

# Massachusetts Health Reform and Access for Children With Special Health Care Needs



**WHAT'S KNOWN ON THIS SUBJECT:** Massachusetts implemented a major health reform in 2006 to reduce uninsurance, improve access to care, and increase financial protection for its citizens, but little is known about its effect on privately and publicly insured children with special health care needs.



**WHAT THIS STUDY ADDS:** Massachusetts health reform improved access to specialists for privately insured children with special health care needs but did not reduce uninsurance, increase access to primary care, or improve financial protection. National reform may produce similarly modest outcomes for these children.

## abstract



**BACKGROUND AND OBJECTIVES:** Children with special health care needs (CSHCN) face unique challenges in accessing affordable health care. Massachusetts implemented major health reform in 2006; little is known about the impact of this state's health reform on uninsurance, access to care, and financial protection for privately and publicly insured CSHCN.

**METHODS:** We used a difference-in-differences (DD) approach to compare uninsurance, access to primary and specialty care, and financial protection in Massachusetts versus other states and Washington, DC before and after Massachusetts health reform. Parent-reported data were used from the 2005–2006 and 2009–2010 National Survey of Children with Special Health Care Needs and adjusted for age, gender, race/ethnicity, non-English language at home, and functional difficulties.

**RESULTS:** Postreform, living in Massachusetts was not associated with significant decreases in uninsurance or increases in access to primary care for CSHCN. For privately insured CSHCN, Massachusetts was associated with increased access to specialists (DD = 6.0%;  $P \leq .001$ ) postreform. For publicly insured CSHCN, however, there was a significant decrease in access to prescription medications (DD = -7.2%;  $P = .003$ ) postreform. Living in Massachusetts postreform was not associated with significant changes in financial protection compared with privately or publicly insured CSHCN in other states.

**CONCLUSIONS:** Massachusetts health reform likely improved access to specialists for privately insured CSHCN but did not decrease instances of uninsurance, increase access to primary care, or improve financial protection for CSHCN in general. Comparable provisions within the Affordable Care Act may produce similarly modest outcomes for CSHCN. *Pediatrics* 2014;134:218–226

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### KEY WORDS

community pediatrics, legislation

### ABBREVIATIONS

ACA—Patient Protection and Affordable Care Act

CHIP—Children's Health Insurance Program

CSHCN—children with special health care needs

DD—difference-in-differences

FPL—Federal Poverty Level

MEPS—Medical Expenditure Panel Survey

NS-CSHCN—National Survey of Children with Special Health Care Needs

OOP—out-of-pocket

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Children with special health care needs (CSHCN) are a clinically heterogeneous group of children with chronic conditions (eg, asthma), rare conditions that respond well to intensive treatment (eg, cancer), and conditions that affect their life course (eg, cerebral palsy).<sup>1</sup> Although nationally representative surveys estimate that 97% of CSHCN are insured for at least part of the year, nearly 1 in 10 CSHCN (9%) has  $\geq 1$  instance without health insurance in a given year. Among insured CSHCN, 29% of families report that their insurance does not provide access to needed services or providers at a reasonable cost.<sup>2</sup> For CSHCN, such problems accessing affordable health care have been associated with lower quality of care and increased hospitalizations in certain chronic conditions.<sup>3–8</sup>

In 2006, Massachusetts passed major health reform legislation that aimed to reduce uninsurance and improve access to care and financial protection.<sup>9</sup> Although the Massachusetts health reform was not focused specifically on CSHCN, elements of the law could reduce uninsurance for these medically complex children. For example, the law required that adults purchase full-year health insurance and expanded public insurance eligibility to help low-income individuals meet this individual mandate. Medicaid eligibility increased from 133% to 300% of the Federal Poverty Level (FPL) and Children's Health Insurance Program (CHIP) eligibility from 200% to 300% of the FPL.<sup>10</sup> Studies suggest that when adults acquire insurance for themselves, they also enroll their children in insurance programs.<sup>11–13</sup> However, the Massachusetts health reform did not require parents to purchase insurance for their children, which could lessen the impact on reducing full or partial-year uninsurance for CSHCN. Because previous research on this state's reform has focused on adults, there is little

information on whether the adult insurance mandate could affect uninsurance in children.

To date, surveys report that 1 in 12 CSHCN (7%) has no usual source of care, and 1 in 7 (15%) has problems accessing needed specialty care.<sup>2</sup> Massachusetts health reform could have a positive, negative, or neutral effect on access by CSHCN to primary and specialty care. It could increase access to physicians for CSHCN because the reform legislation required all private insurers to provide essential health benefits and set limits on enrollee cost-sharing (eg, no copays for preventive care visits, no caps on prescription drug spending).<sup>14</sup> Conversely, Massachusetts health reform could decrease access to care if the influx of newly insured adults and children overwhelmed existing physician supply.<sup>15–17</sup> In the 2 years after initiation of reform, ~400 000 adults and 35 000 children gained insurance in Massachusetts.<sup>18–20</sup> Surveys of physicians in the state reported that, on average, patients had to wait 10 days longer postreform to see a primary care physician.<sup>21</sup> CSHCN who receive care from physicians who see both children and adults (eg, family practitioners) might be particularly likely to experience longer waits in care postreform.<sup>22</sup>

Nationally representative surveys report that 1 (20%) in 5 families experience financial problems due to the cost of care for their CSHCN, such as out-of-pocket (OOP) spending of  $> \$1000$  per year.<sup>2</sup> Massachusetts health reform could increase financial protection for privately insured CSHCN because it specifies maximum OOP spending for private insurance (eg, \$5000 for individuals, \$10 000 for families for in-network services).<sup>14</sup> The Medicaid-CHIP expansion may also improve financial protection because public insurance programs have low co-pays and

premiums. For adults, studies suggest that the Massachusetts health reform resulted in small improvements (2%–4%) in financial protection from 2006 to 2008.<sup>9,23</sup> To our knowledge, estimates for CSHCN have not been published.

The aim of the present study was to examine whether health reform in Massachusetts was associated with reduced instances of uninsurance, greater access to care, and improved financial protection for privately and publicly insured CSHCN. The 2010 federal Patient Protection and Affordable Care Act (ACA) was modeled after the 2006 Massachusetts health reform and included similar provisions: an individual mandate, optional state Medicaid expansion, essential health benefits, and limits on enrollee cost-sharing, including OOP spending. Thus, the experience of CSHCN under Massachusetts health reform is relevant to expectations for CSHCN under the ACA.

## METHODS

A difference-in-differences (DD) study design was used. Our intervention group comprised families of CSHCN in Massachusetts; our comparison group comprised families of CSHCN in other states and Washington, DC. We defined the prereform period as 2006 or before and the postreform period as 2007 or after. Because Massachusetts health reform was constructed to impact private and public insurance differently, we analyzed changes for privately and publicly insured CSHCN separately. This study was granted exemption by the Boston Children's Hospital and Harvard Medical School institutional review boards.

## Data Source

The National Survey of Children with Special Health Care Needs (NS-CSHCN)

was used to assess whether CSHCN: (1) were uninsured at any point during the year; (2) had their needs met when accessing health care; and (3) experienced inadequate financial protection. The NS-CSHCN is a random-digit dial survey of 40 000 families of CSHCN per survey year, designed to be representative at state and national levels. The NS-CSHCN response rate was 56% in 2005–2006 and 26% in 2009–2010; interview completion rates after the survey's screen-in phase were >80% in both years.<sup>24,25</sup> To adjust for low response rates in 2009–2010, we applied nonresponse-adjusted weighting developed by the Centers for Disease Control and Prevention.<sup>26</sup> Analysis of similar surveys has suggested that non-response effects can be adequately adjusted through survey reweighting.<sup>27,28</sup>

The Massachusetts health reform law was enacted in April 2006 and implemented over the ensuing 16 months. We therefore chose the 2005–2006 NS-CSHCN to represent the prereform period and the 2009–2010 survey to signify the postreform period.<sup>24,25</sup> Of note, although the federal CHIP Reauthorization Act passed in February 2009, Massachusetts made no changes to its Medicaid-CHIP program other than health reform during this period.<sup>29,30</sup> Thus, we expect the 2009–2010 NS-CSHCN in Massachusetts to reflect primarily that state's health reform.<sup>31</sup>

## Main Outcomes

Fifteen NS-CSHCN questions were used to assess parent-reported experiences of uninsurance, access to care, and financial protection (Table 1). Access to primary care was defined with 2 variables: whether CSHCN have a personal physician or nurse or a usual source of care. Access to specialists, prescription medications, and vision care was defined by using NS-CSHCN question pairs on each of these topics. The first question asked parents if such

services were “needed,” and the second ascertained whether parents thought their CSHCN received all services needed. Parents had to answer “yes” to both questions for needs to have been considered “met.” We did not study access to physical, occupational or speech therapy, mental health, or substance abuse services because their provision may have been affected by federal parity legislation during our study period.<sup>32</sup>

We used 4 financial protection variables from the NS-CSHCN: (1) OOP spending >\$1000; (2) OOP spending >\$5000; (3) unreasonable OOP spending; and (4) family financial problems related to the cost of CSHCN's health care. Because previous research suggests that average OOP spending for CSHCN is <\$1000, we chose OOP >\$1000 to represent above-average spending.<sup>32–34</sup> Affirmative responses to the remaining variables were used to represent inadequate financial protection.

For all variables (except access to prescription medications and vision care), we had 80% power to detect pre–post difference of  $\geq 3\%$  at a *P*value of .05.

## Covariates

For outcomes among insured CSHCN, we conducted separate analyses for CSHCN with private versus public insurance. CSHCN were classified as privately insured if they answered “yes” to the NS-CSHCN question about “having health insurance through an employer or union, military health care, or another health insurance or health care plan” and “no” to “having Medicaid or SCHIP.” CSHCN were classified as publicly insured if they had public insurance or both public and private insurance. We excluded cases missing insurance status, which was ~0.2% of cases in each survey.

The model was adjusted for age, gender, race/ethnicity (white, non-white), non-English language at home, and func-

tional difficulties.<sup>35–37</sup> Given that all children were CSHCN, we used 14 dichotomous NS-CSHCN items to create a scale of 0 to 7 for functional difficulties. Seven categories of difficulties were defined: vision, hearing, breathing, body (eg, metabolism), learning, feeling or behaving, or activity (eg, problems with self-care).<sup>38</sup> For missing data, we imputed average values for continuous variables and randomly chosen values for categorical variables.

## Analysis

Descriptive statistics of CSHCN in Massachusetts and other states were used to assess similarities in demographic characteristics and insurance status at baseline. For raw, unadjusted differences over time within the intervention and comparison arms, we subtracted rates of uninsurance, access to care, and financial protection in 2005–2006 from those in 2009–2010. For the DD approach, we subtracted pre–post differences in other states from pre–post differences in Massachusetts. This allowed us to assess differences in trends between the intervention group (Massachusetts) and comparison group (other states), control for baseline differences between treatment and control groups, account for secular trends, and isolate effects of health reform in Massachusetts.

To calculate the significance of trend and DD estimates, a multivariate logistic regression model was used to adjust for our covariates of interest. We considered an adjusted *P*value of .05 to be significant. Analyses were conducted by using Stata version 11 (Stata Corp, College Station, TX).

For sensitivity analysis, we compared Massachusetts versus 2 additional comparison groups: New England (CT, ME, NH, RI, and VT) and Pennsylvania. Other New England states are demographically similar to Massachusetts

**TABLE 1** National Survey of CSHCN Questions Corresponding to Uninsurance, Access, and Financial Protection

Domain/Variable	NS-CSHCN Question	Cutoff Values
<b>Uninsurance</b>		
One or more instance of uninsurance	(1) At this time, is [your child] covered by [any] health insurance? (2) During the past 12 mo, was there any time when [your child] was not covered by ANY health insurance?	Insured: Yes to (1) AND (2) Uninsured: No to (1) OR (2)
<b>Access to care</b>		
Insurance benefits met child's needs	Did the insurance offer benefits or cover services that meet [your child's] needs?	Needs met: Always/usually Needs not met: Never/sometimes
Insurance provides access to needed providers	Did the insurance allow [your child] to see the health care providers that he/she needed?	Needs met: Always/usually Needs not met: Never/sometimes
Has a personal physician or nurse	Do you have one or more persons you think of as [your child's] personal physician or nurse?	Personal physician/nurse: Yes, 1 person OR Yes, >1 person No personal physician/nurse: No
Has a usual source of care	(1) Is there a place that [your child] usually goes when [he/she] is sick or you need advice about [his/her] health? (2) Is there a place that [your child] usually goes when [he/she] needs routine preventive care, such as a physical examination or well-child check-up? (3) Is [the place] an emergency department?	Usual source: Yes to (1) and (2) AND No to (3) No usual source: No to (1) or (2) OR Yes to (3)
Needs for specialists met	(1) During the past 12 mo/since [his/her] birth, was there any time when [your child] needed care from a specialty physician? (2) Did [your child] receive all the care from a specialty physician that [he/she] needed?	Needs met: Yes to (1) AND Yes to (2) Needs not met: Yes to (1) AND No to (2)
Needs for prescription medications met	(1) During the past 12 mo/since [his/her] birth, was there any time when [your child] needed prescription medications? (2) Did [your child] receive all the prescription medications that [he/she] needed?	Needs met: Yes to (1) AND Yes to (2) Needs not met: Yes to (1) AND No to (2)
Needs for vision care met	(1) During the past 12 mo/since [his/her] birth, was there any time when [your child] needed eyeglasses or vision care? (2) Did [your child] receive all the eyeglasses or vision care that [he/she] needed?	Needs met: Yes to (1) AND Yes to (2) Needs not met: Yes to (1) AND No to (2)
<b>Financial protection</b>		
OOB spending >\$1000	During the past 12 mo/since [his/her] birth, would you say that the family paid >\$5000, \$1000 to \$5000, or <\$1000 for [your child's] medical care?	>\$1000: Yes to spending \$1000 to \$5000 OR >\$5000 <\$1000: Yes to spending <\$1000
OOB spending >\$5000	During the past 12 mo/since [his/her] birth, would you say that the family paid >\$5000, \$1000 to \$5000, or <\$1000 for [your child's] medical care?	>\$5000: Yes to spending >\$5000 <\$5000: Yes to spending \$1000 to \$5000 OR <\$1000
Unreasonable OOB spending	Are the costs not covered by [your child's] health insurance reasonable?	Unreasonable: Never/sometimes reasonable costs Reasonable: Always/usually reasonable costs OR no OOB spending
Family financial problems	Have [your child's] health conditions caused financial problems for your family?	Has financial problems: Yes No financial problems: No

and had stable Medicaid-CHIP income eligibility levels (>200% FPL) from 2005 to 2010.<sup>39</sup> Pennsylvania's Medicaid program had a benefit design similar to that of Massachusetts prereform and expanded income eligibility to the same level as Massachusetts during the study period.<sup>29,40</sup> This similarity provided comparisons for the impact of eligibility expansion (New England) and other components of Massachusetts health reform (PA). Public insurance status was also specified as CSHCN with

public insurance only versus CSHCN with public and private insurance.

## RESULTS

Prereform, CSHCN in Massachusetts and other states did not differ in terms of age, functional difficulties, gender, or proportion of non-English speakers. Massachusetts CSHCN were significantly more likely to be white, insured, and/or privately insured (Table 2). Postreform in Massachusetts, 67% of CSHCN were privately insured and 32%

publicly insured (*P* for trend = .71 and .74, respectively). Other states' proportion of privately and publicly insured CSHCN also remained stable (57% and 39%; *P* for trend = .51 and .83).

## Uninsurance

The proportion of CSHCN who had  $\geq 1$  instance of uninsurance during the year increased nonsignificantly in Massachusetts (5.2% to 5.6%; *P* for trend = .77) and significantly in other

**TABLE 2** Demographic Characteristics of CSHCN in Massachusetts and Other Areas: Before Massachusetts Health Reform, 2005

Characteristic	Massachusetts	Other States and Washington, DC	P Value
No. of children	788	39 846	
Age, mean $\pm$ SE, y	10.1 $\pm$ 0.2	9.9 $\pm$ 0.04	.43
No. of functional difficulties, mean $\pm$ SE	1.9 $\pm$ 0.07	1.8 $\pm$ 0.01	.13
% Female	39	41	.44
% White	81	70	<.001
% Non-English language at home	5	5	.61
Insurance Status and Type, %			
Uninsured	1	4	.002
Privately insured only	70	61	<.001
Publicly and privately insured	8	6	<.001
Publicly insured only	21	29	<.001

Student *t* and  $\chi^2$  tests were used to assess differences in continuous and categorical variables, respectively.

states (8.9% to 9.4%; *P* for trend = .01). The DD finding (ie, the pre–post difference in Massachusetts compared with the pre–post difference in other states) was 0.1% and nonsignificant (*P* for DD = .85) (Fig 1).

### Access to Care

For privately insured CSHCN (Table 3), access to specialists increased significantly postreform in Massachusetts (*P* for trend  $\leq$  .001) but decreased nonsignificantly in other states (*P* for trend = .25). In the DD model, Massachusetts was associated with a statistically significant increase in access to specialists (DD = 6.0%; *P* for DD  $\leq$  .001). For access to primary care, the postreform period was associated with no significant change in Massachusetts (*P* for trend = .27), a small, significant de-

crease in access to a usual source of care in other states (*P* for trend  $\leq$  .001), and nonsignificant adjusted DDs. The proportion of families reporting that their insurance benefits met the health care needs of their CSHCN showed no significant change in Massachusetts (*P* for trend = .98), a significant decline in other states (*P* for trend = .03), and a nonsignificant adjusted DD. There were no significant trends in access to prescription medications or vision care for privately insured CSHCN in Massachusetts or other states.

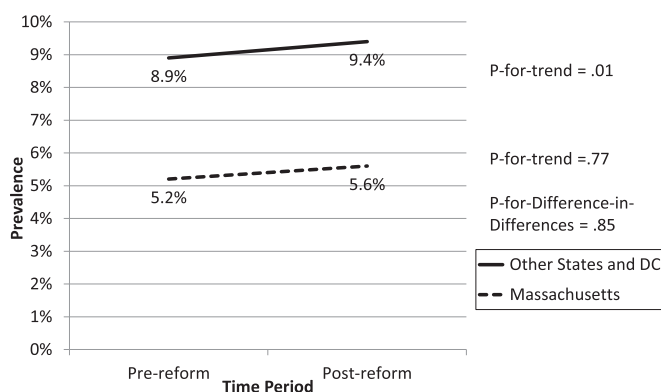
For publicly insured CSHCN in Massachusetts, access to prescription medications decreased significantly postreform (*P* for trend = .01) but remained stable in other states (*P* for trend = .18) (Table 3). Massachusetts was associated

with a statistically significant decrease in access to prescription medications in the DD model (DD =  $-7.2\%$ ; *P* for DD = .003). In Massachusetts, measures of access to primary care remained stable; in other states, the proportion of CSHCN having a usual source of care decreased (*P* for trend  $\leq$  .001). The DDs for measures of access to primary care were nonsignificant. There was no significant change in access to vision care in Massachusetts or other states postreform.

### Financial Protection

For privately insured families in Massachusetts, OOP spending increased postreform: the proportion of families spending greater than \$1000 OOP increased significantly (*P* for trend = .04) (Table 4). In other states, OOP spending also increased: the proportions of families spending  $>$ \$1000 and \$5000 OOP increased significantly (*P* for trend  $\leq$  .001 and 0.002, respectively). Because trends toward increased OOP spending were similar in Massachusetts and other states, the DDs were nonsignificant. For privately insured CSHCN in both Massachusetts and other states, there were no significant changes in families reporting unreasonable OOP spending or financial problems.

For publicly insured CSHCN in Massachusetts, there were no significant changes in financial protection postreform (Table 4). In other states, financial protection decreased: the proportion of families reporting unreasonable OOP spending increased significantly (*P* for trend = .02), as did the proportion reporting financial problems (*P* for trend  $\leq$  .001). The DDs were nonsignificant, suggesting that financial protection for publicly insured CSHCN was not significantly associated with Massachusetts health reform.



**FIGURE 1** CSHCN with  $\geq 1$  instance of uninsurance before and after Massachusetts health reform.



**TABLE 3** Access to Care for Insured CSHCN Before and After Massachusetts Health Reform

Variable	Massachusetts		Other States and Washington, DC		DD	
	Before % (95% CI)	After % (95% CI)	Before % (95% CI)	After % (95% CI)	%	P Value
<b>Privately insured</b>						
Insurance benefits met child's health care needs	91.2 (88.5, 93.9)	89.6 (86.7, 92.5)	89.0 (88.4, 89.7)	87.3 (86.5, 88.1)*	0.1	.74
Insurance provides access to needed providers	93.4 (91.1, 95.8)	91.9 (89.4, 94.4)	92.1 (91.5, 92.7)	90.8 (90.1, 91.6)	-0.2	.62
Has a personal physician or nurse	97.3 (95.7, 98.9)	97.7 (96.1, 99.3)	95.4 (95.0, 95.9)	95.2 (94.6, 95.7)	0.6	.64
Has a usual source of sick and preventive care	96.4 (94.7, 98.1)	94.9 (92.8, 96.9)	95.0 (94.5, 95.5)	92.2 (91.6, 92.8)**	0.9	.76
Need for specialists met	94.6 (91.4, 97.8)	98.9 (98.0, 99.9)*	96.5 (96.0, 97.1)	94.8 (94.1, 95.6)	6.0	<.001
Need for prescription medications met	99.0 (97.8, 100)	99.4 (98.7, 100)	99.0 (98.8, 99.3)	98.4 (98.0, 98.7)	1.0	.33
Need for vision care met	99.0 (97.0, 100)	97.4 (94.8, 100)	97.5 (96.9, 98.1)	96.2 (95.4, 97.0)	-0.3	.58
<b>Publicly insured</b>						
Insurance benefits met child's health care needs	87.5 (82.3, 92.7)	87.0 (80.8, 93.1)	84.2 (83.1, 85.4)	86.1 (85.0, 87.3)**	-2.4	.61
Insurance provides access to needed providers	93.1 (89.5, 96.8)	93.0 (89.2, 96.9)	88.1 (87.0, 89.2)	87.7 (86.6, 88.8)	0.3	.98
Has a personal physician or nurse	94.2 (90.0, 98.4)	94.8 (90.8, 98.8)	91.4 (90.5, 92.3)	91.4 (90.6, 92.3)	0.6	.79
Has a usual source of sick and preventive care	90.6 (85.3, 95.8)	86.5 (78.4, 94.7)	91.2 (90.4, 92.1)	87.2 (86.1, 88.2)**	-0.1	.97
Need for specialists met	96.7 (93.9, 99.5)	91.0 (84.8, 97.3)**	92.8 (91.7, 94.0)	86.9 (85.2, 88.5)**	0.2	.59
Need for prescription medications met	99.8 (99.3, 100)	91.6 (82.7, 100)*	97.5 (97.0, 98.0)	96.5 (95.9, 97.1)	-7.2	.003
Need for vision care met	94.2 (88.6, 99.8)	79.6 (59.8, 99.4)	94.2 (92.9, 95.4)	93.3 (92.2, 94.5)	-13.3	.15

Statistical significance of difference over time and DDs determined from multivariable models adjusted for child's age, gender, race, non-English language at home, and functional disabilities. \*Significant at  $P < .05$  level; \*\*Significant at  $P < .01$  level.

### Sensitivity Analysis

Our sensitivity analysis with 2 alternate comparison groups (New England, PA) confirmed our main findings (Supplemental Appendix Tables 1 and 2). In addition, compared with Pennsylvania, Massachusetts was associated with decreased access to vision care for publicly insured CSHCN postreform (DD = 20.1%;  $P$  for DD = .01). Findings were similar when we analyzed public insurance versus dual public and private insurance (Supplemental Appendix Table 3).

### DISCUSSION

This study found that although Massachusetts health reform did not reduce instances of uninsurance, it was associated with changes in access and financial protection for CSHCN. The reform's effects differed, depending on whether CSHCN were privately versus publicly insured. For privately insured CSHCN in Massachusetts, the postreform period was associated with increased access to specialists compared with other states. For publicly insured

CSHCN, however, the postreform period was associated with decreased access to prescription medications compared with other states. The postreform period in Massachusetts was associated with stable access to primary care for privately and publicly insured CSHCN, whereas CSHCN in other states experienced some decline in access to primary care. The postreform period was not associated with improvements in financial protection for CSHCN in Massachusetts or other states.

**TABLE 4** Financial Protection for Insured Children Before and After Massachusetts Health Reform

Variable	Massachusetts		Other States and Washington, DC		DD	
	Before % (95% CI)	Post % (95% CI)	Before % (95% CI)	After % (95% CI)	%	P Value
<b>Privately insured</b>						
OOP spending >\$1000	23.2 (19.0, 27.3)	32.8 (28.4, 37.2)*	26.7 (25.8, 27.6)	32.7 (31.7, 33.8)**	-3.6	.20
OOP spending >\$5000	2.9 (1.3, 4.5)	5.9 (3.8, 8.1)	3.5 (3.1, 3.9)	5.6 (5.1, 6.1)**	-0.9	.38
Unreasonable OOP spending	29.2 (24.7, 33.7)	31.4 (26.9, 35.8)	31.1 (30.1, 32.1)	33.5 (32.4, 34.6)	0.2	.99
Family financial problems	13.1 (9.7, 16.5)	15.6 (12.1, 19.1)	15.3 (14.6, 16.1)	19.5 (18.5, 20.4)	1.7	.93
<b>Publicly insured</b>						
OOP spending >\$1000	14.3 (8.6, 20.0)	12.3 (6.5, 18.0)	7.3 (6.5, 8.0)	8.0 (7.2, 8.7)	2.7	.50
OOP spending >\$5000	2.3 (0, 4.8)	4.8 (0.6, 9.0)	1.5 (1.2, 1.9)	1.6 (1.2, 2.0)	-2.4	.31
Unreasonable OOP spending	29.5 (21.7, 37.2)	24.2 (16.2, 32.3)	22.8 (21.5, 24.1)	22.8 (21.5, 24.1)*	5.3	.40
Family financial problems	20.3 (13.5, 27.0)	25.3 (17.6, 33.0)	20.7 (19.5, 21.9)	22.1 (20.8, 23.5)**	-3.6	.39

Statistical significance of difference over time and DDs determined from multivariable models adjusted for child's age, gender, race, non-English language at home, and functional disabilities. \*Significant at  $P < .05$  level; \*\*Significant at  $P < .01$  level.

Our study was potentially limited by low response rates in the 2009–2010 NS-CSHCN. However, in addition to our usage of recommended survey weights to account for random nonresponse effects, 5 other studies corroborate the trends we found. An examination of the Medical Expenditure Panel Survey (MEPS) also found a small, non-significant increase in the prevalence of children experiencing uninsurance nationwide from 2005 to 2008.<sup>41</sup> Three studies (1 MEPS, 2 using the National Health Interview Survey) found that access to primary care had not changed for privately or publicly insured children in Massachusetts or nationwide from 2000 to 2010.<sup>42–44</sup> One of these studies reported a significant increase in cost-related delays in care nationwide.<sup>44</sup> Within Massachusetts, a 2010 survey of privately insured families found that 40% reported higher-than-expected OOP spending postreform.<sup>45</sup> One MEPS study did find a decrease in OOP spending (\$100) for privately insured CSHCN from 2005 to 2009; a difference of this magnitude is not detectable with NS-CSHCN questions on OOP spending.<sup>33</sup>

Our study had limitations. We accounted for differences in Medicaid-CHIP income eligibility and benefit design with sensitivity analyses, but we cannot account for all differences between states. We had 80% power to detect pre–post differences of  $\geq 3\%$  at a *P* value of .05 in Massachusetts and other states; at times, smaller trends that were non-significant in Massachusetts were found to be so in other states, given the understandably smaller sample size in Massachusetts. Some variables had high rates of positive responses ( $>95\%$ ), making it challenging to improve (ie, “ceiling effects”), which increased the difficulty of detecting significant changes over time.

The lack of reduction in uninsurance for CSHCN may have stemmed from the lack

of a child-specific mandate within Massachusetts health reform.<sup>20</sup> It may also be attributable to the fact that this state had not yet implemented simplifications in Medicaid-CHIP enrollment or renewal, which have been shown to reduce instances of uninsurance for children from low-income families.<sup>46–48</sup> However, because Massachusetts had high Medicaid-CHIP eligibility levels and rates of insurance prereform, the remaining uninsured CSHCN might be hard-to-reach subjects or undocumented.<sup>49,50</sup> Because the ACA specifically includes children in the individual mandate and incentivizes states to simplify Medicaid-CHIP enrollment and renewal, reductions in uninsurance may be greater under the ACA than under Massachusetts health reform.<sup>51,52</sup>

For privately insured CSHCN, improved access to specialists postreform suggests the value of defining minimum essential health benefits for private insurance plans. Massachusetts health reform mandated that all private insurance plans must cover medical and surgical care, and it placed limits on enrollee cost-sharing (eg, no co-pays for preventive care visits).<sup>14</sup>

Our finding of decreased access to prescription medications for publicly insured CSHCN concurs with findings for adults: prescription medications remain a large unmet need postreform.<sup>53</sup> Contemporary with its 2006 health reform, Massachusetts also changed its Medicaid pharmacy program, including adding a formulary and prior authorization.<sup>54</sup> Such changes may have increased drug substitutions and/or wait times for medications.<sup>55</sup>

Our study found no association between Massachusetts health reform and decreased access to primary care for privately or publicly insured CSHCN, despite well-publicized concerns about primary care shortages.<sup>16,21</sup> This find-

ing may be because, although some CSHCN see family practitioners, the majority (78%) of CSHCN receive care from pediatricians and may be protected from delays observed in adult primary care.<sup>22</sup> Being insured is highly correlated with access to primary care, and therefore increases in access may be greater under the ACA than Massachusetts health reform, given the ACA's additional incentives to insure children.<sup>56–58</sup>

Massachusetts health reform did not have the intended effect of improving financial protection for CSHCN. Our findings of increased OOP spending postreform concur with longer term findings for adults: although gaining insurance initially increased financial protection, many families and individuals have faced higher-than-expected OOP spending postreform.<sup>23,45,59–62</sup> Because OOP spending increased in Massachusetts and other states for CSHCN, the increase may reflect a national trend toward decreased financial protection.

## CONCLUSIONS

Many of the key provisions in Massachusetts health reform are comparable to those in the ACA, such as the individual mandate, essential health benefits with limits on cost-sharing, and state Medicaid expansion. This study suggests that expectations around the ACA's effect on access to primary care and financial protection for families of CSHCN should be modest. Privately insured CSHCN may experience better access to specialists. Further child- or CSHCN-specific policy changes may be necessary to improve access to affordable health care for CSHCN.

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## REFERENCES

- Bethell CD, Read D, Blumberg SJ, Newacheck PW. What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. *Matern Child Health J*. 2008;12(1):1–14
- National Survey of Children's Health. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Available at: [www.childhealthdata.org/browse/survey](http://www.childhealthdata.org/browse/survey). Accessed July 28, 2013
- Liu CL, Zaslavsky AM, Ganz ML, Perrin J, Gortmaker S, McCormick MC. The financial implications of availability and quality of a usual source of care for children with special health care needs. *Matern Child Health J*. 2008;12(2):243–259
- Berman S, Rannie M, Moore L, Elias E, Dryer LJ, Jones MD Jr. Utilization and costs for children who have special health care needs and are enrolled in a hospital-based comprehensive primary care clinic. *Pediatrics*. 2005;115(6). Available at: [www.pediatrics.org/cgi/content/full/115/6/637](http://www.pediatrics.org/cgi/content/full/115/6/637)
- Romairre MA, Bell JF, Grossman DC. Medical home access and health care use and expenditures among children with special health care needs. *Arch Pediatr Adolesc Med*. 2012;166(4):323–330
- Estrada CL, Danielson KK, Drum ML, Lipton RB. Hospitalization subsequent to diagnosis in young patients with diabetes in Chicago, Illinois. *Pediatrics*. 2009;124(3):926–934
- Rewers A, Chase HP, Mackenzie T, et al. Predictors of acute complications in children with type 1 diabetes. *JAMA*. 2002;287(19):2511–2518
- Spivak W, Sockolow R, Rigas A. The relationship between insurance class and severity of presentation of inflammatory bowel disease in children. *Am J Gastroenterol*. 1995;90(6):982–987
- Long SK. On the road to universal coverage: impacts of reform in Massachusetts at one year. *Health Aff (Millwood)*. 2008;27(4):w270–w284
- McDonough JE, Rosman B, Butt M, Tucker L, Howe LK. Massachusetts health reform implementation: major progress and future challenges. *Health Aff (Millwood)*. 2008;27(4):w285–w297
- Gifford EJ, Weech-Maldonado R, Short PF. Low-income children's preventive services use: implications of parents' Medicaid status. *Health Care Financ Rev*. 2005;26(4):81–94
- Davidoff A, Dubay L, Kenney G, Yemane A. The effect of parents' insurance coverage on access to care for low-income children. *Inquiry*. 2003;40(3):254–268
- Dubay L, Kenney G. Expanding public health insurance to parents: effects on children's coverage under Medicaid. *Health Serv Res*. 2003;38(5):1283–1301
- Massachusetts Health Connector. Minimum creditable coverage requirements. Available at: <https://www.mahealthconnector.org/portal/binary/com.epicentric.contentmanagement.servlet.ContentDeliveryServlet/Health%2520Care%2520Reform/What%2520Insurance%2520Covers/MCC%2520Background/MCCRequirements.pdf>. Accessed July 19, 2013
- Mayer ML, Skinner AC, Slifkin RT; National Survey of Children With Special Health Care Needs. Unmet need for routine and specialty care: data from the National Survey of Children with Special Health Care Needs. *Pediatrics*. 2004;113(2). Available at: [www.pediatrics.org/cgi/content/full/113/2/e109](http://www.pediatrics.org/cgi/content/full/113/2/e109)
- Joynt KE, Chan D, Orav EJ, Jha AK. Insurance expansion in Massachusetts did not reduce access among previously insured Medicare patients. *Health Aff (Millwood)*. 2013;32(3):571–578
- Singh GK, Strickland BB, Ghandour RM, van Dyck PC. Geographic disparities in access to the medical home among US CSHCN. *Pediatrics*. 2009;124(suppl 4):S352–S360
- Weissman JS, Bigby J. Massachusetts health care reform—near-universal coverage at what cost? *N Engl J Med*. 2009;361(21):2012–2015
- Division of Health Care Finance and Policy. Health care in Massachusetts: key indicators. Available at: [www.mass.gov/chia/docs/r/pubs/10/key-indicators-november-2010.pdf](http://www.mass.gov/chia/docs/r/pubs/10/key-indicators-november-2010.pdf). Accessed November 8, 2013
- Kenney GM, Long SK, Luque A. Health reform in Massachusetts cut the uninsurance rate among children in half. *Health Aff (Millwood)*. 2010;29(6):1242–1247
- Massachusetts Medical Society. 2012 Massachusetts Medical Society Patient Access to Care Studies. Available at: [www.massmed.org/News-and-Publications/Research-and-Studies/2012-MMS-Patient-Access-to-Care-Studies/](http://www.massmed.org/News-and-Publications/Research-and-Studies/2012-MMS-Patient-Access-to-Care-Studies/). Accessed September 27, 2013
- Freed GL, Dunham KM, Gebremariam A, Wheeler JR. Which pediatricians are providing care to America's children? An update on the trends and changes during the past 26 years. *J Pediatr*. 2010;157(1):148–152.e1
- Long SK, Masi PB. Access and affordability: an update on health reform in Massachusetts, fall 2008. *Health Aff (Millwood)*. 2009;28(4):w578–w587
- Blumberg SJ, Welch EM, Chowdhury SR, Upchurch HL, Parker EK, Skalland BB. Design and operation of the National Survey of Children with Special Health Care Needs, 2005–2006. *Vital Health Stat 1*. 2008;(45):1–188
- Centers for Disease Control and Prevention. 2011–2012 National Survey of Children's Health frequently asked questions. Available at: [ftp://ftp.cdc.gov/pub/Health\\_Statistics/NCHS/slats/nsch\\_2011\\_2012/01\\_Frequently\\_asked\\_questions/NSCH\\_2011\\_2012\\_FAQs.pdf](ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/slats/nsch_2011_2012/01_Frequently_asked_questions/NSCH_2011_2012_FAQs.pdf). Accessed February 8, 2013
- Child and Adolescent Health Measurement Initiative. 2005 and 2010 National Surveys of Children with Special Health Care Needs. Enhanced Data File. Data Resource Center for Child and Adolescent Health. Available at: <http://childhealthdata.org/>. Accessed February 6, 2013
- Skalland B, Montgomery R. An analysis of nonresponse bias resulting from non-resolution of telephone numbers, eligibility screener nonresponse, and interview nonresponse for the National Immunization Survey. In: *American Statistical Association Section on Survey Research Methods*. Anaheim, CA: American Statistical Association; 2007
- Skalland BJ, Blumberg SJ. Nonresponse in the National Survey of Children's Health, 2007. *Vital Health Stat 2*. 2012;(156):1–22
- Ross DC, Cox L. *Findings of a 50 State Survey of Eligibility Rules, Enrollment and Renewal Procedures, and Cost-Sharing Practices in Medicaid and CHIP for Children and Parents During 2009*. Washington, DC; The Henry J. Kaiser Family Foundation, 2009
- Heberlein M, Brooks T, Guyer J, Artiga S, Stephens J. *Findings of a 50 State Survey of Eligibility Rules, Enrollment and Renewal Procedures, and Cost-Sharing Practices in Medicaid and CHIP, 2010–2011*. Washington, DC; The Henry J. Kaiser Family Foundation, 2011
- Kaiser Family Foundation. Children's Health Insurance Reauthorization Act of 2009 (CHIPRA). Available at: <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/7863.pdf>. Accessed July 28, 2013
- Barry CL, Chien AT, Normand SL, et al. Parity and out-of-pocket spending for children with high mental health or substance abuse expenditures. *Pediatrics*. 2013;131(3). Available at: [www.pediatrics.org/cgi/content/full/131/3/e903](http://www.pediatrics.org/cgi/content/full/131/3/e903)
- Karaca-Mandic P, Yoo SJ, Sommers BD. Recession led to a decline in out-of-pocket



- spending for children with special health care needs. *Health Aff (Millwood)*. 2013;32(6):1054–1062
34. Karaca-Mandic P, Choi-Yoo SJ, Lee J, Scal P. Family out-of-pocket health care burden and children's unmet needs or delayed health care. *Acad Pediatr*. 2014;14(1):101–108
  35. Yu SM, Singh GK. Household language use and health care access, unmet need, and family impact among CSHCN. *Pediatrics*. 2009;124(suppl 4):S414–S419
  36. Chen AY, Newacheck PW. Insurance coverage and financial burden for families of children with special health care needs. *Ambul Pediatr*. 2006;6(4):204–209
  37. Newacheck PW, Hung YY, Wright KK. Racial and ethnic disparities in access to care for children with special health care needs. *Ambul Pediatr*. 2002;2(4):247–254
  38. Institute of Medicine Committee on Disability in America. Field M, Jette A, eds. *The Future of Disability in America*. Washington, DC: National Academies Press; 2007
  39. Sonier J, Boudreaux MH, Blewett LA. Medicaid 'welcome-mat' effect of Affordable Care Act implementation could be substantial. *Health Aff (Millwood)*. 2013;32(7):1319–1325
  40. Boston University School of Public Health and Disability Working Group. *Medicaid Buy-In Programs: Reducing Under-Insurance for Children and Youth with Special Health Care Needs*. Boston, MA: Catalyst Center on Improving Financing of Care for Children and Youth with Special Health Care Needs, 2006
  41. Devoe JE, Tillotson CJ, Angier H, Wallace LS. *Recent health insurance trends for US families: children gain while parents lose*. *Matern Child Health J*. 2014;18:1007–1016
  42. Miller S. The impact of the Massachusetts Health Care Reform on Health Care Use Among Children. *Am Econ Rev*. 2012;102(3):502–507
  43. Berdahl TA, Friedman BS, McCormick MC, Simpson L. Annual report on health care for children and youth in the United States: trends in racial/ethnic, income, and insurance disparities over time, 2002–2009. *Acad Pediatr*. 2013;13(3):191–203
  44. Kenney GM, McMorrow S, Zuckerman S, Goin DE. A decade of health care access declines for adults holds implications for changes in the Affordable Care Act. *Health Aff (Millwood)*. 2012;31(5):899–908
  45. Galbraith AA, Sinaiko AD, Soumerai SB, Ross-Degnan D, Dutta-Linn MM, Lieu TA. Some families who purchased health coverage through the Massachusetts Connector wound up with high financial burdens. *Health Aff (Millwood)*. 2013;32(5):974–983
  46. Fairbrother GL, Emerson HP, Partridge L. How stable is Medicaid coverage for children? *Health Aff (Millwood)*. 2007;26(2):520–528
  47. Bansak C, Raphael S. The effects of state policy design features on take-up and crowd-out rates for the State Children's Health Insurance Program. *J Policy Anal Manage*. 2007;26(1):149–175
  48. Bindman AB, Chattopadhyay A, Auerback GM. Medicaid re-enrollment policies and children's risk of hospitalizations for ambulatory care sensitive conditions. *Med Care*. 2008;46(10):1049–1054
  49. DeVoe JE, Ray M, Graham A. Public health insurance in Oregon: underenrollment of eligible children and parental confusion about children's enrollment status. *Am J Public Health*. 2011;101(5):891–898
  50. Flores G, Abreu M, Tomany-Korman SC. Why are Latinos the most uninsured racial/ethnic group of US children? A community-based study of risk factors for and consequences of being an uninsured Latino child. *Pediatrics*. 2006;118(3). Available at: [www.pediatrics.org/cgi/content/full/118/3/e730](http://www.pediatrics.org/cgi/content/full/118/3/e730)
  51. Kenney GM, Buettgens M, Guyer J, Heberlein M. Improving coverage for children under health reform will require maintaining current eligibility standards for Medicaid and CHIP. *Health Aff (Millwood)*. 2011;30(12):2371–2381
  52. McDonough JE. *Inside National Health Reform*. Berkeley, CA: University of California Press; 2011
  53. Raymond A. Massachusetts Health Reform: A Five Year Progress Report. Boston, MA: Blue Cross Blue Shield Foundation; 2011
  54. Thomas CP, Protts J, Fischer M. The MassHealth Pharmacy Program. Available at: [www.communitycatalyst.org/doc\\_store/publications/MassHealth\\_Implementation\\_Rx\\_Report\\_11-09.pdf](http://www.communitycatalyst.org/doc_store/publications/MassHealth_Implementation_Rx_Report_11-09.pdf). Accessed January 8, 2013
  55. West JC, Wilk JE, Rae DS, et al. Medicaid prescription drug policies and medication access and continuity: findings from ten states. *Psychiatr Serv*. 2009;60(5):601–610
  56. Newacheck PW, Stoddard JJ, Hughes DC, Pearl M. Health insurance and access to primary care for children. *N Engl J Med*. 1998;338(8):513–519
  57. Allred NJ, Wooten KG, Kong Y. The association of health insurance and continuous primary care in the medical home on vaccination coverage for 19- to 35-month-old children. *Pediatrics*. 2007;119(suppl 1):S4–S11
  58. Stevens GD, Seid M, Halfon N. Enrolling vulnerable, uninsured but eligible children in public health insurance: association with health status and primary care access. *Pediatrics*. 2006;117(4). Available at: [www.pediatrics.org/cgi/content/full/117/4/e751](http://www.pediatrics.org/cgi/content/full/117/4/e751)
  59. Zhu J, Brawarsky P, Lipsitz S, Huskamp H, Haas JS. Massachusetts health reform and disparities in coverage, access and health status. *J Gen Intern Med*. 2010;25(12):1356–1362
  60. Pande AH, Ross-Degnan D, Zaslavsky AM, Salomon JA. Effects of healthcare reforms on coverage, access, and disparities: quasi-experimental analysis of evidence from Massachusetts. *Am J Prev Med*. 2011;41(1):1–8
  61. Gettens J, Mitra M, Henry AD, Himmelstein J. Have working-age people with disabilities shared in the gains of Massachusetts health reform? *Inquiry*. 2011;48(3):183–196
  62. Long SK, Stockley K. Sustaining health reform in a recession: an update on Massachusetts as of fall 2009. *Health Aff (Millwood)*. 2010;29(6):1234–1241

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