Financial Burden for Families of 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

March, 2006

Supported by a grant from the Deborah Munroe Noonan Memorial Fund

Goals and Objectives

- To better understand the caregiving demands and financial impact on 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 CSHCN[1]
- 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 Statistics[2].
- Phone survey conducted between 10/2000-4/2002
- Nationally representative and state representative sample
- 744 CSHCN in MA; 4,476 in New England; 38,886 in US

Overview of Presentation

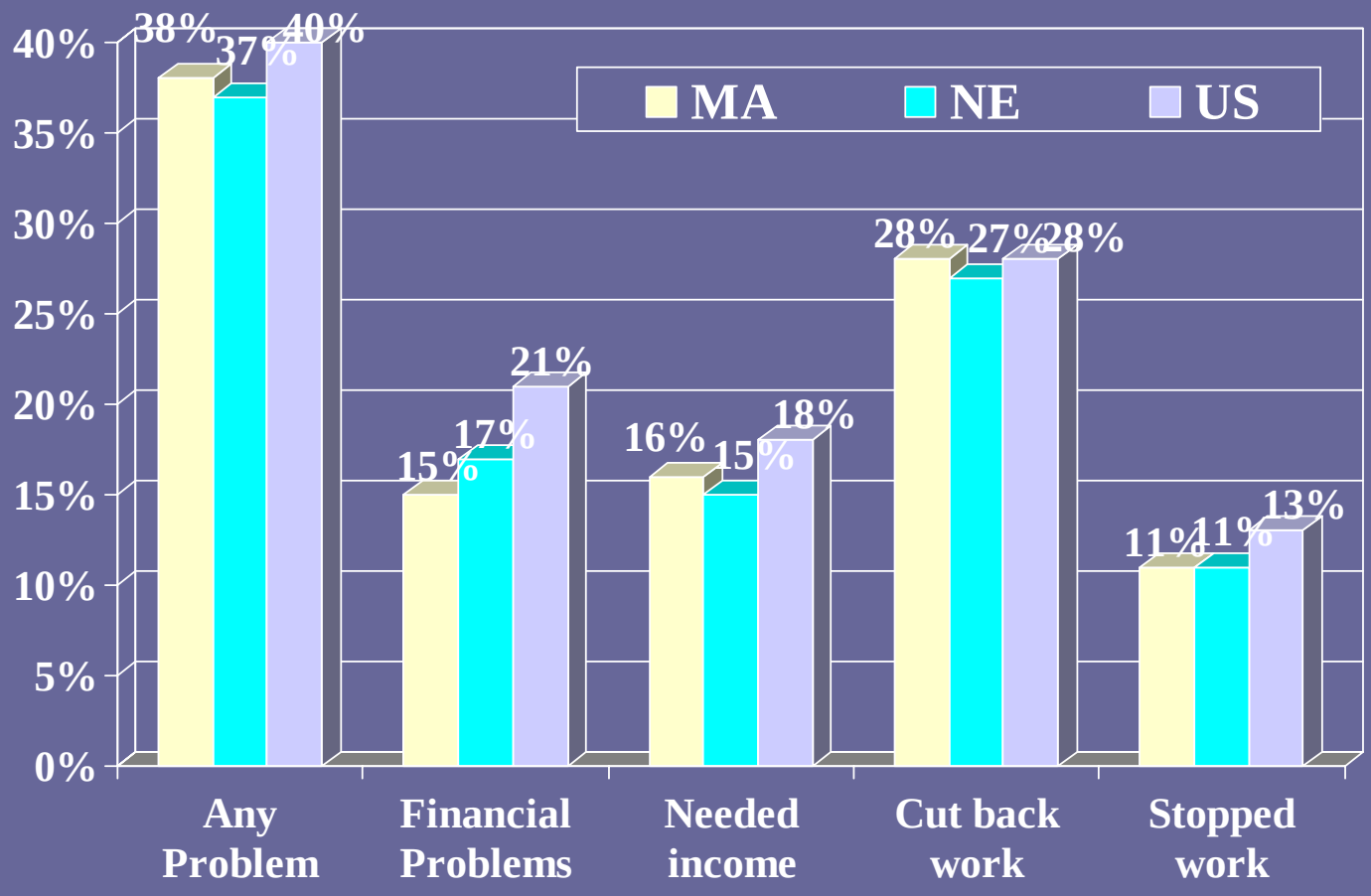
- Percent of MA families reporting financial problems, compared to NE & US
- Percent of MA families reporting good systems of services, compared to NE & US
- How child/family characteristics and service systems relate to financial impact
- Policy implications of these findings

Financial Burden Results

38% of families with CSHCN in MA (an estimated 83,543 families) had a finance-related problem:

Child's health caused financial problems	15%
Needed additional income to cover child's health-related expenses	16%
Family members have had to cut work hours to care for child	28%
Family member stopped working due to child's health	11%

Financial Burden: MA, NE and US



MA analysis of the National Survey of CSHCN - March 2006

MCHB National Agenda

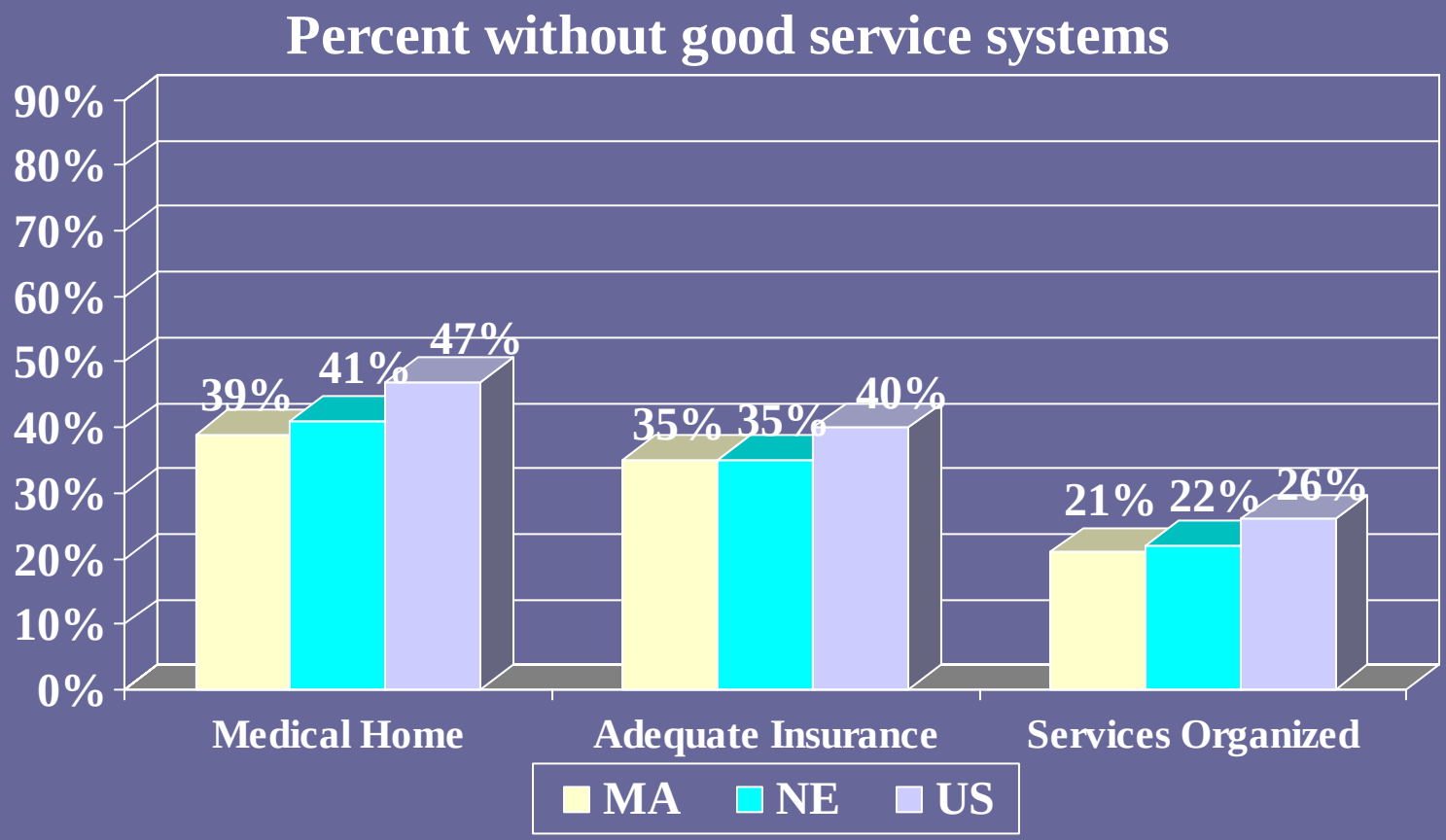
"Provide and promote family-centered, community-based, coordinated care for children with special health care needs and to facilitate the development of community-based systems of services for such children and their families."

Service Systems Results, MA

MA families and progress towards Community-based Systems of Services:

Does not receive coordinated ongoing comprehensive care within a medical home	39%
Does not have adequate health insurance	35%
Does not have organized community-based services for easy use	21%

Service Systems: MA, NE and US

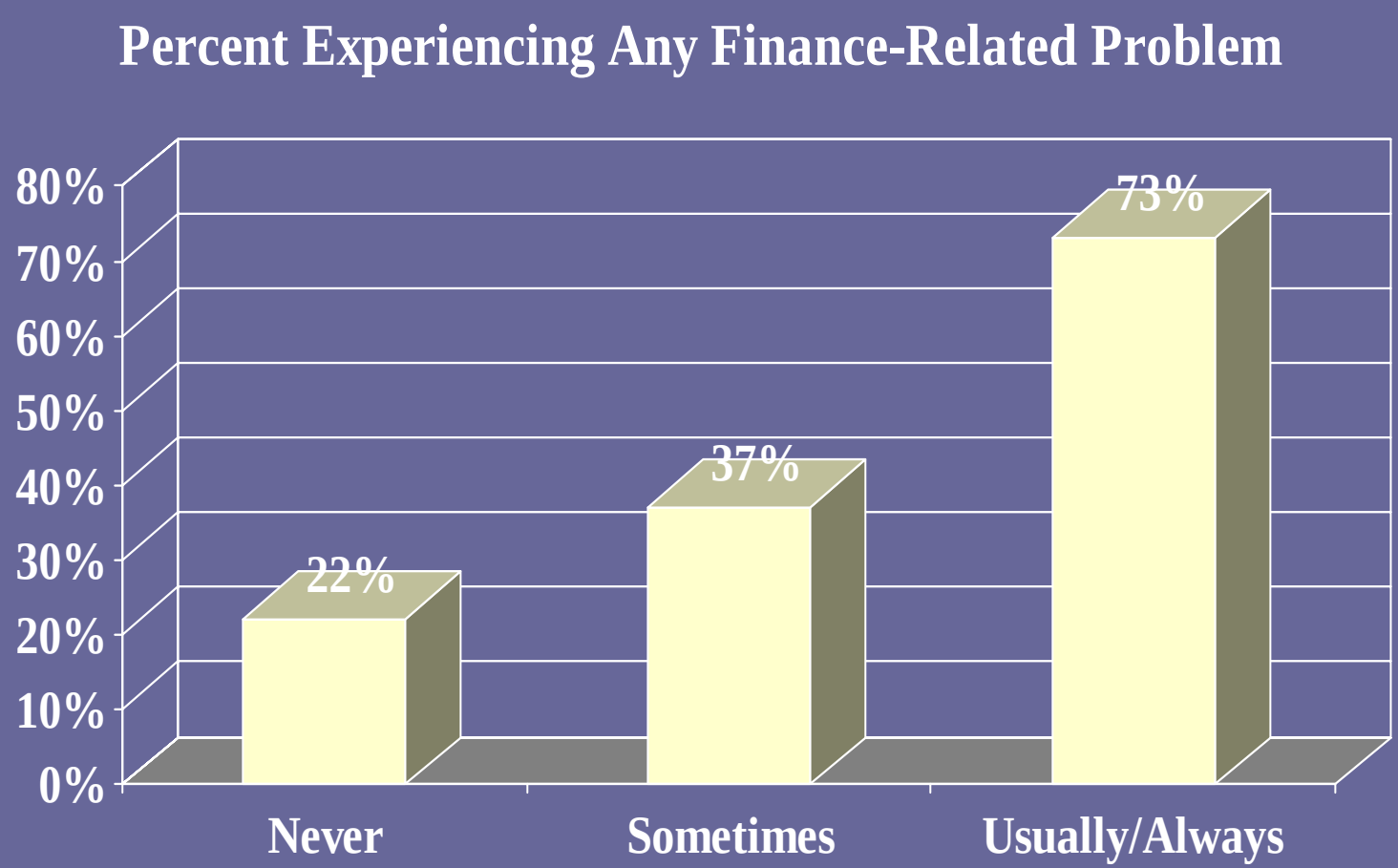


MA analysis of the National Survey
of CSHCN - March 2006

Financial Burden and Child/Family Characteristics, MA

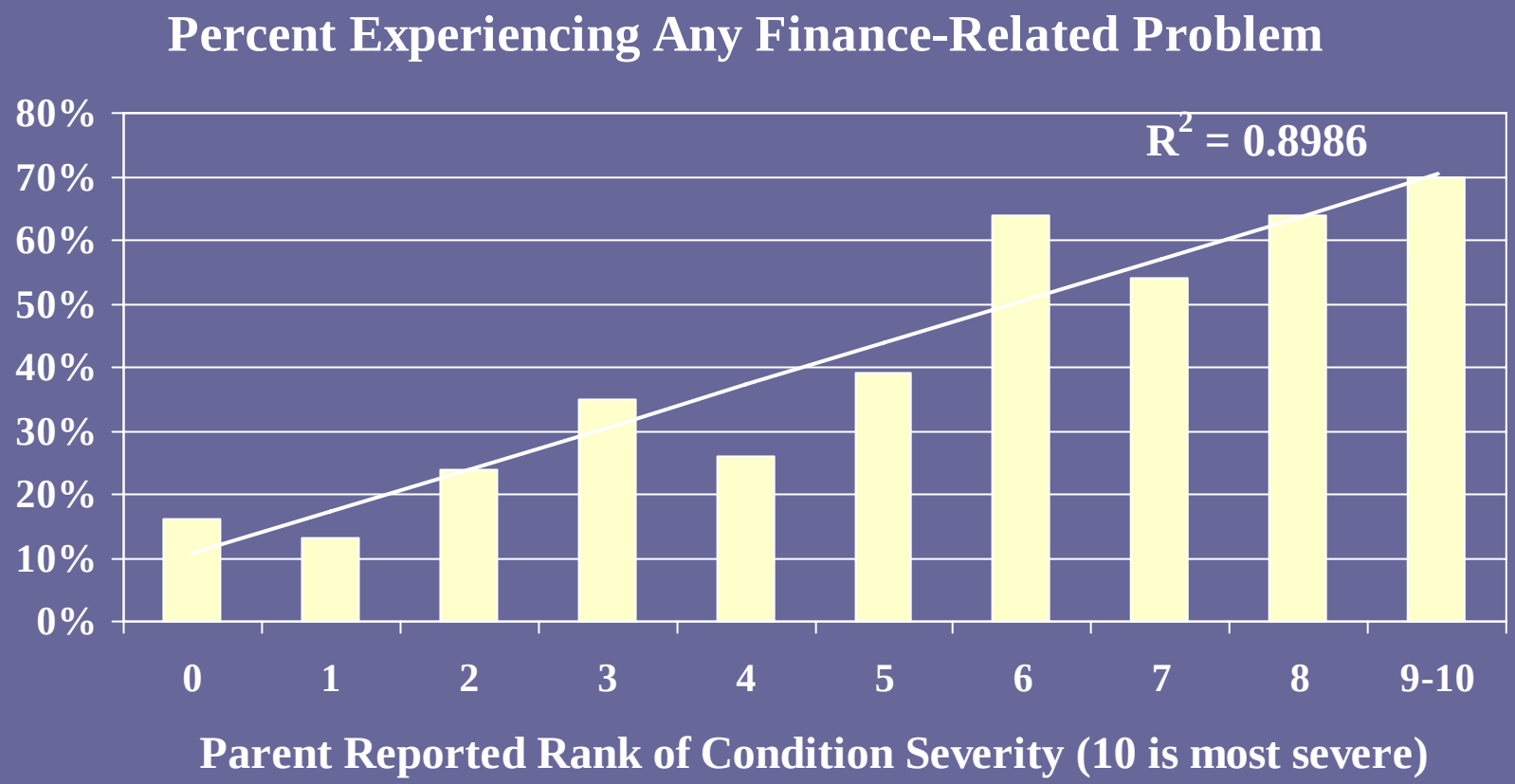
- Children who are usually or always affected by their condition are 3 times more likely to experience a finance related problem than children who are never affected by their condition (OR=3.36).
- On a scale of condition severity from 0-10, families were 1.22 times more likely to report a finance related problem with each increase in rank (OR=1.22).
- There was no significant difference in financial burden for children of different ages, race, Hispanic ethnicity, and poverty levels.

Financial Burden and Time Child is Affected by Condition, MA



MA analysis of the National Survey of CSHCN - March 2006

Financial Burden and Severity of Condition, MA



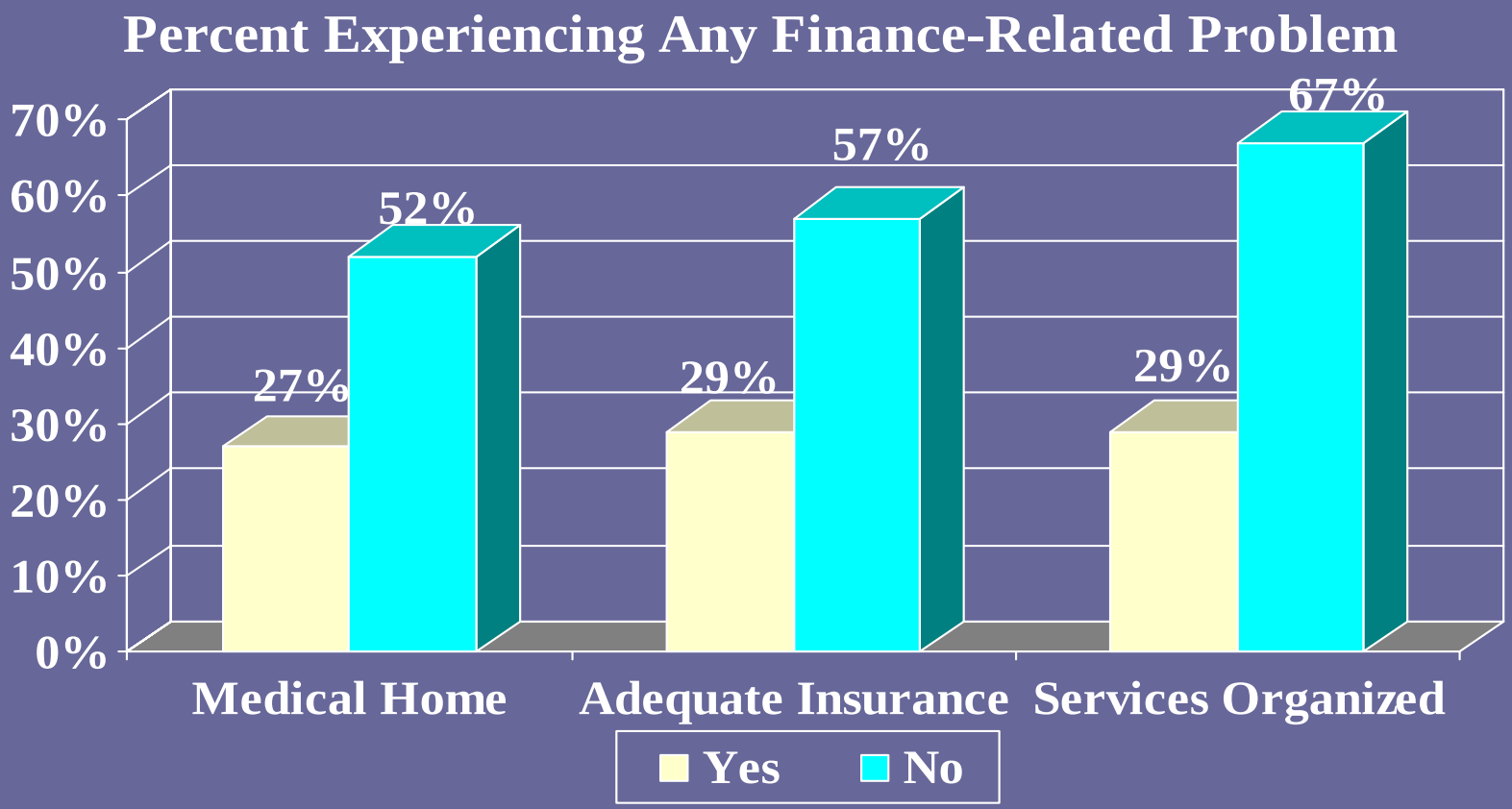
MA analysis of the National Survey of CSHCN - March 2006

Financial Burden and Service Systems, MA

Good systems of care offer protection from having a finance-related problem:

- CSHCN receiving coordinated care within a medical home are nearly half as likely to have financial problems (OR=0.57).
- CSHCN with adequate health insurance are nearly one-third less likely to have financial problems (OR=0.36).
- Families with organized community-based services are less than half as likely to experience financial problems (OR=0.44).

Financial Burden and Service Systems, MA



MA analysis of the National Survey of CSHCN - March 2006

Summary, MA

- Families with children with more severe conditions have more finance-related trouble.
- Families with good systems of care have less finance-related trouble.
  - However, 2 in 5 CSHCN in MA do not have a medical home, more than 1 in 3 do not have adequate health insurance, and approximately 1 in 4 do not have access to organized community based-services.
- Findings support the importance of reducing the financial burden on families with children with disabilities.

Policy Implications

- Policy options include
  - Improve health insurance systems for families of CSHCN.
  - Improve service systems, e.g. ensure medical homes and organize community-based services for easy use.
  - Improve employee benefits (insurance, paid vacation/sick, EAP) to keep families employed.

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 website: 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/slaits/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