

# Children With Special Health Care Needs: The Canary in the Health Care Reform Coal Mine

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**KEY WORDS**

Affordable Care Act, health care reform, children with special health care needs

**ABBREVIATIONS**

ACA—Affordable Care Act

CSHCN—children with special health care needs

OOP—out of pocket

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An article entitled “Massachusetts Health Reform and Access for Children With Special Health Care Needs” by Smith and Chien<sup>1</sup> appears in this month’s issue of *Pediatrics*. The investigators used parent-reported data from the 2005/2006 and 2009/2010 National Survey of Children With Special Health Care Needs to compare findings in Massachusetts before and after the implementation of health care reform. In addition, they compared these findings over the same time period with similar data from other states. Because children with special health care needs (CSHCN) are the most vulnerable to problems in the implementation of health care reform, assessing this population provides a window into how well a state is implementing the Affordable Care Act (ACA). Therefore, CSHCN are the proverbial “canary” in the health care reform “coal mine.”

In 2006, Massachusetts passed health care reforms that were subsequently included in the national ACA.<sup>2</sup> However, it is unclear whether the Massachusetts health care reform experience will be replicated in other states. Before its reforms were implemented in 2006, Massachusetts already had a very generous Medicaid program with children’s coverage to 200% of the federal poverty level. Unlike most states,<sup>3–5</sup> an extensive pediatric primary, subspecialty, and specialty network capacity already existed and reasonable Medicaid payments supported participation and promoted access to primary and specialty care. In addition, Massachusetts health care reforms had broad bipartisan political as well as community support.

The Massachusetts reforms did not reduce CSHCN uninsurance. Lack of insurance can be analyzed as being uninsured at a point in time, for the entire year or at any time during a year. In Massachusetts before reform, ~1% of CSHCN were uninsured at a point in time, 70% were privately insured, 21% publicly insured only, and 8% had both public and private coverage. After implementing its health care reforms, the prevalence of CSHCN uninsurance sometime during the year in states other than Massachusetts increased from 8.9% to 9.4%, whereas in Massachusetts it increased from 5.2% to 5.4%. In Massachusetts there was no direct evidence that coverage gaps for CSHCN increased as families tried to navigate complicated Web sites to select options for coverage. In states with higher rates of uninsured children, studies suggest that when parents become eligible for Medicaid, their children who are eligible for a public plan but not enrolled are more likely to enroll and remain covered throughout the year.<sup>6,7</sup> Other studies also document that private employers in Massachusetts did not drop coverage forcing more adults and children to switch from private to public coverage.<sup>8</sup>

Massachusetts data on access to care for CSHCN in both public and private plans were also presented. Access to care is influenced by the

network's capacity as well as the health plan's covered benefits, medical necessity policies, and pharmacy formulary policies. In Massachusetts Medicaid, primary care access was not affected, whereas primary care access worsened in the other comparison states. In Massachusetts Medicaid postreform, fewer families with CSHCN felt that their need for specialists was being met (96.7% before to 91.0% after; difference, -5.7%). In Massachusetts private plans postreform, more families felt that their specialist need was being met (94.6% before to 98.9% after; difference, +4.3%). However, in other states, Medicaid erosion of access to specialty care was even greater. The implementation of reform in Massachusetts did not affect CSHCN families with respect to whether insurance benefits met their child's health care needs. In other states during the same time period, fewer CSHCN families felt their insurance benefits met their child's health care needs. The introduction of the Massachusetts Medicaid formulary did have a negative

effect, but it is unclear whether it compromised care or simply created administrative hassles.

Affordability is related to premium costs and out-of-pocket (OOP) expenses. With private coverage, OOP expenses went up in both Massachusetts and in other states, but there were no significant changes in Massachusetts families reporting unreasonable OOP expenses or financial problems. It is unlikely that many families switched from Medicaid to private exchange plans because both premiums and OOP expenses are likely to be much lower with public coverage than with private coverage, even with a subsidy. Postreform there was little impact on financial protection for Massachusetts families enrolled in public plans, although financial protection decreased slightly in other states. Overall, Massachusetts reform did not improve or diminish affordability and financial protections for families with CSHCN compared with other states.

This article provides child advocates with a guide for evaluating the impact of ACA health care reform in their states by focusing on CSHCN, the group who is most vulnerable to problems with access to primary and specialty care and affordability. The large adult Medicaid expansion will likely stress the provider delivery capacity, especially in areas where family physicians care for most children. Increases in premium costs and OOP expenses due to enrollment of an adverse risk population in exchange plans will disproportionately affect families with CSHCN. The use of the National Survey of Children With Special Health Care Needs should be supplemented with state surveys of CSHCN to identify regional problems that will not be apparent with the national survey. Tracking whether any shifts between public and private coverage occur would also be helpful. It will be especially important to monitor access to primary and specialty care as well as affordability and financial protection.

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