

Financial Burden for Families of Children with Special Health Care Needs in Massachusetts:

**State Analysis of the National Survey of Children
with Special Health Care Needs**

Detailed Tables

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Policy in collaboration with The Massachusetts Consortium for Children with Special
Health Care Needs Family Participation Workgroup. Supported by a grant from the
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Introduction

The [Center for Child and Adolescent Health Policy](#) collaborated with members of the Family Participation Workgroup of the [Massachusetts Consortium for Children with Special Health Care Needs](#) to determine what information from a national survey would be most relevant to families of children with chronic conditions. Funded through a grant from the Deborah Munroe Noonan Memorial Fund, this project sought to better understand the needs of families with children with special health care needs (CSHCN) in Massachusetts.

Families experience a variety of consequences of caring for a child with a chronic condition including increased health care costs, lost employment, and increased stress. The current economic situation in Massachusetts may further exacerbate the financial strain, and subsequently stress, on families with CSHCN.

This study examines the financial impact on Massachusetts' families with CSHCN. Massachusetts' data from the [National Survey of Children with Special Health Care Needs](#) was analyzed. Children with special health care needs were identified using the [CSHCN Screener](#), a 5-item parent survey-based tool that identifies children based on consequences of their condition, as opposed to their specific diagnosis. This telephone survey includes 744 CSHCN in Massachusetts. Financial burden on families was further examined as it relates to the U.S. Maternal and Child Health Bureau's (MCHB) key indicators of progress towards [Healthy People 2010](#) national goal for service systems for CSHCN.

MCHB has set a national agenda for CSHCN that has been the foundation of state Title V CSHCN programs. The agenda calls for the development of systems of care for CSHCN that are family-centered, community-based, coordinated and culturally competent. A national goal (Healthy People 2010) was set to increase the proportion of states that have these service systems in place for CSHCN and their families. Six core outcomes have been identified to measure states' progress towards this goal. This study examined financial burden among families in MA and how it relates to 3 of these 6 outcomes: #2) CSHCN will receive coordinated ongoing comprehensive care within a medical home; #3) Families of CSHCN will have adequate private and/or public insurance to pay for the services they need; #5) Community-based service systems will be organized so families can use them easily. For more information on these outcomes visit <http://www.mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm>.

For more information on this project visit <http://www.massgeneral.org/children/ccahp> or contact Kristen Hill (kshill@partners.org) or Karen Kuhlthau (kkuhlthau@partners.org) at the MGH Center for Child and Adolescent Health Policy or Linda Freeman (lfreeman@neserve.org) or Stephanie Calves (scalves@neserve.org) at the Massachusetts Consortium for CSHCN.

Table 1: Children with Special Health Care Needs Sample Characteristics: Massachusetts, New England and United States.

	MA	NE	US
Age %			
0-5	17.2	18.0	19.4
6-12	47.6	47.0	47.3
13-17	35.2	35.0	33.4
Sex – percent male	62.0	60.5	59.8
Race – percent non-White	15.5	14.2	24.9
Ethnicity – percent Hispanic	9.3	8.2	11.5
Respondent’s relationship to child %			
Mother	79.7	80.9	79.8
Other relative or friend	20.3	19.1	20.8
Maternal education %			
Less than high school degree	13.8	11.4	15.0
High school degree	26.8	28.4	30.2
Some post high school	29.7	30.7	31.3
4-year college degree or more	29.8	29.5	23.5
Family poverty level %			
Below 100% FPL	16.6	13.3	15.0
100%-199% FPL	15.0	17.2	22.0
200%-299% FPL	15.1	16.4	18.2
300%-399% FPL	16.9	18.6	16.5
400%+ FPL	36.5	34.6	28.3
Insurance status %			
Uninsured at time of survey	2.1	2.8	5.2
Public	24.2	22.8	22.4
Both public and private	12.7	11.2	10.0
Private	61.0	63.3	62.4
Time child affected by condition %			
Never	41.0	40.9	39.4
Sometimes	39.1	39.0	39.2
Usually or always	19.9	20.1	21.4
Mean severity rank of child’s condition (0-10)	4.2	4.1	4.2
Mean school days missed due to condition, past year	4.5	4.5	4.5
Child does not receive care in medical home %	39.0	41.4	47.4
Child does not have adequate health insurance %	34.9	35.5	40.4
Community-based services are not organized %	21.0	22.1	25.7

Data from the State and Local Area Integrated Telephone Survey National Survey of Children with Special Health Care Needs, 2001. Centers for Disease Control and Prevention, National Center for Health Statistics. Results are weighted and adjusted for complex survey design. CSHCN=Children with special health care needs; MA=Massachusetts; NE=New England; US=United States; FPL=Federal Poverty Level.

Table 2: Financial Burden for Families with Children with Special Health Care Needs: Massachusetts, New England and United States.

	MA %	NE %	US %
Child's health care caused financial problems	15.3	16.8	20.9
Needed additional income for child's medical expenses	16.0	14.5	18.0
Family members cut work to care for child	28.1	27.3	27.7
Family member quit working due to child's health	11.4	11.4	13.2
Any finance-related family problem	38.1	37.1	40.4

Data from the State and Local Area Integrated Telephone Survey National Survey of Children with Special Health Care Needs, 2001. Centers for Disease Control and Prevention, National Center for Health Statistics. Percentages are weighted and adjusted for complex survey design.

CSHCN=Children with special health care needs; MA=Massachusetts; NE=New England; US=United States; Any Finance-Related Family Problem is defined as answering 'yes' to any of the following questions: 'Child's Health Care Has Caused Financial Problems'; 'Family Members Have Cut Work Hours to Care for Child'; 'Needed Additional Income for Child's Medical Expenses'; 'Family Member Stopped Working Due to Child's Health.'

Table 3: Financial Burden for Families with Children with Special Health Care Needs, Bivariate Analysis[†]: Massachusetts, New England and United States.

	Percent (%) with Any Finance-Related Family Problem		
	MA	NE	US
Age			
0-5	40.8	44.4†	47.6†
6-12	38.4	37.5	39.5
13-17	36.7	33.1	37.5
Sex			
Male	38.6	38.7	40.7
Female	37.5	34.9	39.9
Race			
White	37.8	36.5	38.5†
Other	38.4	39.1	45.9
Ethnicity			
Hispanic	43.2	42.2	51.5†
Non-Hispanic	37.4	36.5	38.9
Respondent's relationship to child			
Mother	39.3	38.2	41.4†
Other relative or friend	33.1	32.4	36.3
Maternal education			
Less than high school degree	40.0*	41.2†	49.2†
High school degree	40.1	37.6	40.6
Some post high school	46.7	42.7	41.1
4-year college degree or more	29.2	30.4	34.3
Family poverty level			
Below 100% FPL	43.3†	45.9†	55.0†
100%-199% FPL	47.0	46.3	51.3
200%-299% FPL	52.6	47.4	42.4
300%-399% FPL	41.1	36.8	34.8
400%+ FPL	27.0	25.6	28.0
Insurance status			
Uninsured at time of survey	54.4†	47.5†	63.5†
Public	44.7	46.0	50.0
Both public and private	57.0	52.0	50.8
Private	31.1	30.9	33.3
Time child affected by condition			
Never	22.2†	20.5†	21.7†
Sometimes	37.0	38.4	44.1
Usually or always	72.6	68.3	67.8

continued

Table 3: Financial Burden for Families with Children with Special Health Care Needs, Bivariate Analysis[‡]: Massachusetts, New England and United States (*continued*).

	Percent (%) with Any Finance-Related Family Problem		
	MA	NE	US
Condition severity rank (10 most severe)			
0	15.6†	14.8†	18.1†
1	13.1	13.5	19.9
2	24.3	21.6	24.6
3	35.2	33.1	33.5
4	26.3	31.5	38.1
5	39.0	39.0	44.6
6	64.1	55.3	55.0
7	54.1	59.2	59.6
8	63.5	64.0	64.6
9-10	69.9	70.4	67.6
Child receives care in medical home			
Yes	26.7†	25.8†	30.2†
No	52.3	51.1	50.9
Child has adequate health insurance			
Yes	28.7†	27.5†	29.3†
No	57.4	55.3	56.7
Community-based services organized			
Yes	29.2†	28.7†	32.9†
No	66.5	62.4	58.2

Data from the State and Local Area Integrated Telephone Survey National Survey of Children with Special Health Care Needs, 2001. Centers for Disease Control and Prevention, National Center for Health Statistics. Percentages are weighted and adjusted for complex survey design.

[‡] Bivariate analysis does not control for child's age, race or other characteristics. Differences between groups (e.g. between males and females) are significant at *p < .05 and †p < .01 using Chi-square test.

CSHCN=Children with special health care needs; MA=Massachusetts; NE=New England; US=United States; FPL=Federal Poverty Level.

Any Finance-Related Family Problem is defined as answering 'yes' to any of the following questions: 'Child's Health Care Has Caused Financial Problems'; 'Family Members Have Cut Work Hours to Care for Child'; 'Needed Additional Income for Child's Medical Expenses'; 'Family Member Stopped Working Due to Child's Health.'

Table 4: Financial Burden for Families with Children with Special Health Care Needs, Multivariate Analysis[‡]: Massachusetts, New England and United States.

	Any Finance-Related Family Problem					
	MA		NE		US	
	OR	95% CI	OR	95% CI	OR	95% CI
Age	0.95	(0.91-1.00)	0.94	(0.92-0.97)	0.95	(0.94-0.96)
Sex - male	0.88	(0.60-1.31)	1.06	(0.82-1.37)	1.00	(0.92-1.10)
Race – non-White	0.79	(0.44-1.43)	0.83	(0.56-1.22)	0.95	(0.85-1.06)
Hispanic	0.64	(0.32-1.30)	0.66	(0.39-1.12)	1.25	(1.07-1.46)
Respondent's relationship to child						
Other relative or friend (v. Mother)	0.83	(0.52-1.32)	0.92	(0.62-1.36)	0.87	(0.77-0.98)
Maternal education	1.09	(0.86-1.38)	1.14	(0.99-1.32)	1.06	(1.00-1.13)
Family poverty level	1.08	(0.87-1.33)	0.91	(0.79-1.05)	0.91	(0.87-0.94)
Insurance status (v. Private)						
Uninsured at time of survey	1.45	(0.37-5.73)	0.92	(0.48-1.76)	1.40	(1.13-1.73)
Public	1.65	(0.93-2.92)	1.14	(0.72-1.81)	0.96	(0.84-1.09)
Both public and private	2.33	(1.27-4.25)	1.56	(0.94-2.57)	1.21	(1.05-1.40)
Time child affected by condition (v. Never)						
Sometimes	1.35	(0.87-2.08)	1.43	(1.07-1.92)	1.99	(1.80-2.19)
Usually or always	3.36	(1.88-6.03)	2.86	(1.97-4.14)	3.48	(3.05-3.97)
Condition severity rank (scale 0-10)	1.22	(1.12-1.33)	1.20	(1.14-1.28)	1.15	(1.13-1.17)
Missed school days, past year	1.08	(1.03-1.15)	1.08	(1.05-1.12)	1.07	(1.03-1.11)
Child receives care in medical home	0.57	(0.37-0.87)	0.54	(0.42-0.70)	0.61	(0.56-0.67)
Child has adequate health insurance	0.36	(0.24-0.54)	0.41	(0.31-0.54)	0.42	(0.39-0.46)
Community-based services organized	0.44	(0.20-0.97)	0.54	(0.35-0.81)	0.87	(0.77-0.99)

Data from the State and Local Area Integrated Telephone Survey National Survey of Children with Special Health Care Needs, 2001. Centers for Disease Control and Prevention, National Center for Health Statistics. Odds ratios are weighted and adjusted for complex survey design and item nonresponse using multiple imputation.

Multivariate analysis controls for child's age, race, ethnicity and other characteristics listed in table. Bold figures are statistically significant at p<.05.

CSHCN=Children with special health care needs; MA=Massachusetts; NE=New England; US=United States.

Any Finance-Related Family Problem is defined as answering 'yes' to any of the following questions: 'Child's Health Care Has Caused Financial Problems'; 'Family Members Have Cut Work Hours to Care for Child'; 'Needed Additional Income for Child's Medical Expenses'; 'Family Member Stopped Working Due to Child's Health.'