



## Secondary Health Coverage for Children with Special Health Care Needs: A Fact Sheet for Families

Children with special health care needs (CSHCN) have a greater need for health and rehabilitative services than typically developing children. This higher level of need may place considerable demands upon families' financial resources, particularly when the cost of care is high and/or when children have unusual needs that are not covered by their primary insurance plan. Some families obtain additional coverage to help pay for these expenses.

This research brief focuses on the role that secondary health coverage can play in helping families pay for their children's care. It describes secondary health coverage, presents survey findings regarding insured families' experiences using such coverage for their CSHCN, and provides information for families who may want to consider obtaining additional coverage for their children.

### What is Secondary Health Coverage?

Secondary health coverage helps pay for costs not covered by a family's primary insurance plan. For example, it may pay for the deductibles and co-pays a family would otherwise pay out of pocket. Or it may pay for goods and services, such as medical supplies or equipment that are not covered by a family's primary insurance plan.

Families may obtain secondary coverage through "private" or "public" sources. Families who have "private" secondary coverage purchase a second health insurance policy, often through a parents' employer. Families who have "public" secondary coverage receive assistance obtaining and paying for their children's care through a variety of public programs, including Medicaid and the Title V program for CSHCN.

### Study Methods

The information presented here is based on data from a survey conducted in 1998-1999 of 2,220 parents of CSHCN in 20 states. (Please see the shaded box on page 2 for more information on the study.) Brandeis University and Family Voices partnered to design and conduct the survey project, which collected statistical data and parents' comments about their experiences obtaining care for their children. Of the families surveyed, 97% were covered by a primary health plan, and 39% also had secondary coverage (34% had "public" secondary coverage and 5% had "private" secondary coverage). This research brief reports findings for the 39% (868) of families who had secondary coverage.

### When Do Families Find Secondary Coverage Helpful?

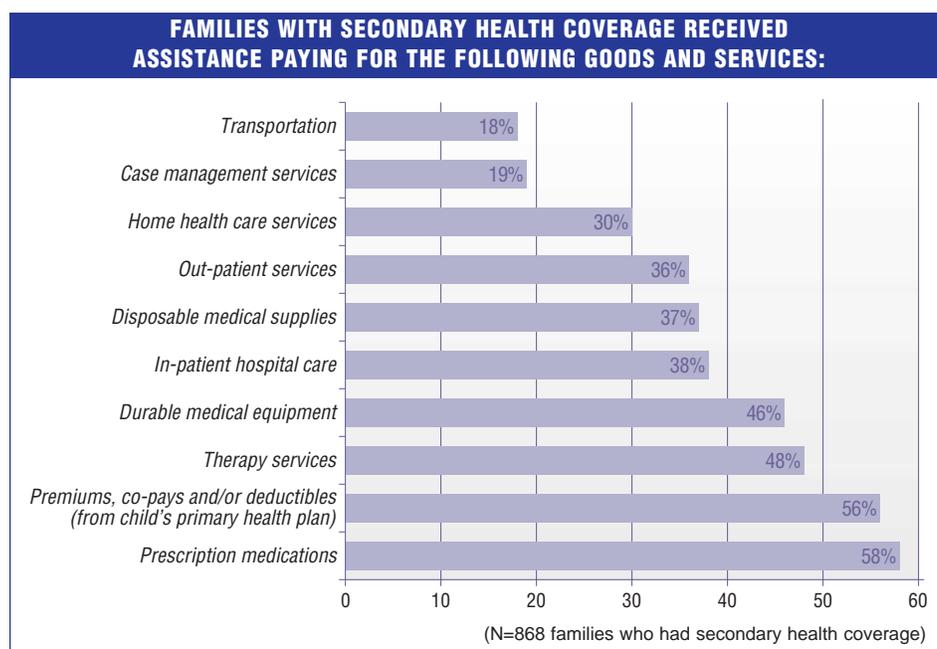
Families reported two types of gaps in the coverage provided by their primary health insurance. One type of gap was caused by some insurance plans' high deductibles and/or limitations on coverage. One mother explained that, "Medicaid pays the outstanding cost that Blue Cross doesn't pay." For example, Medicaid picked up deductibles, co-payments, and families' share of medical costs when they were insured through "80/20" insurance plans (in which the plan pays for 80% of costs, and the family is responsible for the other 20% of costs).

A second type of gap was created by insurance plans' policies regarding the types of goods and services they cover. Some insurance plans do not offer much coverage for "special" care, especially therapies, or medical equipment, devices or supplies. One mother said that secondary coverage paid for the "deficits" in her child's primary insurance plan. Secondary coverage can help, especially through public programs specifically for CSHCN. One mother

reported that Medicaid had helped her pay for a bath chair, an augmented communication device, and diapers, none of which were covered under their private insurance. Another mother explained,

*“His normal health care needs are met by his primary insurance. Most of his special health care needs are met by Medicaid.”*

Secondary coverage helped many families fill these gaps in coverage, by paying (partially or completely) for a wide range of goods and services related to health care, as shown below:



## What Issues Should Families Consider?

One mother told us, “I wish I could have found out about it years ago,” suggesting that not all families who could benefit from secondary coverage know about it when they need it. What kinds of information might families want when deciding whether secondary coverage might be helpful in caring for their children?

- ◆ **How much is your family paying “out of pocket” for your child’s health care?** If your share of the costs is large, you might consider looking into purchasing private secondary coverage. However, such coverage is expensive, and families should make sure that their children’s pre-existing condition(s) would be covered.
- ◆ **Is your family eligible for public health care programs?** Often families think that their children are not eligible for public health care programs

because their family income is too high. But some families are eligible for public coverage of health costs based only on their children’s needs, especially if their children need a lot of health care. For example, Medicaid has “waiver” programs that allow families of children with more severe conditions to receive coverage for their children, even if families’ incomes exceed the usual cut-offs for Medicaid eligibility. The eligibility and guidelines for these Medicaid programs vary from state to state.

- ◆ **How would coverage be coordinated between a family’s existing health plan and a new secondary plan?**

Sometimes the primary and secondary plans work out all of the paperwork, and sometimes families are required to do a lot of that work themselves. Families should ask the secondary plan about how they must obtain approvals and who coordinates “who pays for what,” and then decide if the amount of work required is worth the amount of money saved. Many families reported that the plans simply worked out the details themselves (especially if Medicaid provided secondary coverage), but a few parents complained about the amount of work involved, saying that their children’s primary plan and

secondary coverage fought with each other, including one mother who said, “Basically, both plans don’t work together.”

- ◆ **Are the providers your child uses covered by the secondary coverage you are considering?** Your child’s health care providers will be able to tell you if they accept the coverage that you are considering.
- ◆ **What is the cost of purchasing another insurance policy?** For a few families, the cost of paying for a second insurance plan is less than the costs that they are paying out of pocket for their children’s health needs. If so, families may want to consider obtaining a second insurance policy, particularly if more than one parent is employed and can get insurance through work. When considering purchasing a second insurance plan, it is important to confirm that the secondary plan covers the services that your child needs.

## How Can Families Learn More?

- ◆ Title V is a partnership between federal and state governments that helps ensure that children with special health care needs have adequate health care coverage. The toll-free national hotline number is: 1-800-311-2229 in English and 1-800-504-7081 in Spanish.
- ◆ The Medicaid program helps to pay for special, state-run programs for children with special health care needs. To get the toll-free phone number for your state's program, go to: [www.cms.hhs.gov/medicaid/tollfree.asp](http://www.cms.hhs.gov/medicaid/tollfree.asp) or call toll-free 1-877-267-2323.
- ◆ If your child receives Supplemental Security Income (SSI) benefits, in most states he or she automatically qualifies for Medicaid coverage. Call the Social Security Administration (SSA) for more information: 1-800-772-1213.
- ◆ Family Voices is a national organization of families and friends, speaking on behalf of children with special health care needs. Family Voices has family coordinators in each state who can help you figure out which programs might help you and your child. Their toll-free number is 1-888-835-5669 and their web page is [www.familyvoices.org](http://www.familyvoices.org).

*This is one in a series of fact sheets designed to help families improve their children's access to health and rehabilitative services. These publications can be obtained directly from The Consortium for Children and Youth with Disabilities and Special Health Care Needs. The Consortium is funded by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education.*

*The information presented here is based on data from a survey conducted in 1998-1999 of 2,220 parents of children with special health care needs in 20 states. The survey was conducted by Brandeis University and Family Voices. For more information on the survey, please see: Marty Wyngaarden Krauss, Nora Wells, Stephen Gulley, and Betsy Anderson. (2001). Navigating systems of care: Results from a national survey of families of children with special health care needs. *Children's Services: Social Policy, Research, and Practice* 4: 165-187.*

*For further information on these analyses, please contact the author, Valerie Leiter, Ph.D. ([leiter@brandeis.edu](mailto:leiter@brandeis.edu)) or Marty W. Krauss, Ph.D. ([krauss@brandeis.edu](mailto:krauss@brandeis.edu)) at the Heller School for Social Policy and Management, Brandeis University. Analytical assistance was provided by Kristen Stelljes.*



*For further information on the Consortium for Children and Youth with Disabilities and Special Health Care Needs, its partners or projects, please contact Tammy Edwards at [nrrtc@georgetown.edu](mailto:nrrtc@georgetown.edu)*



This project is supported by Grant H133B001200 from the National Institute on Disability and Rehabilitation Research, U.S. Department of Education.

### Notice of Non-Discrimination

In accordance with the requirements of Title VI of the Civil Rights Act of 1964, Title IX of the Education Amendments of 1972, Section 504 of the Rehabilitation Act of 1973, and implementing regulations promulgated under each of these federal statutes, Georgetown University does not discriminate in its programs, activities, or employment practices on the basis of race, color, national origin, sex, age, or disability. The statutes and regulations are supervised by Rosemary Kilkenny, Special Assistant to the president for Affirmative Action Programs. Her office is located in Room G-10, Darnall Hall, and her telephone number is 202/687-4798.