CMMI is to give preference to models that improve the coordination, quality and efficiency of health care services. The ACA makes a significant investment to carry out the functions of the CMMI, with an appropriation of \$5 million in 2010 and \$10 billion for the period 2011 through 2019. At least \$25 million each year will be made available for the design, implementation and evaluation of models.

Medicaid Primary Care Rate Increase

The ACA provides enhanced Medicaid payment rates in 2013 and 2014 for primary care services provided by a physician with a primary specialty designation of family, general internal or pediatric medicine. Federal funding will support the cost of increasing Medicaid payments to no less than 100 percent of the Medicare rate. This increase is intended to improve participation of primary care providers, including those caring for children, in Medicaid.

Discussion: Opportunities and Challenges in the ACA in Promoting Adequate Coverage for CSHCN through Medicaid and CHIP

Against these many opportunities to improve the coverage of services that CSHCN receive through Medicaid and CHIP, the ACA also poses some challenges.

One substantial challenge for states in this extremely difficult fiscal climate is maintaining benefits and service levels in Medicaid and CHIP programs, including for children with special health care needs.

Benefits and Provider Rates Vulnerable

One substantial challenge for states in this extremely difficult fiscal climate is maintaining benefits and service levels in Medicaid and CHIP programs, including for CSHCN. Because states are looking for ways to contain costs and the ACA's maintenance of effort provision restricts them from decreasing eligibility levels or adopting more restrictive eligibility processes until 2019, states may consider reducing the amount, duration or scope of CHIP benefits within the parameters of federal CHIP benefit requirements. States such as Nevada and California, when faced with difficult budgetary constraints, took this step in their CHIP programs pre-ACA. Other states may consider this option as they try to balance their budgets while retaining the required MOE-eligibility levels. While Medicaid's EPSDT should protect benefits for children from direct cuts, reductions in provider rates could limit the availability of services. These are steps that state policymakers will want to weigh against their impact on access, quality and outcomes of care, as well as potential increased costs to the system if CSHCN are unable to obtain needed services on a timely basis.

Provider Shortages

Shortages of specialists, particularly as more children are enrolled, put access to benefits at risk. As new children are enrolled in coverage, shortages of specialists and providers such as dentists likely will be exacerbated and will strain the capacity of a health care system already under pressure. States will have to take a leadership role in addressing needed system capacity, including specifically for CSHCN who require pediatric primary and subspecialist care providers who are qualified to address their specific needs. Some of the grant opportunities described in Appendix B are intended to address these issues.



ACA PROVISIONS CONTRIBUTING TO AFFORDABLE COVERAGE OF CSHCN

Affordability is perhaps the most challenging aspect of the ACA to analyze in terms of its implications for CSHCN and their families. CSHCN use more services than other children, so the combined cost of premiums, co-payments, coinsurance and deductibles, along with the cost of any uncovered services, can be quite high for families of CSHCN. The ACA contains a number of provisions to make private health insurance more available and affordable, but it may still fall short of meeting the needs of many families of CSHCN.

The factors that influence affordability include the scope of covered services, and the cost of premiums, coinsurance and deductibles, and copayments. The scope of covered services was addressed in the previous section; the following section focuses on the general framework for premium tax credits and cost-sharing subsidies available through the Exchanges. The ACA does not change the affordability of Medicaid and CHIP, both of which prohibit or restrict cost sharing for children, but we discuss opportunities and challenges in affordability of these public coverage programs at the end of this section.

The Private Insurance Market and the Exchanges

The Role of Exchanges

The ACA creates Exchanges to help people shop for insurance when they do not have access to employer coverage or have employer-based coverage that costs them more than a certain threshold.

“18.1% of families report their child’s special health care needs have caused them financial problems.”

Source: National Survey of Children with Special Health Care Needs
www.cshcndata.org

Categories of Coverage

Beginning in 2014, Exchanges will certify and offer qualified health plans for individuals and small employers. All of these plans will be required to provide a set of essential benefits but they will differ in their cost-sharing features. Families or individuals who are eligible for cost-sharing subsidies (because they cannot obtain affordable employer-sponsored coverage and have incomes under 250 percent of the FPL) can receive these subsidies only if they purchase plans through the Exchanges that have a “silver” level of coverage. Plans in the silver category will have an actuarial value of 70 percent, meaning that on average the plans will pay 70 percent of covered medical expenses, and plan members will pay the rest.

Premium Tax Credits

- **Available January 1, 2014**
- **Subsidize purchase of coverage**
- **Provided on a sliding scale**
- **Families up to 133% of the FPL pay no more than 2% of income on premiums**
- **Percentages increase on a sliding scale up to a maximum of 9.5% of income for families from 300% to 400% of the FPL.**

For example, a mother with two children makes \$24,400 (just over 133% of the FPL). The policy she buys costs \$11,500. She receives a tax credit of \$10,768, making her annual premium payment \$732 (3% of her income).

Premium Tax Credits

Refundable tax credits for premiums are available when eligible individuals and families buy health plans in any category through Exchanges. As illustrated in the box, tax credits reduce the cost of premiums for families based on a sliding scale. Eligible families with incomes up to 400 percent of the FPL pay a percentage of the premium based on their income; the balance is covered by the premium tax credit.

Cost Sharing Subsidies

Families who qualify for premium tax credits also are eligible for subsidies that reduce their share of the costs for covered benefits if they purchase the silver category of coverage and have incomes below 250 percent of the FPL. As with the premium tax credits, the cost-sharing subsidy is calculated on a sliding scale based on family income, as illustrated below.

Cost Sharing Subsidies in Exchange Silver Plans

Family Income	Average Proportion of Covered Expenses Paid by Plan (Actuarial Value)
Up to 150% FPL	94%
151 – 200% FPL	87%
201 – 250% FPL	73%

Limits on Out-of-Pocket Expenditures

Beginning in 2014, all new individual and group plans both inside and outside of Exchanges must limit out-of-pocket expenses for individuals and families.²⁵ This limit is \$11,900 (in 2010 dollars) for family coverage; the actual amount will be calculated annually based on a cost-of-living adjustment. These limits on out-of-pocket costs are not applicable to self-insured and grandfathered plans, where the majority of CSHCN are expected to obtain coverage in the immediate future.

Additionally, families with incomes under 400 percent of the FPL purchasing a silver plan through the Exchanges will benefit from further limits on their out-of-pocket expenditures. The table below illustrates out-of-pocket maximums for families at various income levels. Out-of-pocket limits include expenditures for co-pays, coinsurance and deductibles, but do not include premiums and non-covered services.

Out-of-Pocket Limits by Income in Exchange Silver Plans²⁶

Family Income	Out-of-Pocket Limits
Up to 150% FPL	\$3,927
151 – 200% FPL	\$3,927
201 – 250% FPL	\$5,950
251 – 300% FPL	\$5,950
301 – 400% FPL	\$7,973

Preventive Services Specific to Children without Cost Sharing

To improve the affordability of preventive care and promote its use, preventive care must be covered under new individual and group plans, effective September 23, 2010, with no cost sharing. Preventive care must include items rated A or B by the U.S. Preventive Services Task Force,²⁷ immunizations recommended by a federal advisory committee, and preventive care and screenings called for under Bright Futures, guidelines for care of children and youth that were developed by HRSA, in conjunction with the American Academy of Pediatrics and other experts.²⁸

Understandable Cost Data

One critical function of the Exchanges is to provide a calculator to help individuals and families determine their actual cost of coverage after taking into account any premium credits and cost-sharing subsidies and limits. This calculator will enable comparisons of both the benefits and cost of coverage

across plans. Exchanges are required to create and maintain a website to provide standardized information to help consumers compare plans. To provide immediate assistance to families in locating affordable health coverage options, the Secretary has already established www.HealthCare.gov. This website includes a central portal for individuals, families and employers to find tailored information on both public and private coverage options.

Discussion: Opportunities and Challenges in the ACA in Promoting Affordable Coverage for CSHCN through the Private Insurance Market and Exchanges.

While the ACA's provisions will promote access to more affordable coverage for many, as noted earlier, they may fall short of meeting the needs of many families of CSHCN.

Continued Financial Burden

Because many families of CSHCN will continue be covered through grandfathered or self-insured plans where limits on out-of-pocket expenditures do not apply, they will continue to bear heavy financial burdens for children who are high users of service. For families covered under new plans, there are limits on out-of-pocket expenditures. However, the costs to families remain significant if they are not eligible for premium tax credits or reduced cost sharing, and even with these subsidies, families of CSHCN in particular still may see a significant gap in covering the total costs of health care coverage for their family.

Premium Increases and Adverse Selection

The ACA intends to create a level playing field by imposing many of the same requirements on plans inside and outside the Exchanges and by requiring the purchase of coverage by all people to spread health insurance risk as much as possible. However, concerns about adverse selection can be seen in insurers' reaction to the prohibition on pre-existing conditions and required issuance of coverage in relation to child-only plans. Depending on state law, plans may be able to raise premiums to discourage enrollment of children considered to be high-risk. While the ACA requires that the states and federal government review premiums annually to identify unreasonable premium increases, insurers are only required to submit justification, and are not prohibited from increasing premiums.

Plan Coverage Comparable to CHIP

The ACA requires that the Secretary of HHS certify which plans in Exchanges offer benefits and cost sharing for children that are comparable to state CHIP plans. This is important because CHIP has its own child-specific federal benefit options and requirements and a cost-sharing cap of 5 percent of family income. One actuarial study found that in the 17 states examined, which together enrolled more than half of the children on CHIP, the majority of these states adopted coverage that was more generous than the federal CHIP benefit options and cost-sharing limits, and well below the cost-sharing cap of 5 percent of family income allowed by the CHIP statute. On average, enrolled children were exposed to two percent or less of medical expenses.²⁹ The federal certification of CHIP comparability will be useful information for families and might help focus attention of states and plans on children's coverage; however uncertified plans will still be able to operate within the Exchanges.

Discussion: Opportunities and Challenges in the ACA in Promoting Affordable Coverage for CSHCN through Medicaid and CHIP

The ACA requires eligibility MOE for children in both Medicaid and CHIP programs until 2019. This means that states must maintain their eligibility levels and restrain from imposing new requirements that are more restrictive than what was in effect on the date of the ACA's passage. While guidance had not been issued when this paper was published, it is possible that this requirement could be interpreted by the federal government as also restricting states from increasing cost sharing or reducing benefit levels, as either of these actions could dissuade families from enrolling their children in the programs.

While Medicaid continues to provide maximum affordability for low-income CSHCN, the cost of coverage in CHIP for CSHCN is lower than the cost of private coverage. CHIP premiums are often very modest. The estimated average premium in CHIP comes to just 0.7 percent of income, on average, for a family of three at 201 percent of the FPL.³⁰ This is quite a contrast to the premium of 6.3 percent of income for a family at the same income level in the Exchange.³¹ These amounts include the cost of the parent(s)' premiums, but even if they were excluded, the premium cost of the Exchange plan would still be significantly higher than the CHIP premium cost.



“Realizing the promise of the legislation for children with special health care needs requires special attention on the part of policy-makers.”

STEPS STATE POLICYMAKERS CAN TAKE TO PROMOTE **UNIVERSAL, CONTINUOUS, ADEQUATE AND AFFORDABLE COVERAGE OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS**

The Affordable Care Act (ACA) promises improved coverage for millions of Americans, including CSHCN and their families. However, realizing the promise of the legislation for CSHCN requires special attention on the part of state policymakers. The tools available through the ACA must be used thoughtfully and carefully to meet the needs of CSHCN while guarding against any unintended consequences that could jeopardize vital comprehensive coverage. Following are some steps that state policymakers can consider to promote coverage for CSHCN.

To Promote **Universal and Continuous Coverage** of CSHCN

► **Consider enacting more protective standards in the private insurance market.**

States are responsible for regulating private insurers and plans and can enact rules that address the needs of CSHCN. For example, if issuers of child-only plans are allowed to impose time-limited open enrollment periods to address their concerns about adverse selection in lieu of dropping these policies, families of CSHCN would have to assume the financial burden of care or care would be delayed while waiting for the open enrollment period. This could have negative medical consequences for children and financial consequences

for the health care system. At least one state, New Hampshire, has invoked its guaranteed issue policy to make it clear that insurers must offer policies for all individuals, regardless of age, in the state.³²

► **Ensure monitoring, compliance, and enforcement of insurance market reforms.**

It is critical for CSHCN that states ensure that plans are complying with the new reforms under the ACA including disallowance of pre-existing exclusions and coverage rescissions; guaranteed issue of coverage and renewal; prohibition of excessively long waiting periods before insurance becomes effective; and elimination of annual and lifetime limits on essential health benefits.

► **Ensure that Medicaid and CHIP target CSHCN in their outreach, enrollment and retention efforts, including collaboration with partner organizations.**

The ACA requires that Medicaid target vulnerable populations, including CSHCN, in outreach efforts. Medicaid can partner with a range of organizations to assist in these efforts, including programs for CSHCN funded by the federal Title V Maternal and Child (MCH) Health Services block grant. Family-to-Family Health Information Centers in every state that have had their funding continued under the ACA can be particularly helpful in reaching and enrolling CSHCN. States also can work closely with organizations that have been awarded federal outreach grants to reach and promote enrollment of children eligible for Medicaid and CHIP. By working with these grantees, states not only provide them with the benefit of their expertise in providing outreach, they also can ensure that children are enrolled and linked to services. States can also work with partners to promote a focus on retaining coverage at renewal. This is extremely important for all children, but particularly CSHCN, who cannot afford the consequences to their ongoing medical care if they are covered intermittently. It is critical to maintain continuous coverage for CSHCN, and states can work closely with these grantees on achieving that goal. Contact information for key collaborative resources can be found in Appendix B.

► **Incorporate methods in eligibility processes for Medicaid, CHIP and Exchanges to ensure that CSHCN are identified and can be channeled to needs-specific pathways for coverage at the time of application.**

Because children will shift eligibility among programs, identifying ways in which states can promote continuity of coverage among programs is essential, particularly for CSHCN. With the eligibility and enrollment simplifications contained in the ACA, it is critical to have a means of ensuring that timely eligibility and enrollment pathways based on factors other than income remain for CSHCN. Screening questions have already been developed to identify CSHCN could be incorporated into eligibility processes and systems. This identification could prevent children whose

**To promote
universal and
continuous
coverage**

To promote adequate coverage

family income is higher than the Medicaid eligibility level from being denied eligibility when they may qualify for Medicaid through another pathway, such as TEFRA, medical spend-down or a Medicaid buy-in program. Early identification of CSHCN also would promote linkage to appropriate resources, such as those offered by the Title V MCH programs, medical homes or home and community based waiver programs.

To Promote Adequate Coverage of CSHCN

- ▶ **Collaborate with families, advocates and providers of care for CSHCN to obtain their input on “essential health benefits” for this population.**
States then can include this information in providing input and working with the federal Department of HHS as the definitions and standards for essential health benefits are developed. States also will be better equipped to assure that selection of qualified plans and contracts for services assure appropriate coverage, including amount, duration, and scope of benefits.
- ▶ **Promote CHIP benefits as an additional minimum standard for the adequacy of coverage for children.**
CHIP benefits must meet federal standards and, while not as comprehensive as Medicaid, generally rival private insurance. Given the requirement that the Secretary certify which plans offer CHIP-comparable coverage, this standard can be utilized along with the essential health benefits package to promote coverage that meets pediatric-specific medical-necessity requirements and the needs of CSHCN.
- ▶ **Harmonize benefit packages to encourage continuity of coverage across Medicaid, CHIP and the Exchange in providing adequate benefits for CSHCN.**
This is particularly important since families’ incomes will change and children’s eligibility and enrollment will churn across programs. In defining these benefits, a preventive pediatric medical necessity standard should be included that promotes health, growth and development; lessens the effects of chronic disease; and maintains function. Addressing children’s physical, social, emotional and cognitive development should be intertwined in this standard.
- ▶ **Implement a Medicaid buy-in program for children with disabilities whose families are over income for Medicaid.**
Several states, including Maryland, Louisiana, North Dakota, Iowa, and Pennsylvania have implemented Medicaid buy-in programs for children with disabilities and Vermont has implemented a buy-in program for any child whose family income is under 300 percent of the FPL. Massachusetts and Pennsylvania have no family-income limit for the program, but premiums for the CommonHealth program in Massachusetts are based on a sliding fee scale. There are no premiums

associated with the Pennsylvania buy-in program for CSHCN. The Family Opportunity Act now allows families of children who meet the functional disability criteria for Supplemental Security Income (SSI) and whose income is less than 300 percent of the FPL to access Medicaid coverage for their child through a state plan option.

► **Develop funding strategies that incentivize plans to add benefits and promote care coordination.**

Plans have the option to provide additional benefits to the essential plan. States also have the opportunity to use their purchasing levers to work with and support plans in adding benefits to meet the specific needs of CSHCN. Care coordination, a key benefit that is essential for CSHCN and their families, could be promoted through this model. States could develop incentives to promote additional benefits that are tied to performance in serving CSHCN through Accountable Care Organizations (ACO) or other mechanisms. Finding effective ways to provide continuous, quality coverage of CSHCN across programs, including for specific diagnostic categories, can go a long way in addressing the significant costs in benefit utilization and the level of care they require.

► **Ensure access to easily understood, comparable information for families of CSHCN.**

Exchanges are required to create and maintain a website to provide standardized information to help consumers compare plans. Parents should be able to compare plans on the type, scope, and duration of benefits that are most needed by their children, review each plan's performance on quality measures related to CSHCN, and see if the provider network has sufficient pediatric specialty providers and support services to meet their children's needs. The Exchange has the opportunity to work with families of CSHCN and other consumers to develop an easily accessible and understandable website that provides meaningful information, creates easy-to-understand ratings for plans and offers search engines that allow families to look at the factors most important to them in selecting a plan. State Title V programs and state Family-to-Family Health Information Centers are resources for helping to develop information content and systems relevant to CSHCN.

► **Evaluate and consider adopting the health home option.**

The health home expands on medical home models and delivery systems by building linkages with other community supports to enhance the coordination of care. Persons who may enroll in health homes established under the Medicaid state plan must have specific conditions, many of which are more relevant to adults than children; however, the Secretary of HHS has the authority to expand the set of qualifying conditions and could incorporate some that would be more applicable to children.

**To promote
adequate
coverage**

To promote affordable coverage

- **Propose innovative service and payment arrangements that include CSHCN through demonstrations established by the Center for Medicare and Medicaid Innovation (CMMI).**

This new center is required to give preference to testing models that improve the coordination, quality and efficiency of health care services—all of which are important priorities for CSHCN. States could develop proposals for demonstrations that focus on CSHCN either as the primary population or as one of several target groups.

- **Work with families, advocates and legislators to secure federal funding for authorized grant programs in the ACA.**

There is a significant list of initiatives in the ACA that, if funded, have the potential to increase system capacity, improve access to services, and provide education and outreach (see appendix).

To Promote Affordable Coverage of CSHCN

- **Design and develop Exchanges that promote plan participation sufficient to spread risk.**

States will need to closely examine whether there will be sufficient plan participation within the state to spread insurance risk across a broad population. If not, perhaps multi-state or regional Exchanges would better serve enrollees by having a risk pool sufficiently large to absorb risk and mitigate concerns about adverse selection.

- **Consider expanding the state's income eligibility for CHIP.**

In light of the cost of the Exchange plans for moderate income families, states that do not currently have CHIP programs with an upper income eligibility level of 300 percent of the FPL, which is the maximum level for which non-grandfathered states receive the CHIP match, may want to consider expanding their program to that level. Although this is a difficult economic time in which to consider an expansion, for those states that may be able to afford the state match, this could be a step to ensure that children, particularly CSHCN, receive necessary health services at an affordable cost.

CONCLUSION

The Affordable Care Act (ACA) provides new pathways to universal, continuous, adequate and affordable coverage for all, including CSHCN. The ACA offers coverage to individuals, including CSHCN, who had previously been excluded or priced out of private coverage because of pre-existing conditions, expensive medical conditions and high utilization of benefits and services. The availability of new coverage options for parents and children through the Exchanges creates the possibility of seamless, family-centered coverage.

The complexity and scope of reforms demand that states take an organized, comprehensive approach to implementing the provisions of the ACA. Some of the greatest opportunities and challenges will come with implementing a unified and simplified eligibility and enrollment system across the Exchanges, Medicaid and CHIP, in which there is “no wrong door” for applying for coverage. Assuring continued enrollment pathways for children who qualify through other categories including SSI, foster care, and spend-down adds to this challenge. It is critical, however, that states assure coverage for CSHCN, and indeed for all children, who are all vulnerable due to their growth and developmental needs as well as their dependence on adults. Including families of CSHCN in the design of the eligibility and enrollment pathways is important to states’ ability to identify CSHCN during the enrollment process, and assure that they receive the benefits and provider networks they need.

States that adopt an organized, strategic approach will find that they have many new tools and opportunities for improving the financing, coordination, delivery and quality of services that support the health and development of CSHCN, as well as the overall performance of the state’s health care system. Having a continuum of care that starts with the early identification of health and developmental concerns through screening and then connects the family with accessible, adequate medical care and support services is particularly important for CSHCN. States that can successfully transition children across public and private coverage and delivery systems, while ensuring that they remain connected to the providers and services they need, will serve as models in being able to address the needs of CSHCN.

States that adopt an organized, strategic approach will find that they have many new tools and opportunities for improving the financing, coordination, delivery and quality of services that support the health and development of CSHCN, as well as the overall performance of the state’s health care system.

The extent to which the promises of the ACA will be realized for all, including CSHCN, is as yet unknown, but reform holds significant promise for alleviating many of the challenges posed by the current system of coverage and financing care for CSHCN. The ACA provides a framework with many helpful tools for achieving the ambitious goal laid out in the federal Healthy People 2010 that CSHCN and their families “... have access to adequate public and/or private insurance to pay for the services they need,” so they may reach their full potential.

Endnotes

- ¹ U.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, MD: U.S. Department of Health and Human Services, 2007).
- ² McPherson, M, et al. A new definition of children with special health care needs (Elk Grove Village, IL: Pediatrics, 1998),102: 137-140
- ³ Catalyst Center for Improving Financing of Care for Children and Youth with Special Health Care Needs, The Essential Components of Health Care Reform for Children and Youth with Special Health Care Needs (Boston, MA: Catalyst Center Health & Disability Working Group, Boston University School of Public Health, 2009).
- ⁴ U.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. op. cit.
- ⁵ Catalyst Center for Improving Financing of Care for Children and Youth with Special Health Care Needs, The Essential Components of Health Care Reform for Children and Youth with Special Health Care Needs op. cit.
- ⁶ U.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. op. cit.
- ⁷ Ibid.
- ⁸ Ibid.
- ⁹ Newacheck, PW, Kim SE. A National Profile of Health Care Utilization and Expenditures for Children with Special Health Care Needs. (Chicago, IL: American Medical Association, Archives of Pediatrics & Adolescent Medicine, 2005), 159(1):10-17.
- ¹⁰ U.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. op. cit.
- ¹¹ Ibid.
- ¹² U.S. Department of Health and Human Services, Health Resources and Services Administration, Federal Register 75, no. 116 (July 17, 2010).
- ¹³ Ibid.
- ¹⁴ America’s Health Insurance Plans, Individual Health Insurance 2009: A Comprehensive Survey of Premiums, Availability, and Benefits (Washington, D.C.: AHIP Center for Policy and Research, 2009).
- ¹⁵ Beutler, Brian. “State Official Orders Insurance Company to Sell Insurance to Children.” October 15, 2010. Talking Points Memo. Retrieved November 5, 2010. <http://tpmdc.talkingpointsmemo.com/2010/10/state-official-orders-insurance-company-to-sell-insurance-to-children.php>
- ¹⁶ U.S. Department of Health and Human Services, Questions and Answers on Enrollment of Children Under 19 Under the New Policy that Prohibits Pre-Existing Condition Exclusions, updated September 24, 2010. (Washington: D.C.: U.S. Department of Health and Human Services, 2010).
- ¹⁷ VanLandeghen, K. and Brach, C. Who’s Enrolled in SCHIP? CHIRI™ Issue Brief 3. AHRQ Publication No. 04-0015, December 2003. Agency for Healthcare Research and Quality, Rockville, MD. <http://www.ahrq.gov/chiri/chirischip.htm>.
- ¹⁸ VanLandeghen, K. and Brach, C. Does SCHIP Benefit All Low-Income Children? CHIRI™ Issue Brief No. 4. AHRQ Publication No. 05-0010, December 2004. Agency for Healthcare Research and Quality, Rockville, MD. <http://www.ahrq.gov/chiri/chiribrf4/chiribrf4.htm>.

- ¹⁹VanLandeghem K and Brach C. What has been learned about expanding children's health insurance? Highlights from CHIRI™. CHIRI™ Issue Brief No. 10. Rockville, MD: Agency for Healthcare Research and Quality; September 2009. AHRQ Pub. No. 09-0034. <http://www.ahrq.gov/chiri/chiribrf10/chiribrf10.pdf>.
- ²⁰A temporary restricted annual limit is allowed until 2014, as long as access to needed services is made available with minimal impact on premiums. The interim final rule defines the temporary permissible restriction, starting with a \$750,000 limit for plan years starting on or after September 23, 2010 and increasing incrementally to \$2 million for plan years starting on or after September 23, 2012 to December 31, 2013, at which point the complete restriction would go into effect for new individual coverage and all group plans.
- ²¹Hess C et. al. Charting CHIP IV: A Report on CHIP Programs Prior to Major Federal Policy Changes in CHIPRA and ACA (Washington, D.C.: National Academy for State Health Policy, forthcoming).
- ²²First Focus, Children in Health Reform: Comparing CHIP to the Exchange Plans (Washington, D.C.: First Focus, 2009), 8.
- ²³Pediatric Asthma. Models for Advancing Asthma Care. "Innovation in Action: the Improving Asthma Care for Children Program." Retrieved November 5, 2010. www.pediatricasthma.org/medicaid_managed_care.
- ²⁴Rosenbaum, S., Wilensky, S., Allen, K., EPSDT at 40: Modernizing Pediatric Health Policy to Reflect a Changing Health Care System, (Hamilton, N.J.: Center for Health Care Strategies, 2008)
- ²⁵This limit is the maximum established for Health Savings Account/High Deductible Plans. High deductible health plans (HDHP) can be linked to tax-free health savings accounts (HSA), established in 2003 through the Medicare Modernization Act (MMA). The MMA limits the total amount of out-of-pocket costs that can be incurred by families and individuals enrolled in high deductible plans.
- ²⁶Adapted from Chaikind, H; Fernandez, B; Newsom, M; Peterson, C. Private Health Insurance Provisions in PPACA (P.L. 111-148), Congressional Research Service, 2010.
- ²⁷The U.S. Preventive Task Force is an independent panel of experts in primary care and prevention that systematically reviews evidence of effectiveness and develops recommendations for clinical preventive services. Services rated A are recommended because there is a high certainty that the net benefit is substantial, i.e., screening newborns for sickle cell anemia. Services rated B are recommended because there is a high certainty that the net benefit is moderate to substantial, i.e., depression screening for adolescents.
- ²⁸Bright Futures is a health prevention and promotion initiative, currently based at the American Academy of Pediatrics. Bright Futures provides guidance on the 31 recommended health supervision visits from infancy through late adolescence and is considered an important standard for screening, diagnosis and prevention for infants, children and adolescents.
- ²⁹Watson Wyatt Worldwide, Implications of Health Care Reform for Children Currently Enrolled in CHIP Programs (Washington, D.C.: First Focus, 2009).
- ³⁰Georgetown University Center for Children and Families, Premium Payments for Two Children in a Family of Three at 201% of FPL (Washington, D.C.: Georgetown University, 2009).
- ³¹Angeles, J. Making Health Care More Affordable: The New Premium and Cost-Sharing Credits (Washington, D.C.: Center for Health Care and Budget Priorities, 2010).
- ³²U.S. Department of Health and Human Services, letter from Kathleen Sebelius, Secretary of the Department of Health and Human Services, Letter to the National Association of Insurance Commissioners, October 13, 2010. <http://www.hhs.gov/news/press/2010pres/10/20101013a.html>.

APPENDIX A: Federal Grant Opportunities for Systemic Improvements Benefiting CSHCN

Funded federal grant opportunities for systemic improvements benefiting CSHCN

The ACA enacted and funded a number of grant programs that will support access to benefits and services required by CSHCN and enhance the supply of providers that are critically important to the care of these children.

Maternal, Infant and Early Childhood Home Visitation Grant Program

Of particular importance in promoting healthy development and providing coordination and referral to other programs and community support, all essential for CSHCN, is the Maternal, Infant and Early Childhood Home Visitation Grant Program. This program is intended to promote improvements in prenatal, maternal and newborn health, child health and development, parenting skills, school readiness, juvenile delinquency and family economic self-sufficiency. \$1.5 billion dollars is available from 2010 through 2014.

Community Transformation Grants

These grants, incorporated into a Prevention Fund, would promote health and reduce the incidence of chronic disease associated with overweight, tobacco use, and mental illness by addressing policy, environmental, programmatic and infrastructure changes needed to promote healthy living and reduce health disparities.

Training Grants for Targeted Health Professionals

The ACA funds training grants designed to stimulate the supply and enhance the knowledge of certain provider specialties important in the care of CSHCN. These include primary care providers in medical homes, mental health and behavioral professionals working with children and adolescents, and pediatric and general dentists.

Grants for State Health Care Workforce Development

State health care workforce development grants provide \$8 million for planning grants and \$150 million for implementation grants in 2010 to states to plan and implement comprehensive health care workforce development strategies that address workforce gaps at the state and local levels.

Unfunded federal grant opportunities for systemic improvements benefitting CSHCN

There are numerous other grant opportunities that could be advantageous to CSHCN, but have not yet had funds appropriated. Congress would need to take additional action, and the odds for future funding are uncertain. Many of these initiatives offer promising methods for improving coordination and access to services, and a lack of funding is a lost opportunity for improving care for all children, including those with special health care needs.

Pediatric Accountable Care Organization (ACO) Demonstration

Designed to support pediatric providers in a Pediatric ACO, financial incentives can be provided to organizations that meet quality guidelines, improve patient health and reduce unnecessary costs. Programs are authorized from 2012 through 2016.

Community Health Team Grants

The ACA creates a federal grant program to establish community health teams charged with supporting patient-centered medical homes. Eligible entities are states, state designated entities, and Indian tribal organizations. The interdisciplinary community health teams supported under this program must contract with primary care providers to deliver support services such as care coordination, chronic disease management, care planning, and similar functions. This model could be effective for CSHCN in ensuring the delivery of services in an integrated system that tracks the services received by a child to prevent duplication or unnecessary services.

The Primary Care Extension Program

The program will educate primary care providers about preventive medicine, health promotion, chronic disease management, mental and behavioral health services and evidence-based therapies and techniques to improve community health by working with community-based health connectors, called health extension agents (HEAs). These HEAs are community-based health workers who facilitate quality improvement or system redesign, including the principles of a patient-centered medical home, to improve primary care in culturally and linguistically appropriate ways and to improve linkages of primary care practices with diverse health system resources. Hubs will be developed to assist primary care extension agents in developing and supporting primary care learning communities.

Community-Based Collaborative Care Networks

Grants would build further on providing comprehensive, coordinated and integrated health care services by using funds for assisting low-income individuals in obtaining access to services that include the medical home and care management, as well as outreach and enrollment in health coverage programs.

APPENDIX B: Resources for State Policymakers

Family Voices

Through their national network, Family Voices provides families of CSHCN with tools to make informed decisions, advocates for improved public and private policies, builds partnerships among professionals and families, and serves as a trusted resource on issues related to health care for CSHCN and their families.

<http://www.familyvoices.org>

Family-to-Family Health Information Centers

The Family-to-Family Health Information Centers are non-profit, family-staffed organizations located in each state and the District of Columbia that help families of CSHCN and the professionals who serve them by providing information and referral services, benefits counseling, education, training and more.

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

Maternal and Child Health (MCH) Services Title V Block Grant Program

The Title V MCH and CSHCN programs are administered by the Maternal and Child Health Bureau (MCHB, <http://mchb.hrsa.gov>) as part of the Health Resources and Services Administration, U.S. Department of Health and Human Services. In partnership with the States and the District of Columbia, MCHB provides the leadership and resources needed to advance the health and safety of the nation's mothers, infants, children, adolescents, and CSHCN. For a list of the state Title V MCH and CSHCN program directors, go to:

https://perfddata.hrsa.gov/mchb/mchreports/link/state_links.asp

Maternal and Child Health Bureau-funded National Centers

MCHB has funded several national centers which provide leadership and support states in making measurable progress towards achieving the Healthy People 2010 performance outcomes for CSHCN.

Here is a list of the six performance outcomes with links to the appropriate national center(s):

- **Families of children with special health care needs (CSHCN) will participate in decision-making at all levels and will be satisfied with the services they receive.**

Family Voices

<http://www.familyvoices.org>

National Center for Cultural Competence

<http://www11.georgetown.edu/research/gucchd/nccc>

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- **CSHCN will receive regular, ongoing comprehensive care within a medical home.**

National Center for Medical Home Implementation
<http://www.medicalhomeinfo.org/>

- **Children will be screened early and continuously for special health care needs.**

National Center for Hearing Assessment and Management
<http://www.infanthearing.org/>

National Newborn Screening and Genetics Resource Center
<http://genes-r-us.uthscsa.edu>

American College of Medical Genetics Coordinating Center
<http://www.acmg.net>

- **Families of CSHCN will have access to adequate public and/or private insurance to pay for the services they need.**

The Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs
<http://www.catalystctr.org>

- **Community-based service systems will be organized so families can use them easily.**

National Center for Community-Based Services
<http://www.communityinclusion.org>

- **Youth with special health care needs (YSHCN) will receive the services necessary to make transitions to all aspects of adult life.**

National Health Care Transitional Center for Youth with Special Health Care Needs
<http://gottransition.org>

Association of Maternal and Child Health Programs

The Association of Maternal and Child Health Programs (AMCHP) is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs.

<http://www.amchp.org>

State Refor(u)m

State Refor(u)m is a listserv community which organizes and shares state-developed resources on a variety of health reform topics in order to support state officials working to implement federal health reform legislation.

www.statereforum.org

Centers for Medicare and Medicaid Services

The Centers for Medicare and Medicaid Services (CMS) created this website to help families find state-specific information about Medicaid and CHIP programs.

<http://www.insurekidsnow.gov>

Department of Health and Human Services

HHS has created this website to provide immediate assistance to families in locating affordable health coverage options. It includes a central portal for individuals, families and employers to find tailored information on both public and private coverage options.

www.healthcare.gov

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