

Unmet Need Among Children with Special Health Care Needs in Massachusetts:

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

Detailed Tables

**Massachusetts General Hospital for Children Center for Child and Adolescent Health
Policy in collaboration with The Massachusetts Consortium for Children with Special
Health Care Needs Family Participation Workgroup. Supported by a grant from the
Deborah Munroe Noonan Memorial Fund**

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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.

CSHCN require a range of services, such as an increase in health and mental health services, a need for professional care coordination, and guidance with transition into adulthood. National studies have shown that CSHCN have higher rates of unmet need for medical services compared to children in the general population. Access to needed health care is vital to these children, as well as all children, for optimal growth and development.

This study examines unmet need among CSHCN in Massachusetts. 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. Unmet need 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. Additionally, the study reports on unmet need among CSHCN with a more severe condition.

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 4 of these 6 outcomes: #1) Families of CSHCN will partner in decision-making and will be satisfied with the services they receive; #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 (%)
<i>Predisposing Factors</i>			
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
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
<i>Enabling Factors</i>			
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			
Ever uninsured past year	6.9	8.3	11.6
Public	21.9	20.4	19.2
Both public and private	11.6	10.4	9.3
Private	59.6	60.9	59.8
Family does not partner in decision making	35.6	37.9	42.5
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
<i>Need</i>			
Amount of 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
Stability of child's health care needs			
Needs change all the time	5.0	5.5	6.7
Need change once in awhile	29.6	29.7	29.9
Needs usually stable	65.3	64.9	63.5
Severity of condition-more severe	14.7	14.2	14.4

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; FPL=Federal Poverty Level. Severity of Condition=More severe selected if positive for 2+ CSHCN Screener items AND either of the following: Condition affects ability 'a great deal'; Parent Rank of severity 8+ (on scale of 0-10).

Unmet Need Among CSHCN in Massachusetts. MGH Center for Child and Adolescent Health Policy in collaboration with The MA Consortium for CSHCN Family Participation Workgroup. March, 2006

Table 2: Types and Frequency of Needs Reported by Children with Special Health Care Needs: Massachusetts, New England and United States.

	MA %	NE %	US %
Need health care or family support services	98.0	98.8	98.7
Need health care services	97.5	98.5	98.6
Need family support services	29.1	28.2	27.4
Health care services			
Routine preventive care	87.3	84.7	74.4
Specialty care	55.5	54.8	51.0
Dental care	85.5	84.8	78.2
Prescriptions	87.5	88.3	87.9
Special therapy (physical, occupational, speech)	26.6	26.7	23.5
Mental health care/counseling	33.3	29.8	25.4
Substance abuse treatment (age 8+)	2.6	2.2	2.8
Home health care	4.3	4.5	5.4
Eyeglasses and vision care	33.4	33.8	35.6
Hearing aids and hearing care	5.2	6.0	6.5
Mobility aids or devices (age 3+)	4.9	4.6	4.7
Communication aids or devices (age 3+)	2.5	2.6	2.1
Medical supplies (disposable items, e.g. bandages)	21.3	23.3	24.9
Medical equipment (non-disposable items, e.g. hospital bed)	10.6	10.3	10.6
Family support services			
Respite care	6.5	7.5	8.8
Genetic counseling	5.7	6.0	6.9
Mental health care/counseling for family member(s)	16.7	15.8	13.2
Professional care coordination	11.0	12.3	11.8

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

Table 3: Prevalence of Unmet Need Among Children with Special Health Care Needs: Massachusetts, New England and United States.

	Percent (%) with Any Unmet Need		
	MA	NE	US
Health care or family support service need	16.9	16.5	20.9
Health care need	13.2	13.5	18.4
Family service support service need	21.2	20.1	22.9
Two or more needs	5.9	5.9	8.4

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 of those reporting a need and are weighted and adjusted for complex survey design. CSHCN=Children with special health care needs; MA=Massachusetts; NE=New England; US=United States

Table 4: Prevalence of Unmet Need Among Children with Special Health Care Needs and Children with more severe condition: Massachusetts and United States.

	Percent (%) with Any Unmet Need			
	Massachusetts		United States	
	All CSHCN	CSHCN with more severe condition	All CSHCN	CSHCN with more severe condition
Health care or family support service need	16.9	37.3	20.9	40.8
Health care need	13.2	28.7	18.4	34.5
Family service support service need	21.2	37.1	22.9	34.0
Two or more needs	5.9	17.3	8.4	21.3

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 of those reporting a need and are weighted and adjusted for complex survey design. CSHCN=Children with special health care needs. Children with a more severe selected if positive for 2+ CSHCN Screener items AND either of the following: Condition affects ability 'a great deal'; Parent Rank of severity 8+ (on scale of 0-10).

Table 5: Unmet Need Among CSHCN, Bivariate Analysis[‡]: Massachusetts, New England and United States.

	Percent (%) with Any Unmet Need		
	MA (%)	NE (%)	US (%)
<i>Predisposing Factors</i>			
Age			
0-5	18.9	16.9	19.4
6-12	13.2	15.0	20.6
13-17	20.4	18.1	22.2
Sex			
Male	18.7	18.1*	20.4
Female	14.0	13.9	21.6
Race			
White only	16.2	16.0	18.6†
Other	20.2	18.0	27.8
Ethnicity			
Hispanic	30.4	23.3	27.5†
Non-Hispanic	15.4	15.7	20.0
Maternal Education			
Less than high school degree	26.4†	25.4†	30.3†
High school degree	15.2	15.7	20.8
Some post high school	22.4	19.8	21.1
4-Year college degree or more	7.9	10.3	15.3
<i>Enabling Factors</i>			
Family Poverty Level			
Below 100% FPL	26.8†	28.7†	36.8†
100%-199% FPL	38.2	27.2	30.5
200%-299% FPL	16.4	18.7	19.7
300%-399% FPL	8.8	11.1	16.4
400%+ FPL	10.0	9.9	10.6
Insurance Status			
Ever uninsured past year	48.9†	38.8†	47.7†
Public	20.0	21.2	27.0
Both public and private	29.5	25.8	23.5
Private	10.4	10.6	13.4
Family partners in decision making			
Yes	7.4*	8.6†	11.2†
No	22.8	24.6	32.4
Child receives care in medical home			
Yes	8.7†	9.1†	12.2†
No	28.3	25.9	29.6

continued

Table 5: Unmet Need Among CSHCN, Bivariate Analysis[‡]: Massachusetts, New England and United States. (continued).

	Percent (%) with Any Unmet Need		
	MA (%)	NE (%)	US (%)
Child has adequate health insurance			
Yes	11.0†	10.7†	11.6†
No	27.5	27.0	33.8
Community-based services organized			
Yes	10.7	11.6†	13.6†
No	24.9	27.9	39.1
Need			
Amount of time child affected by condition			
Never	8.2†	7.4†	9.5†
Sometimes	13.5	15.1	22.2
Usually or always	40.7	37.6	39.0
How severely condition affected child's ability			
Not at all	8.3†	7.3†	9.5†
Some or very little	18.0	18.2	24.0
A great deal	46.6	45.6	46.1
Stability of child's health care needs			
Needs change all the time	41.6	41.5†	43.1†
Need change once in awhile	17.5	19.7	26.1
Needs usually stable	14.1	12.6	16.0
Severity of condition			
Less severe	13.4†	12.8†	17.5†
More severe	37.3	39.2	40.8

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 of those reporting a need and 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 male 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.

Severity of Condition=More severe selected if positive for 2+ CSHCN Screener items AND either of the following: Condition affects ability 'a great deal'; Parent Rank of severity 8+ (on scale of 0-10).

Table 6: Any Unmet Health Care or Family Support Services Need Among CSHCN, Multivariate Analysis[‡]: Massachusetts, New England and United States.

	Any Unmet Need					
	Odds Ratio (95% Confidence Interval)					
	MA		NE		US	
	OR	95% CI	OR	95% CI	OR	95% CI
Predisposing Factors						
Age	1.07	(1.00-1.15)	1.02	(0.98-1.07)	1.02	(1.00-1.05)
Sex - male	1.06	(0.58-1.95)	1.10	(0.76-1.59)	0.90	(0.81-0.99)
Race – non-White	0.79	(0.27-2.28)	0.84	(0.48-1.46)	1.10	(0.98-1.24)
Hispanic	1.44	(0.44-4.69)	0.94	(0.48-1.84)	0.95	(0.79-1.13)
Maternal education	0.95	(0.69-1.31)	1.05	(0.83-1.32)	1.01	(0.96-1.08)
Enabling Factors						
Family poverty level	0.75	(0.57-1.00)	0.79	(0.67-0.93)	0.87	(0.83-0.90)
Type of insurance (v. Private)						
Ever uninsured past year	4.95	(1.69-14.51)	2.80	(1.45-5.38)	2.23	(1.87-2.66)
Public	0.71	(0.29-1.78)	1.00	(0.61-1.64)	1.25	(1.07-1.47)
Both public and private	2.06	(0.81-5.26)	1.63	(0.89-3.02)	1.18	(1.01-1.38)
Family partners in decision making	0.62	(0.23-1.67)	0.51	(0.28-0.93)	0.61	(0.53-0.71)
Child receives care in medical home	0.46	(0.23-0.90)	0.58	(0.40-0.84)	0.55	(0.49-0.62)
Child has adequate health insurance	0.82	(0.45-1.50)	0.71	(0.47-1.07)	0.50	(0.45-0.57)
Community-based services organized	0.76	(0.24-2.44)	0.70	(0.37-1.31)	0.78	(0.68-0.89)
Need						
Time child affected by condition (v. Never)						
Sometimes	1.02	(0.54-1.94)	1.37	(0.87-2.15)	1.59	(1.38-1.82)
Usually or always	3.15	(1.59-6.24)	2.71	(1.70-4.32)	2.42	(2.06-2.83)
Stability of child's needs (v. Usually stable)						
Needs change all the time	3.26	(1.33-8.00)	2.32	(1.33-4.02)	1.66	(1.39-1.98)
Need change once in awhile	1.15	(0.58-2.28)	1.22	(0.84-1.77)	1.20	(1.06-1.35)
Severity of condition						
More severe (v. Less)	1.74	(0.89-3.38)	1.76	(1.17-2.66)	1.39	(1.21-1.60)

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.
OR=Odds Ratio, 95%CI=95% Confidence Interval. 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.

Severity of Condition=More severe selected if positive for 2+ CSHCN Screener items AND either of the following: Condition affects ability 'a great deal'; Parent Rank of severity 8+ (on scale of 0-10).