

Financial Burden for Families of CSHCN

Massachusetts Results from the National Survey of CSHCN

Introduction

This study examines the financial impact on Massachusetts' families with children with special health care needs (CSHCN). Massachusetts' data from the National Survey of Children with Special Health Care Needs¹ was analyzed. This telephone survey includes 744 CSHCN in Massachusetts. Analysis was conducted by the MGH Center for Child and Adolescent Health Policy in collaboration with the Massachusetts Consortium for Children with Special Health Care Needs Family Participation Workgroup. This project was supported through a grant from the Deborah Munroe Noonan Memorial Fund.

Summary of Results

- **More than one third (38%) of families of CSHCN in Massachusetts reported a finance-related problem associated with their child's health status.**
 - 15% reported that the child's health has caused financial problems.
 - 16% needed additional income to cover their child's health-related expenses.
 - 28% reported family members had to cut work hours to care for their child.
 - 11% reported that a family member stopped working due to child's health.
- **Families whose children have a severe condition were more likely to experience a finance-related problem.**
 - Children who are usually or always affected by their condition were 3 times more likely to experience a finance-related problem than children who are never affected by their condition.
- **Families with good systems of care reported fewer finance-related problems.**
 - Children who receive coordinated ongoing comprehensive care within a medical home are nearly half as likely to experience a finance-related problem than children who do not receive care in a medical home.
 - Children who have adequate health insurance are nearly one third less likely to experience financial problems than children who do not have adequate insurance.
 - Children who have organized community-based services are less than half as likely to experience a finance-related problem than children who do not have organized community-based services.

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 nearly 1 in 4 do not have organized community based-services.

Policy Options

- Improve health insurance systems for families of CSHCN.
- Improve service systems, e.g. ensure medical homes and organize community-based services.
- Improve employee benefits (insurance, paid vacation/sick leave, Employee Assistance Programs) to keep families employed.

For More Information

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.

References

¹Centers 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>