Family Well-being in Massachusetts: State Analysis of the National Survey of Children with Special Health Care Needs

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 on the Massachusetts analysis of the National Survey of Children with Special Health Care Needs. The results of this study are provided here for families, advocates, providers and policymakers in the hopes of improving systems of care and relevant public policies for children with special health care needs.

About the Project:

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 the 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. This project had 4 primary goals:

1. To better understand the caregiving demands and financial impact on families with children with special health care needs in Massachusetts.
2. To determine a second topic of analysis, based on input from the Family Participation Workgroup. The workgroup chose to examine unmet need for health care and family support services among children with special health care needs.
3. To relate financial impact and unmet need to the Maternal and Child Health Bureau’s key indicators of progress towards implementing community-based service systems for children with special health care needs.
4. To provide policy relevant state-specific information to consumers and advocates in Massachusetts.

The results of this study are provided here for families, advocates, providers and policymakers in the hopes of improving systems of care and relevant public policies for children with special health care needs and in so doing improving the lives of children with special health care needs and their families.

Click on ‘Available Data’ for the results. For each topic of analyses, a PowerPoint presentation, a one-page summary and the detailed tables of results are provided.

Background on data:

The survey, the National Survey of Children with Special Health Care Needs, was sponsored by the Maternal and Child Health Bureau and administered by the National Center for Health Statistics. The survey is a random digit dial telephone survey conducted from October 2000 to

April 2002 that screened households for children under age 18 in all 50 states and the District of Columbia. Children with special health care needs (CSHCN) 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. The Massachusetts sample includes 744 children with special health care needs, the New England sample includes 4,476 CSHCN and the national sample includes 38,886 CSHCN.

Two sets of analyses were conducted. First, we examined the financial impact on Massachusetts' families with CSHCN. Second, based on input from the Family Participation Workgroup, we examined unmet health care and family service needs for CSHCN in Massachusetts and for a subset of CSHCN with a more severe condition. We further examined financial impact and unmet need as it relates to child and family characteristics and to the Maternal and Child Health Bureau's key indicators of progress towards Healthy People 2010 national goal for service systems for CSHCN.

The Maternal and Child Health Bureau has set a national agenda for children with special health care needs that has been the foundation of state Title V programs. The agenda calls for the development of systems of care for children with special health care needs 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. Six core outcomes have been identified to measure states' progress towards this goal:

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.
4. Children will be screened early and continuously for special health care needs.
5. Community-based service systems will be organized so families can use them easily.
6. Youth with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence.

This study examined financial burden among families of CSHCN as it relates to 3 of the above outcomes (2, 3 and 5) and unmet need as it relates to 4 of the above outcomes (1, 2, 3 and 5). For more information on these outcomes visit http://www.mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm.

Available Data:

Financial Burden for Families of Children with Special Health Care Needs 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 children with special health care needs (CSHCN).

This study examines the financial impact of having a child with a disability in Massachusetts, and how certain child characteristics, such as race and severity of condition, and family characteristics such as poverty status relate to the financial burden experienced by families. It further examines how financial impact relates to the Maternal and Child Health Bureau's key indicators of progress towards Healthy People 2010 national goal for service systems for CSHCN.

PowerPoint Presentation
One-page summary of Results
Detailed Tables

Unmet Need for Children with Special Health Care Needs in Massachusetts
Children with special health care needs (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 and how certain child characteristics (such as race and condition severity), and family characteristics (such as poverty status) relate to unmet need experienced by children. It further examines how unmet need relates to the Maternal and Child Health Bureau's key indicators of progress towards Healthy People 2010 national goal for service systems for CSHCN. Lastly, this study examines unmet need among CSHCN in Massachusetts with a more severe condition.

PowerPoint Presentation
One-page summary of Results
Detailed Tables

Definition of terms:

Bivariate Analysis: An analysis of the relationship between two variables.

CSHCN: Children with special health care needs as defined by the U.S. Maternal and Child Health Bureau: "children who have or are at risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally."

CSHCN Screener: A 5-item parent survey-based tool developed to identify CSHCN based on the U.S. Maternal and Child Health Bureau's definition. A well-tested survey, developed by a national group of state leaders, families, experts and policymakers, it identifies a broad group of children based on consequences of their condition, as opposed to their specific diagnosis. It includes children with a wide array of conditions, levels of severity and service use need. The survey consists of 5 multi-part questions that each ask about a consequence the child might experience because of a physical or mental health condition. Those 5 health consequences are 1) use or need of prescription medication; 2) above average use or need of medical, mental health or educational services; 3) limited or prevented in ability to do things compared with others of same age; 4) use or need of specialized therapies (OT, PT, speech, etc.); and 5) treatment or counseling for emotional or developmental problems. In order to be identified as a child with special health care needs, the parent must report at least one of the above consequences and that the health consequence is due to a health condition that has lasted or is expected to last at least 12 months. For a copy of the CSHCN Screener click here.

Medical Home: A medical home is not a building, house, or hospital, but rather an approach to providing comprehensive primary care. A medical home is defined as primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. A medical home addresses how a primary health care professional works in partnership with the family/patient to assure that all of the medical and non-medical needs of the patient are met. For more information on medical homes visit the National Center of Medical Homes Initiatives for Children with Special Needs.

Multivariate Analysis: An analysis of the relationship between a dependent variable (e.g. unmet need) and several independent variables (e.g. age, race, etc) simultaneously.

Odds Ratio (OR): The odds ratio is a way of comparing whether the probability of a certain event is the same for two groups. For example, suppose that seven out of 10 males are admitted to an engineering school while four of 10 females are admitted. The probability for admitting a male is $p = 7/10 = .7$. The probability for admitting a female is $p = 4/10 = .4$. Now we can use the probabilities to compute the admission odds for both males and females: odds(male) = .7/.4 = 1.75 and odds(female) = .4/.7 = .571. Next, we compute the odds ratio for admission: OR = 1.75/.571 = 3.06. Thus, the odds of a male being admitted are 3.06 times greater than for a female. Conversely, we can say that the odds of a female being admitted is one-third that of a male (.571/1.75 = .326 = approximately 1/3). (Adapted from http://www.ats.ucla.edu/stat/SAS/faq/oratio.htm).

Statistical significance, Confidence Interval (CI) and p-value: The statistical significance of a result tells us something about the degree to which the difference found between groups is "true" or if the result could have occurred by chance alone (that is, the data accurately represents the true population). Conventionally, the difference is statistically significant if the difference between groups could have occurred by chance alone in less than 1 time in 20. This is expressed as a p value < 0.05. The p-value represents the probability of error that is involved in accepting our observed result as valid. For example, a p-value of 0.05 indicates that there is a 5% probability that the relation between the variables found in our sample is just by chance and that we are 95% confident that estimates derived from the sample data accurately represent the true population value. Thus, the 95% confidence interval is the range of values within which we can be 95% sure that the true value lies for the whole population from whom the study population was selected.

More Statistics Help: For more help interpreting survey data, visit the BRFSS Data Systems Course, an excellent interactive teaching resource. Examples are from the Behavioral Risk

Factor Surveillance System (BRFSS) survey; however, the concepts apply to National Survey of CSHCN and similar data.

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Links:

Massachusetts Consortium for Children with Special Health Care Needs:
http://www.neserve.org/maconsortium/index.html

National Survey of Children with Special Health Care Needs Data Resource Center:
http://www.cshcndata.org

Achieving and Measuring Success: A National Agenda for Children with Special Health Care Needs, Maternal and Child Health Bureau:
http://mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm

Healthy People 2010: http://www.healthypeople.gov/

CSHCN Screener: http://www.markle.org/resources/facct/doclibFiles/documentFile_446.pdf

National Center of Medical Homes Initiatives for Children with Special Needs:
http://www.medicalhomeinfo.org/index.html

Center for Medical Home Improvement: http://www.medicalhomeimprovement.org