

Unmet Need Among CSHCN in Massachusetts:

State analysis of the National Survey of
Children with Special Health Care Needs

Kristen Hill, MPH and Karen Kuhlthau, Ph.D.

MGH Center for Child and Adolescent Health Policy

In collaboration with

The MA Consortium for CSHCN Family Participation Workgroup

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Goals and Objectives

- To better understand the needs of families with CSHCN in MA
- To relate this to the Maternal and Child Health Bureau's key indicators of progress towards implementing community-based service systems for CSHCN¹
- To provide policy relevant state-specific information to consumers and advocates in Massachusetts

National Survey of CSHCN

- Administered by Centers for Disease Control and Prevention and National Center for Health Statistics²
- Phone survey conducted between 10/2000-4/2002
- Nationally representative and state representative samples
- 744 CSHCN in MA; 4,476 in NE; 38,886 in US

Outline of Presentation

- Select sample demographics
- Types and frequency of needs reported
- How child/family characteristics and service systems relate to unmet need
- Unmet need among CSHCN with more severe conditions
- Policy implications and options

Analysis of all CSHCN

Sample Demographics, MA

Age	
0-5	17%
6-12	48%
13-17	35%
Percent Female	38%
Percent non-White	16%
Percent Hispanic	9%
Percent below 100% FPL	17%
Percent ever uninsured in past year	7%

Types of Needs

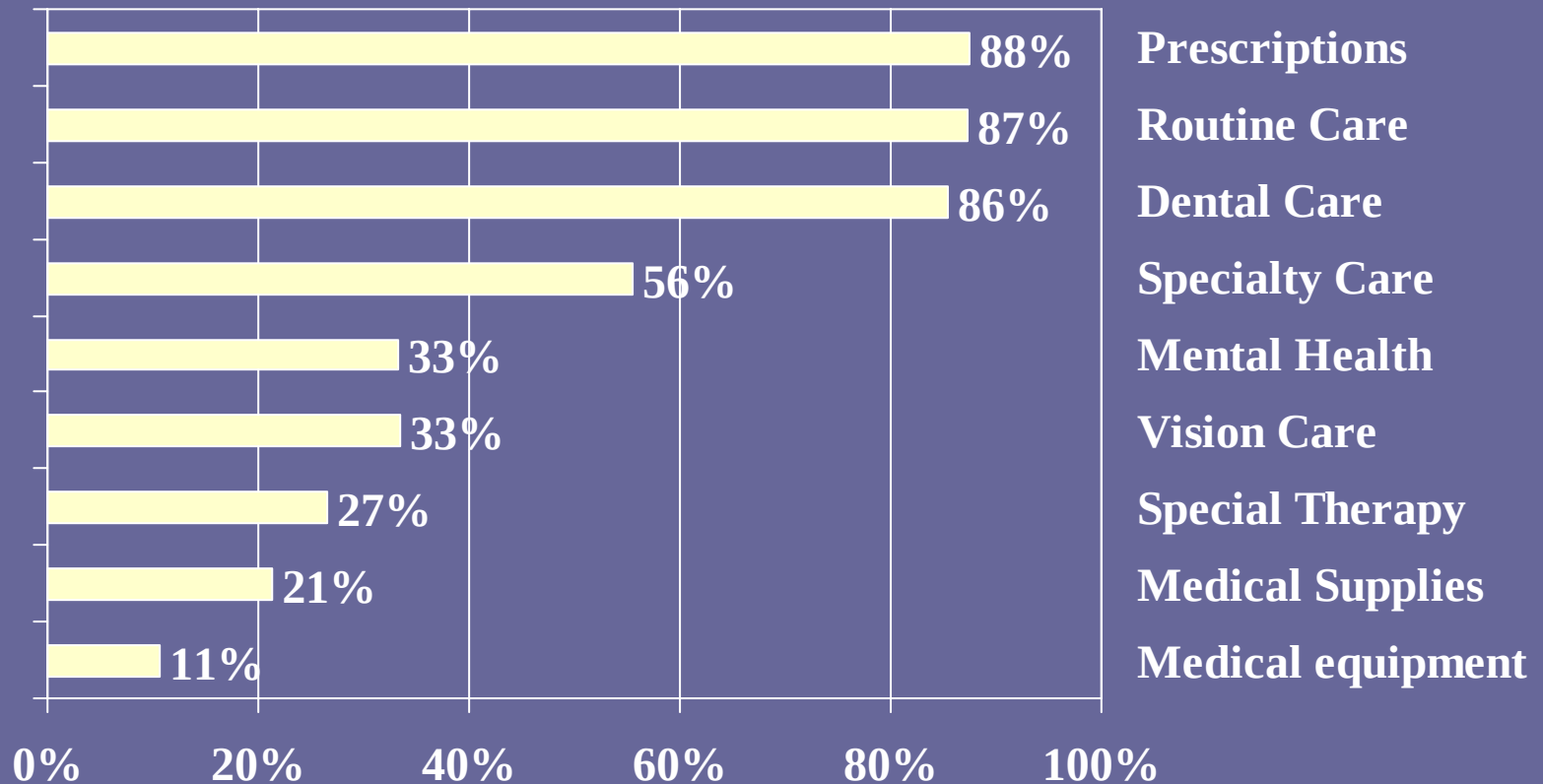
Health Care Services

- Routine care
- Specialty care
- Dental care
- Prescription medication
- Special therapy
- Mental health services
- Substance abuse treatment (age 8+)
- Vision/hearing care and devices
- Home health care
- Medical supplies and equipment
- Mobility aids (age 3+)
- Communication aids (age 3+)

Family Support Services

- Professional care coordination
- Mental health care/ counseling for family member(s)
- Respite care
- Genetic counseling

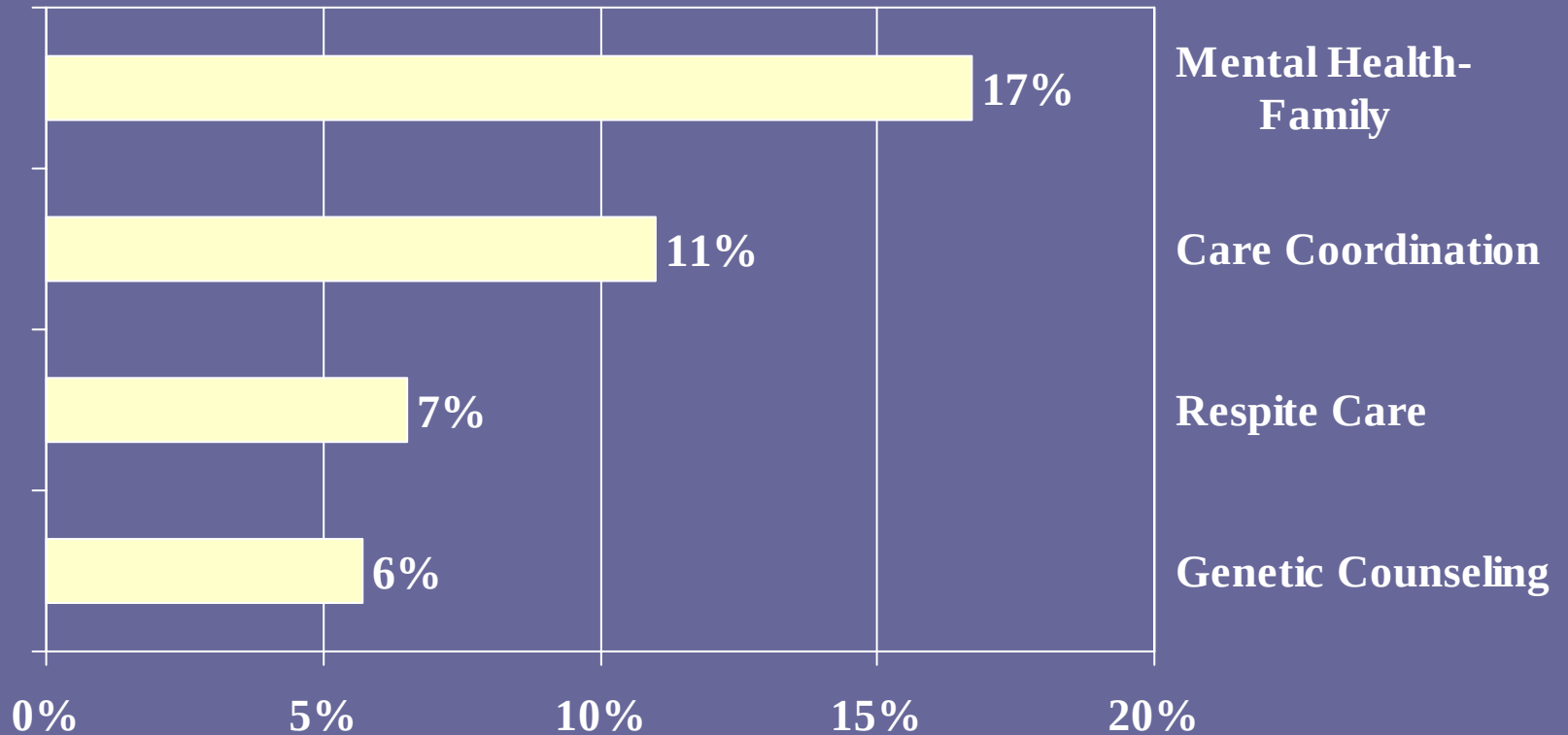
Need for Health Care Services, MA



Hearing care/devices, Mobility aids, Home health care, Substance abuse treatment and Communication aids all less than 10%

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Need for Family Support Services, MA



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Frequency of Needs - MA Summary

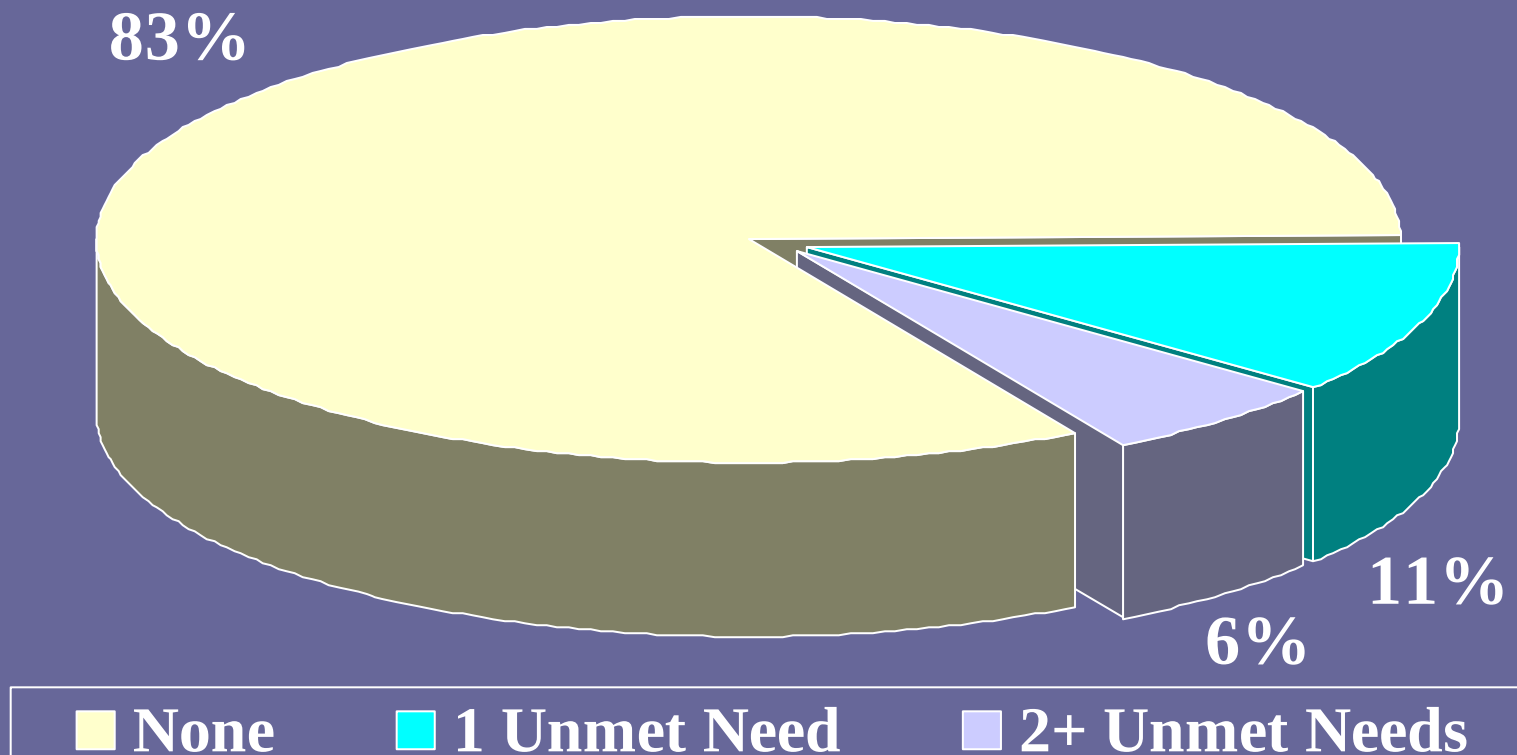
- 98% of CSHCN in MA needed at least 1 health care or family support service in the past year.
 - 98% needed at least 1 health care service
 - 29% needed at least 1 family support service

Unmet Need, MA

- 1 in 6 CSHCN in MA (or an estimated 35,140) who reported a need for services in the past year did not receive the needed care.
 - 13% had an unmet need for health care services
 - 21% had an unmet need for family support services
 - 6% had more than one need unmet

Percentages are of those reporting a need

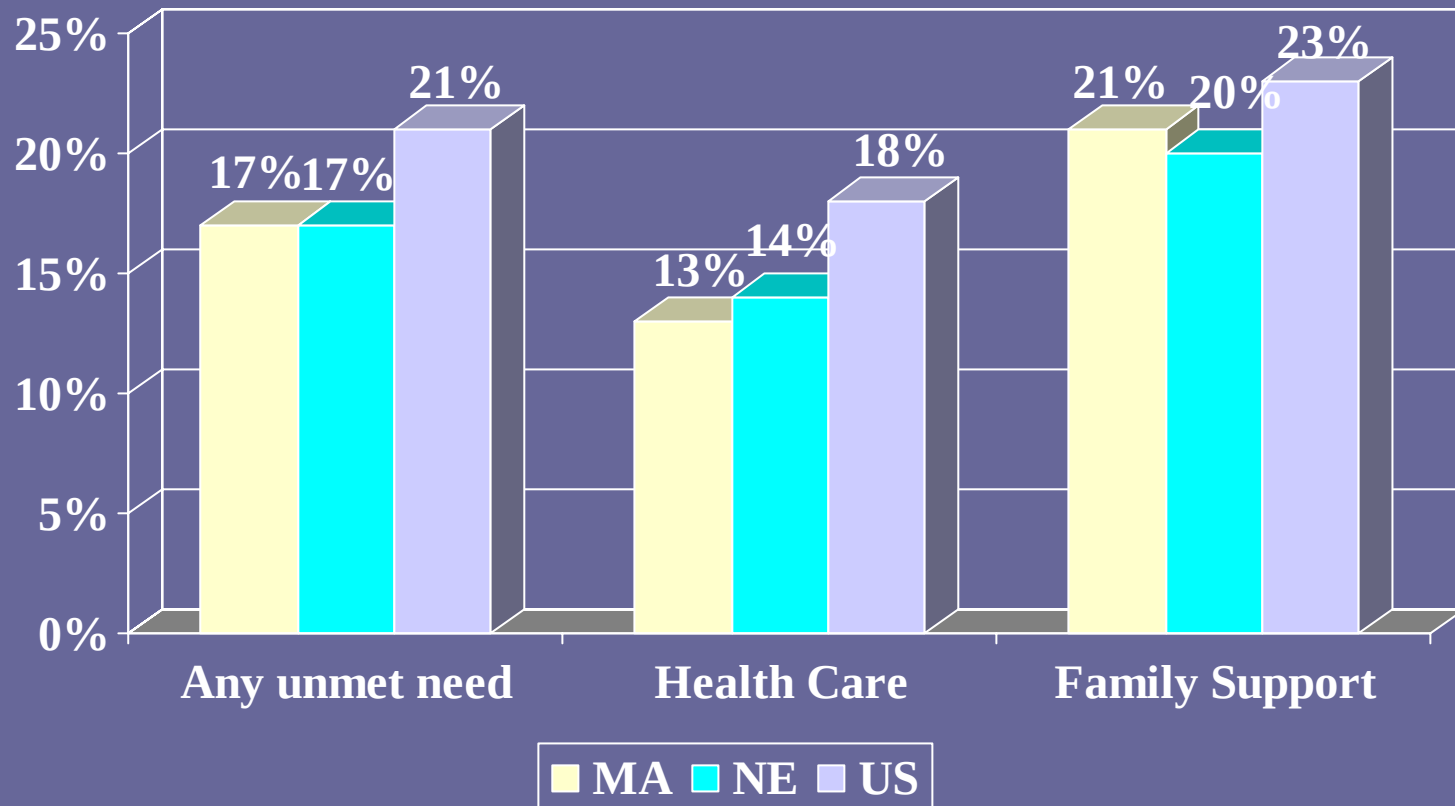
Unmet Need, MA



Percentages are of those reporting a need

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Unmet Need - MA, NE & US



Percentages are of those reporting a need

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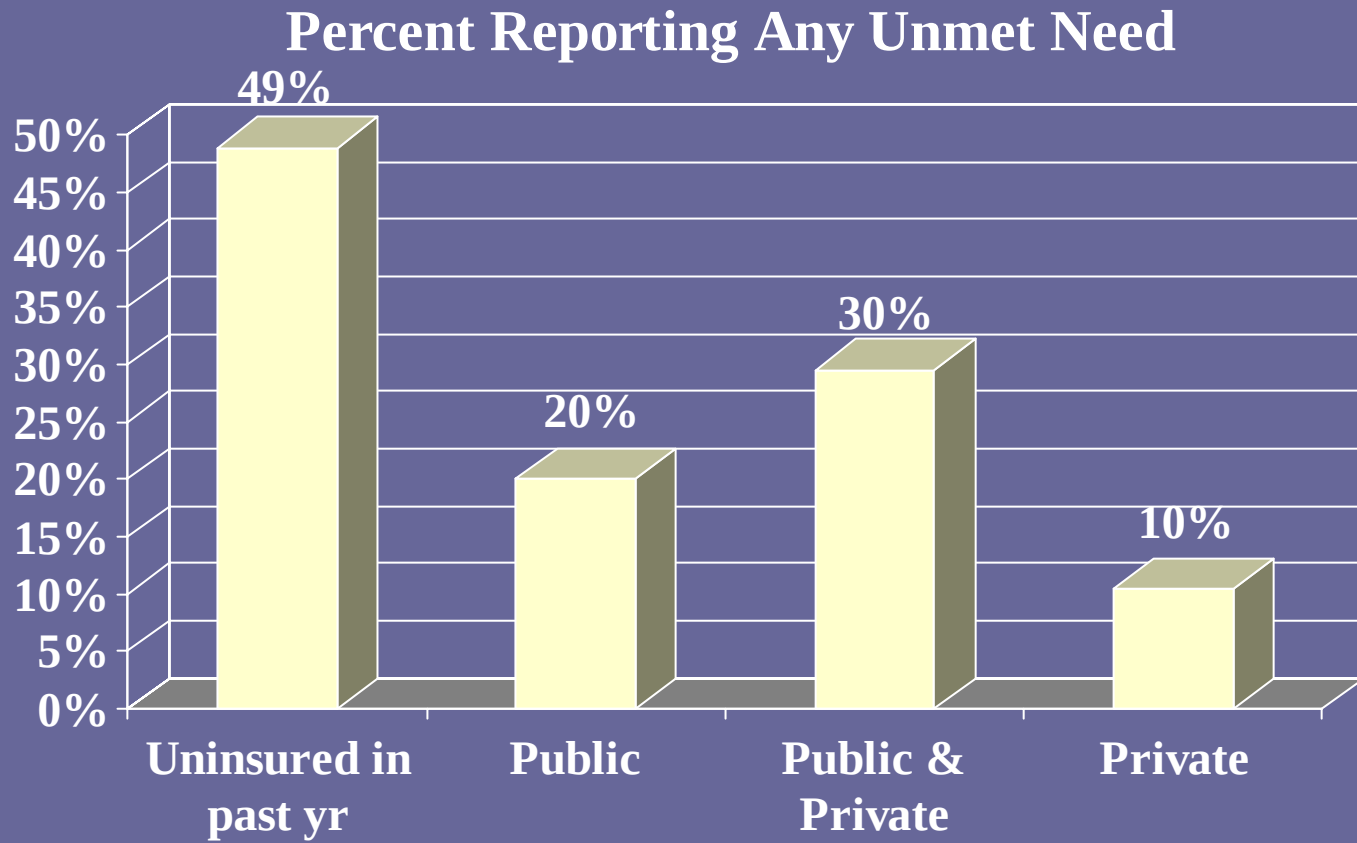
Unmet Need and Child/Family Characteristics, MA

- With each increase in age, CSHCN were 1.07 times more likely to have an unmet need (OR=1.07).
- CSHCN who were uninsured anytime in past year were nearly 5 times more likely to have an unmet need than CSHCN privately insured (OR=4.95).
- There was no significant difference in unmet need for children of different gender, race, and Hispanic ethnicity.

Unmet Need and Child/Family Characteristics, MA (cont.)

- CSHCN who are usually or always affected by their condition were 3 times more likely to have an unmet need than children who are never affected by their condition (OR=3.15).
- CSHCN who have health care needs that constantly change were 3x more likely to have an unmet need than CSHCN whose needs are stable (OR=3.26).

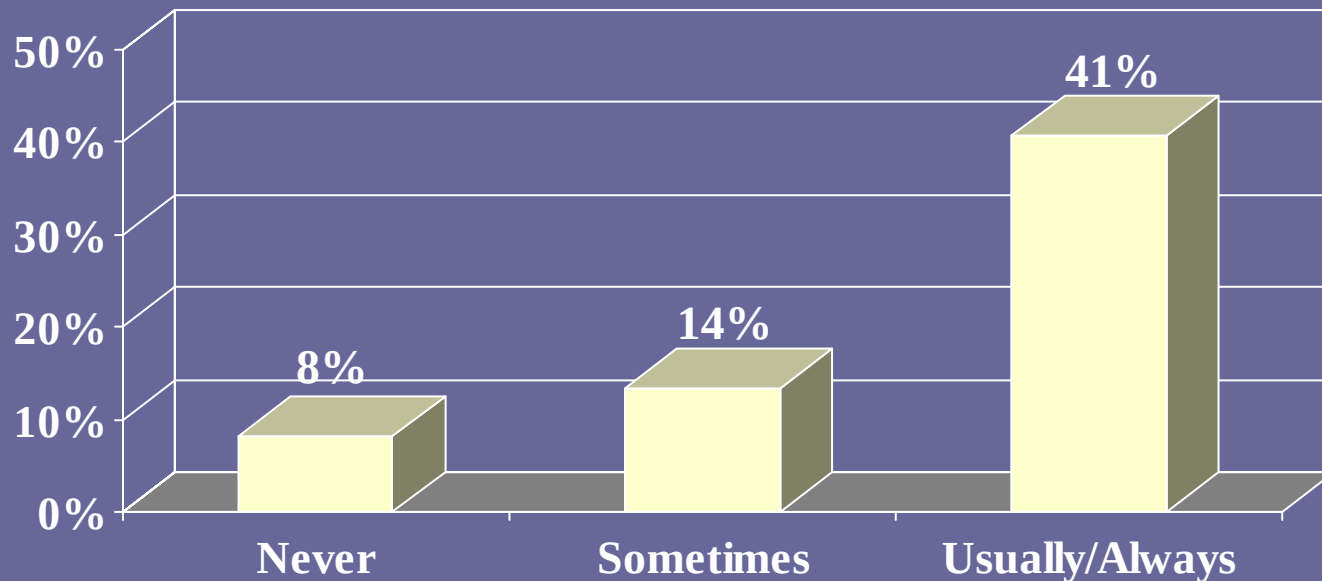
Unmet Need and Insurance, MA



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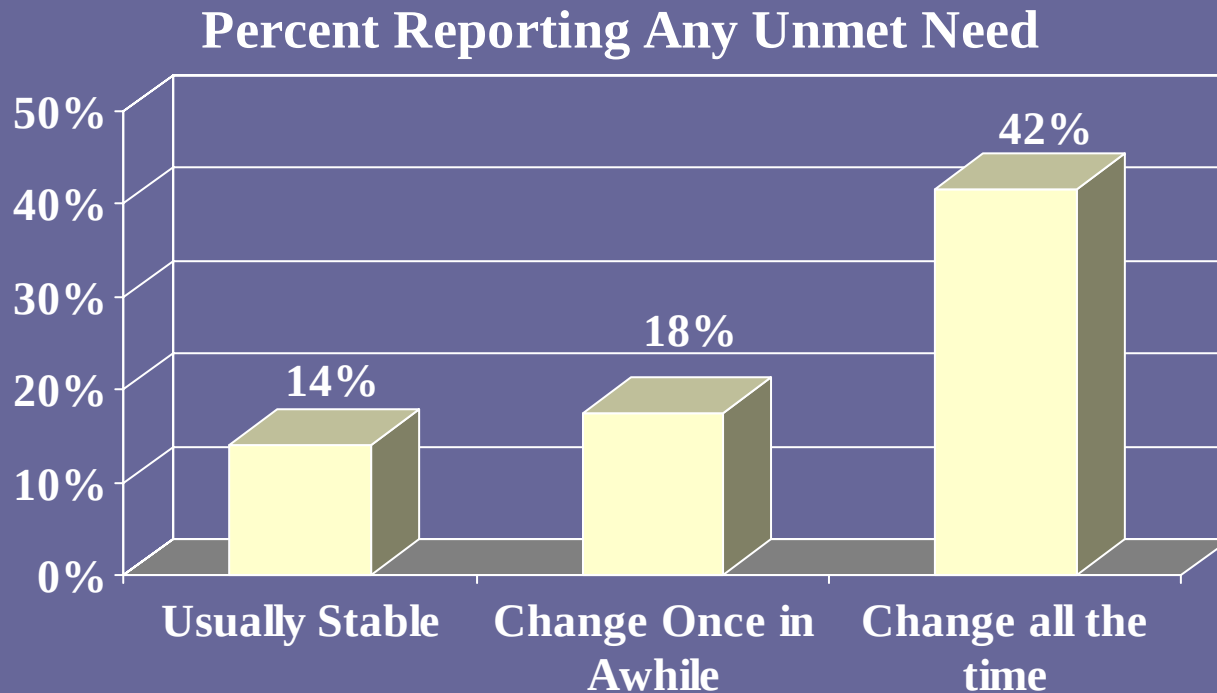
Unmet Need and Time Child Affected by Condition, MA

Percent Reporting Any Unmet Need



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Unmet Need and Stability of Child's Needs, MA



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of CSHCN - March 2006

MCHB National Agenda

“Provide and promote family-centered, community-based, coordinated care for children with special health care needs and to facilitate the development of community-based systems of services for such children and their families.”

Service Systems Results, MA

MA families and progress towards community-based systems of services:

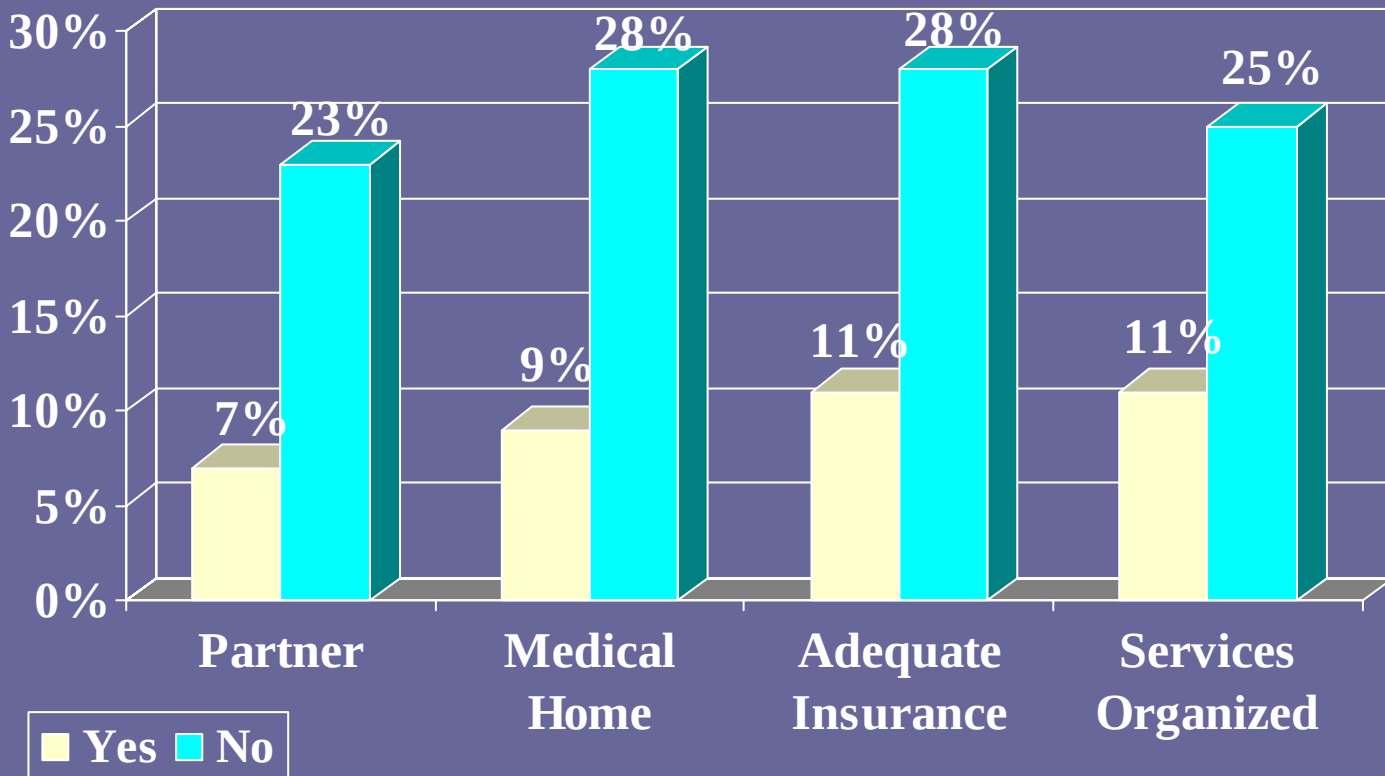
Family does not feel like a partner in decision-making	36%
Child does not receive care within a medical home	39%
Child does not have adequate health insurance	35%
Community-based services not organized	21%

Unmet Need and Service Systems, MA

- Protection from having an unmet need is related to:
 - CSHCN receiving coordinated care within a medical home were less than half as likely to have an unmet need than CSHCN who did not receive care in a medical home (OR=0.46).

Unmet Need and Service Systems, MA

Percent Reporting any Unmet Need



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All CSHCN, MA - Summary

- The most vulnerable of CSHCN (uninsured, more severely affected by condition) were more likely to report an unmet need.
- Receiving coordinated care in a medical home seems to be a protective factor against unmet need.
- However, 2 in 5 CSHCN in MA do not receive care in a medical home.

Analysis of CSHCN with More Severe Conditions

Severity Sub-sample

- Unmet need related to severity of the child's condition.
- Therefore, a sub-sample of CSHCN with more severe conditions was selected to compare types of need and rates of unmet need among this population.
- Includes 94 (13%) CSHCN in MA selected if:
 - Positive for 2 or more CSHCN Screener items AND either:
 - Condition affects ability 'a great deal'
 - Parent Rank of severity 8+ (on scale of 0-10)

Sample Demographics, MA

	All CSHCN	CSHCN Severe
Age		
0-5	17%	21%
6-12	48%	42%
13-17	35%	37%
Female	38%	31%
Non-White	16%	19%
Hispanic	9%	10%
Below 100% FPL	17%	24%
Ever uninsured in past year	7%	4%

Differences were not determined to be statistically significant at $p < .05$

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Top 10 Needs, MA

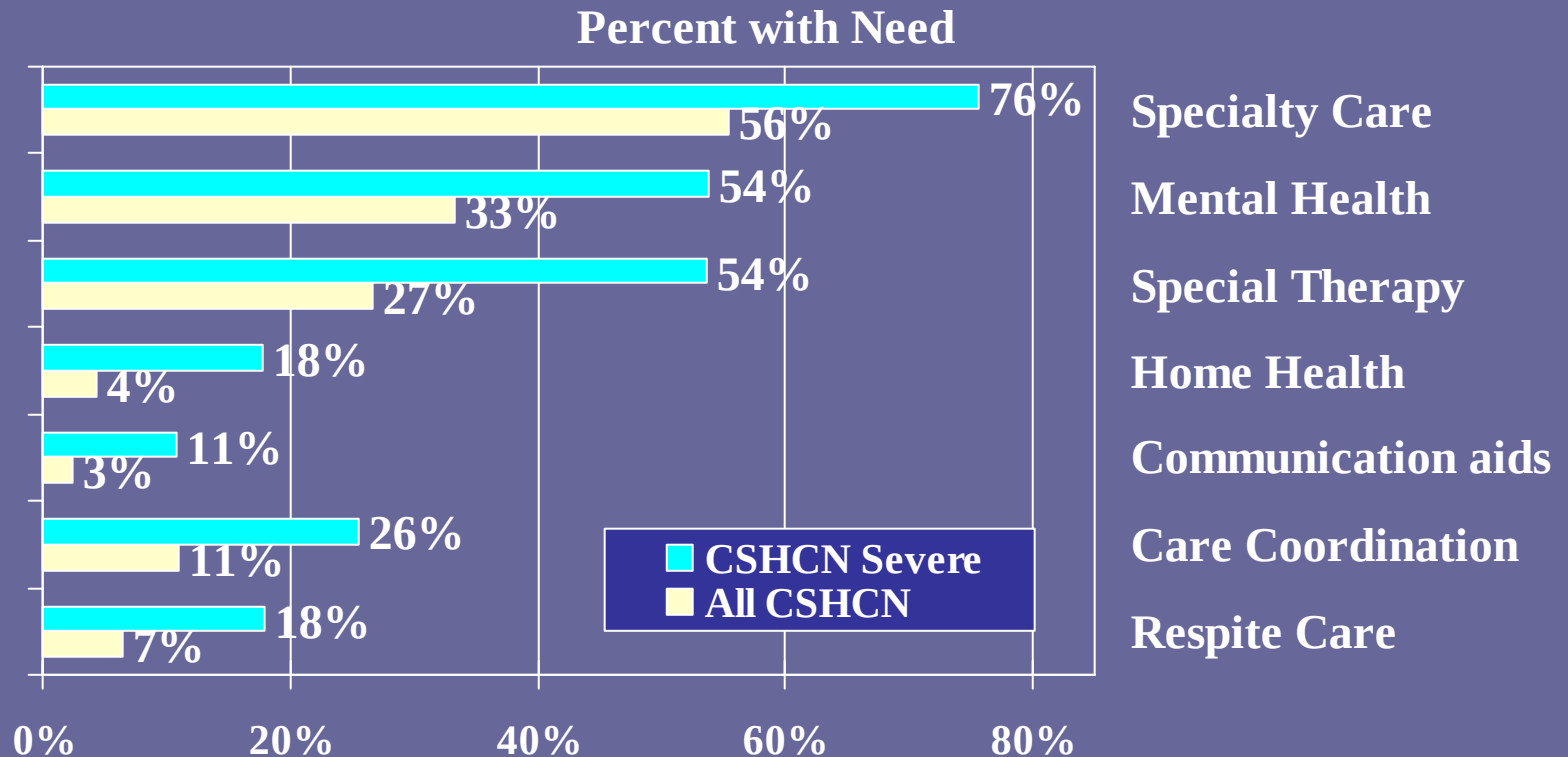
All CSHCN

1. Prescription medication
2. Routine care
3. Dental care
4. Specialty care
5. Eyeglasses/vision care
6. Mental health services
7. Special therapy
8. Medical supplies
9. Mental health for family
10. Professional care coordination

CSHCN with Severe Condition

1. Prescription medication
2. Routine care
3. Dental care
4. Specialty care
5. Mental health services
6. Special therapy
7. Eyeglasses/vision care
8. Medical supplies
9. Mental health for family
10. Professional care coordination

Need for Services, MA

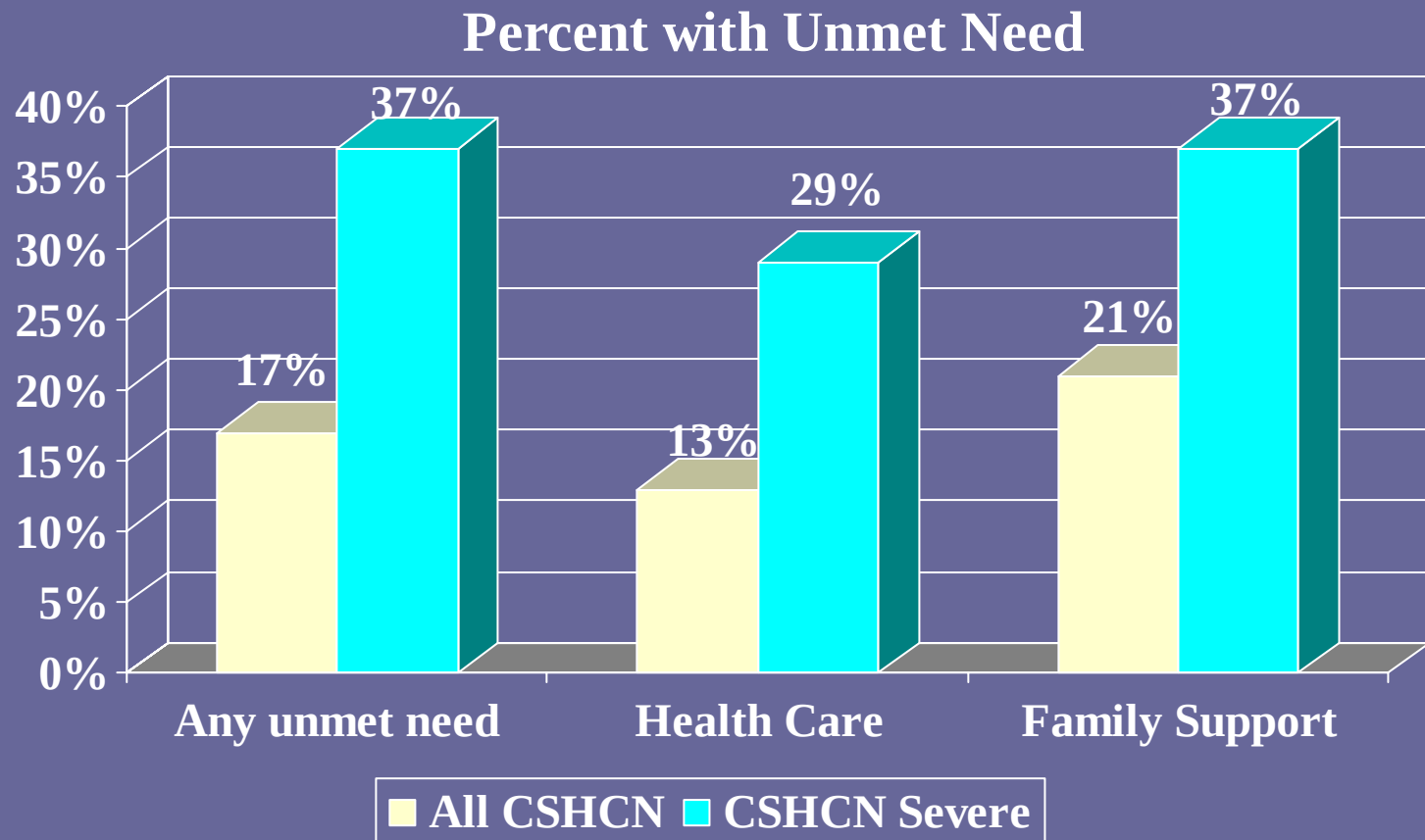


All differences on chart were statistically significant at $p < .05$

Needs for all other services were not significantly different between all CSHCN and CSHCN with more severe conditions.

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Unmet Need, MA



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Severity Sub-sample, MA - Summary

- CSHCN with a more severe condition need more services (such as specialty care, mental health care, care coordination and respite care) than all CSHCN.
- More than 1 in 3 CSHCN in MA with a more severe condition who reported a need for services in the past year did not receive the needed care.

Policy Implications

- Policy options include
 - Improve health insurance systems for families including employer-based insurance.
 - Improve employee benefits (e.g. paid time-off for doctor visits).
 - Improve service systems, in particular, ensure coordinated care in medical homes.
 - Develop targeted services for CSHCN with severe conditions.

References

1. *Achieving and Measuring Success: A National Agenda for Children with Special Health Care Needs*. Retrieved January 12, 2005, from the United States Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau:
<http://www.mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm>
2. Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey National Survey of Children with Special Health Care Needs, 2001.
<http://www.cdc.gov/nchs/about/major/slait/cshcn.htm>

Contact

MGH Center for Child and Adolescent Health Policy

50 Staniford Street, Suite 901, Boston, MA 02114 617-724-1885

Kristen Hill, MPH

Research Coordinator

617-724-2843

Kshill@partners.org

Karen Kuhlthau, Ph.D.

Associate Director

617-724-2842

Kkuhlthau@partners.org

MA Consortium for Children with Special Health Care Needs, New England SERVE

101 Tremont Street, Suite 812 Boston, MA 02108 617-574-9493

Linda Freeman

Director of Family Initiatives

lfreeman@neserve.org

Stephanie Calves, JD, MPH

Project Director

scalves@neserve.org