

Children with Special Health Care Needs: Minding the Gaps

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OVERVIEW — *This background paper examines the issue of children with special health care needs and their interaction with the health care system. Results from recent national and state surveys and studies were used to review the medical expenditures, utilization, and insurance coverage of these children. The paper also discusses weaknesses within the private and public delivery and financing systems that may hinder the access of certain families with children with special health care needs to important services.*

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Families with children with special health care needs (CSHCN) seek a variety of services from a complex web of public and private programs in the nation's health care, social service, and education systems. Caring for CSHCN can be an emotionally and financially draining challenge for families, particularly with respect to meeting the medical needs of these children.

Consistent access to a wide range of health care services is important to ensuring positive health outcomes for special needs children. Health insurance, whether provided privately or through public programs, is a key element for continuous access to care. The overall picture for CSHCN, in terms of insurance and access to services, appears good. However, a closer look at health care utilization, expenditures, insurance coverage, unmet need, and public program participation reveals problems within the current systems of care for certain groups of CSHCN, namely children of low-income families and children with emotional and behavioral needs. Some of these children and their families are slipping through gaps in the current health care delivery system: gaps within and between private and public insurance coverage; gaps between covered services for physical versus mental health conditions; and gaps within public safety net programs. The number of families with CSHCN falling through these system gaps is small, but their needs can be both complicated and expensive to address.

Public programs are critical to serving and supporting families with CSHCN. Substantial policy changes in the past decade [for example, Temporary Assistance for Needy Families, State Children's Health Insurance Program (SCHIP), Health Insurance Portability and Accountability Act] have affected the economic and public insurance environments for CSHCN. Congress has extended and expanded Medicaid for all low-income children in general and has recently turned its attention to CSHCN, specifically with the Family Opportunity Act. However, federal and state budget deficits, the continuously rising costs of health care, and possible restructuring of the Medicaid program, are factors that counteract efforts to expand public health programs, particularly for high-need, high-cost individuals.

As policymakers attempt to address the needs of low-income children while balancing the fiscal needs of the nation, it is important to examine the issues faced by CSHCN. Understanding who CSHCN are, what their needs are, and how they are being served in the current health care environment may facilitate discussion of how best to serve and support this vulnerable population and their families.

A BROADLY DEFINED GROUP OF CHILDREN WITH A LARGE RANGE OF NEEDS

The term “children with special health care needs” is a broad classification that encompasses children with a range of conditions and medical needs. The term can cover not only children with disabilities but also children with chronic conditions that range from mild to severe. Children with chronic physical health conditions (such as asthma, juvenile diabetes, sickle cell anemia), developmental disabilities or delays (such as mental retardation or cerebral palsy), acquired disabilities (such as paralysis or brain injury), behavioral and mental health conditions (such as attention deficit disorder, hyperactivity disorder, depression), or a combination of conditions can all be considered CSHCN.

The type and degree of medical, therapeutic, and social service needs vary among CSHCN. Some children require routine services to maintain their health; some need periodic care to treat chronic conditions; and some require frequent subspecialist visits and long-term specialized services.¹ This diverse range in need for services translates to highly variable health care expenses. Catastrophic conditions such as spina bifida can require thousands of dollars in care each month, whereas single chronic conditions such as attention deficit disorder require a couple hundred dollars in care per month.

The type and degree of medical, therapeutic, and social service needs vary among CSHCN.

As with any group, defining a population is necessary in order to assess its numbers and needs. Yet there is no uniform definition of CSHCN. States, insurers, providers, and public programs use different definitions and strategies to identify CSHCN for various purposes. The federal Social Security Administration (SSA) definition for childhood disability focuses solely on functionality, but CSHCN definitions can be based on different factors, capturing children with different levels of medical, social, and educational needs.² CSHCN can be defined on the basis of services needed, limits in ability to function, diagnosis, or categorical eligibility in a program [for example, Supplemental Security Income (SSI), which is discussed later in this paper].³

Assessing the size and needs of the CSHCN population is further complicated by the limited availability of standardized data at the national and state level. Administrative data on diagnosis and use of services is

used by certain programs (for example, Medicaid, and SCHIP) to identify CSHCN. Others rely on surveys or interviews of families for data and information about CSHCN. Because there are so many differing definitions and strategies for identifying CSHCN, estimates of the size of the population vary.

For planning and policy purposes, all 50 states use a definition of CSHCN adopted by The Maternal and Child Health Bureau (MCHB) within the Health Resources and Services Administration (HRSA). The MCHB definition is different in scope from the SSA definition. MCHB has defined CSHCN as “those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”⁴ This is a broad, service-based definition that includes children who are “at risk” of these conditions as well as those who have been diagnosed. It also includes “related services” not traditionally considered health services (for example, social and home care services, school and developmental programs). The purpose of this definition is to assist state CSHCN programs in planning for the needs of this population, and the inclusion of the at risk population encourages a “focus on the prevention of a primary and secondary disability.”⁵ Many researchers use the MCHB definition for CSHCN, although they may not include the at risk population in their analyses.

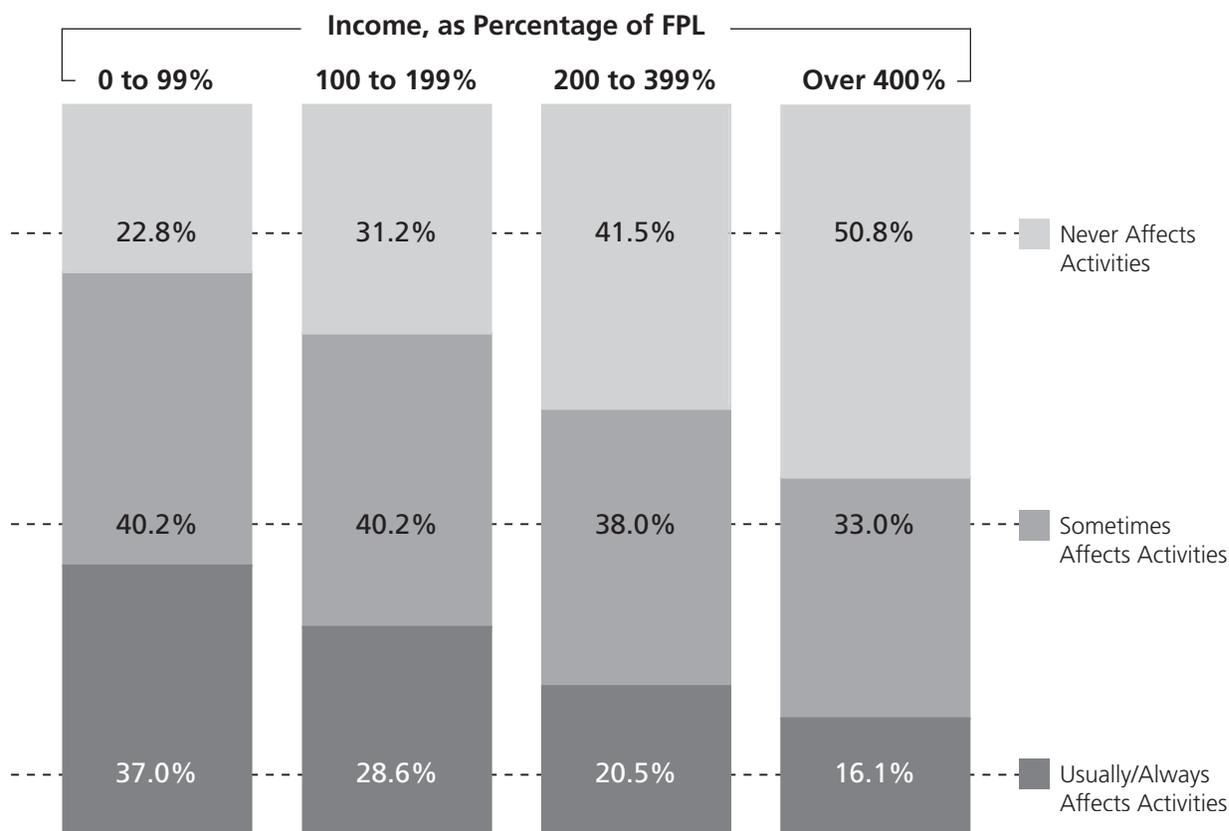
The first nationwide survey of families with CSHCN was conducted by MCHB from October 2000 to April 2002. The goal of this survey, called the National Survey of Children with Special Health Care Needs, is to assess the prevalence and impact of special health care needs among children in all 50 states and the District of Columbia. The household survey explores the extent to which CSHCN, as defined by the MCHB, have “medical homes,” adequate health insurance, and access to needed services.⁶ In each state and the District of Columbia, interviews of 750 families with CSHCN and at least 2700 non-CSHCN families were conducted.⁷

On the basis of the National Survey of Children with Special Health Care Needs, an estimated 12.8 percent of children in the United States (approximately 9.3 million individuals) have special health care needs and 20 percent of households with children include at least one child with a special health care need. Based on parent responses, nearly one-quarter of CSHCN are “affected usually, always or a great deal” in their “ability to do things other children do,” and another 37 percent are “sometimes affected by their abilities.” The remaining 39 percent are never affected in their ability to do what other children do; this group likely includes children with lower cost conditions, such as attention deficit disorder or childhood asthma.

The impact of the children’s conditions is greater among children in low-income families. Overall, 37 percent of CSHCN in poverty are “affected usually, always or a great deal,” compared with 16 percent of children in families with incomes of 400 percent of the federal poverty level (FPL) or more (Figure 1).

According to the MCHB, the reported effect of children’s conditions likely reflects the critical role of medical services, therapies, and prescription drugs in maintaining children’s ability to function like other children.⁸ Children with special health care needs are three times as likely as other children to be ill and almost three times as likely to miss school due to illness.⁹ They are also twice as likely to have unmet health care needs as

FIGURE 1
Effect of Condition(s) on Activity Level, by Family Income
(as Percentage of Federal Poverty Level)



Source: Maternal Child Health Bureau (MCHB), National Survey of Children with Special Health Care Needs: Chartbook 2001, *Health Resources and Services Administration, U.S. Department of Health and Human Services, 2004.*

other children. Without proper preventive care and treatment, they are at greater risk for complications and poor health outcomes.¹⁰

Health Care Utilization and Expenditures for CSHCN

CSHCN have different patterns of health care spending in comparison to other children. Using data from the 2000 Medical Expenditure Panel Survey (MEPS) and incorporating the MCHB definition of CSHCN,

Autism: A Puzzle with Many Pieces

Children with autism and autism spectrum disorders (ASD), five disorders with varying degrees of impairment similar to autism, are generally considered CSHCN and are considered disabled in severe cases. Autistic disorders are the fastest growing developmental disability: as many as 1.5 million Americans are believed to have autism or an ASD.* It is not clear whether the increase is due to changes in how autism and ASDs are classified and identified in people or whether there is a true increase in prevalence.

Symptoms — Autism affects brain development with symptoms and characteristics ranging from mild to severe. Autistic children typically have difficulties with social interaction, such as failure to develop age-appropriate peer relationships; problems with verbal and nonverbal communication, such as speech delays; and repetitive behaviors, such as inflexible adherence to routines and rituals. Dysfunctional behaviors such as rocking, hand slapping, head banging, sleeping and eating problems, attention deficits, hyper- and/or hypoactivity are common.** Many autistic children have impairments in one or more senses (for example, auditory, visual, tactile, taste) that affect the way they process information and may make it difficult for them to withstand normal stimulation. It is not uncommon for a child with autism to appear to “shut off from the world” due to sensory overload.

Cause — There is no known single cause of autism. Genetics and environment are both believed to play a role. The possibility of a link between vaccines and autism has been hotly debated. A 2001 report by the Institute of Medicine concluded that the “evidence favors rejection of a causal relationship between the MMR vaccine and autism.”†

Diagnosis — There are no medical tests for diagnosing autism. Diagnosis is based on observation of a child’s communication, behavior, and developmental levels.

Treatment — There is also no cure for autism. Therapies and behavioral interventions are used to help children develop social and language skills. Medication is used to address symptoms of anxiety, depression, obsessive-compulsive disorders, hyperactivity, and impulsivity.

With the right mix of interventions, most children with autism are able to improve their behavior and social and communication skills.

* Autism Society of America, “What is Autism?” available at www.autism-society.org/site/PageServer?pagename=whatisautism.

** Stephen M. Edelson, “Overview of Autism,” Center for the Study of Autism, Salem, Oregon, 1999; available at www.autism.org/overview.html.

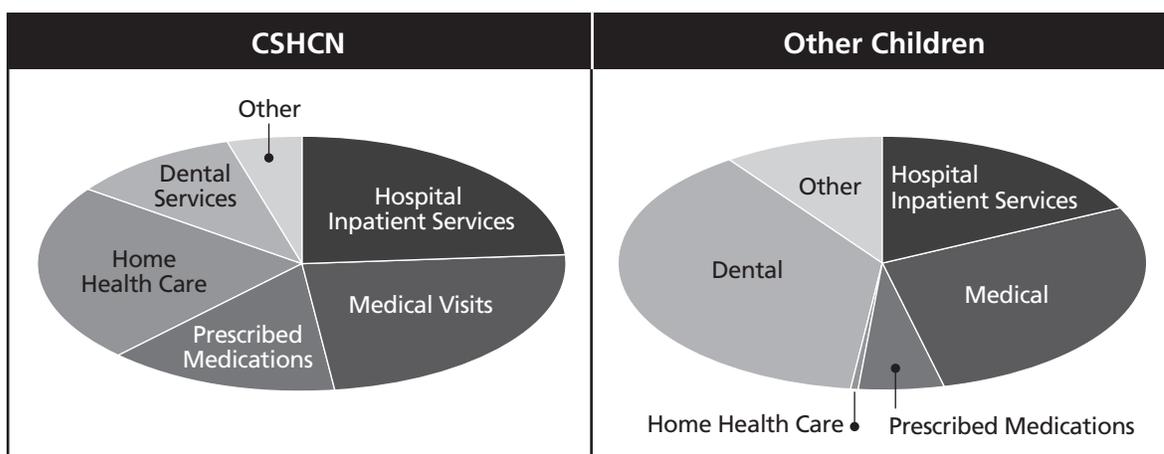
† Institute of Medicine of the National Academies, “Immunization Safety Review: Vaccines and Autism,” press release, May 17, 2004; available at www.iom.edu/report.asp?id=20155.

researcher Paul Newacheck found the composition of health expenditures for CSHCN to be different from that for other children (Figure 2). For example, prescription medications and home health care together account for one-third of health care expenses for CSHCN but account for only about one-twentieth of spending for other children. In contrast, dental care accounts for about one-tenth of total average health expenditures for CSHCN but more than one-third of expenditures for other children.

In general, CSHCN use more health services than other children and therefore have significantly higher health care expenses.¹¹ Newacheck's analysis found that CSHCN use much higher levels of inpatient hospital services than other children.¹² They have over three times as many hospitalizations and spend about seven times as many days in hospitals as other children. Special needs children make more than twice as many physician visits and almost seven times as many nonphysician visits as other children. These children have one and one-half times as many visits to the emergency department and receive five times as many prescribed medications as other children.¹³

This greater use of medical services by CSHCN results in much higher health care expenditures. The Newacheck analysis shows that total health care expenditures for children with special needs are more than three times the average for other children: \$2335 for the children with special needs versus \$652 for other children. Hospital inpatient care expenditures are almost five times higher than the average for other children, nonphysician

FIGURE 2
Patterns of Health Expenditures for CSHCN and Other Children, 2000



Source: Telephone conversation with Dr. Paul Newacheck, May 18, 2005; 2000 Medical Expenditure Panel Survey, as cited in Paul Newacheck and Sue E. Kim "National Profile of Health Care Utilization and Expenditures for Children with Special Health Care Needs," *Archives of Pediatrics and Adolescent Medicine*, 159 (January 2005): 10–28. Please note that data in article was found in error after publication. Author must be contacted for the correct data tables; he can be contacted at pauln@itsa.ucsf.edu.

services are almost six times higher, and average prescription drug expenditures are nine times higher for children with special needs.

Average out-of-pocket expenditures for CSHCN are twice those for other children (Table 1). Although absolute out-of-pocket expenses are higher for children with special needs, the Newacheck analysis found that CSHCN have better financial protection against out-of-pocket expenditures relative to total health care expenses. In particular, CSHCN are best protected against hospital and home health expenses: less than 1 percent of inpatient hospital and home health services are paid out-of-pocket among this group. This reflects the higher rate of insurance coverage for CSHCN compared with other children.

TABLE 1
Average Total Health Care Expenditures and
Out-of-Pocket Expenditures for CSHCN and Other Children

Expenditures, by Services	CSHCN	Other Children
Hospital Inpatient	\$ 552	\$ 116
Physician	412	160
Prescribed Medications	329	34
Nonphysician*	146	25
Emergency Department Visits	67	47
Home Health	525	3
Dental	242	249
Other	9	17
Average Total Health Care Expenditures	\$ 2335	\$ 652
	▼	▼
Total Paid Out-of-Pocket	\$ 343	\$ 171
Percent Paid Out-of-Pocket	14.7%	26.2%

* Includes nurses and nurse practitioners, physician assistants, optometrists, podiatrists, occupational therapists, physical therapists, psychologists, social workers, chiropractors, midwives, or other medical providers.

Source: Telephone conversation with Dr. Paul Newacheck, May 18, 2005; 2000 Medical Expenditure Panel Survey, as cited in Paul Newacheck and Sue E. Kim "National Profile of Health Care Utilization and Expenditures for Children with Special Health Care Needs," Archives of Pediatrics and Adolescent Medicine, 159 (January 2005): 10–28. Please note that data in article was found in error after publication. Author must be contacted for the correct data tables; he can be contacted at pauln@itsa.ucsf.edu.

The distribution of total and out-of-pocket expenses for CSHCN are highly skewed. A small portion of the population accounts for a large portion of total expenses. The median total expense for health care for CSHCN is \$558. Ten percent of this population, however, have expenses of \$4304 or more. These high cost individuals account for 61 percent of all health care expenses for CSHCN. The distribution of out-of-pocket expenses is similar. The median amount for annual out-of-pocket expenses for health care among families with CSHCN is \$100. For 10 percent of these families, however, expenses total \$811 or more, accounting for 54 percent of out-of-pocket expenses for CSHCN population. This leads to the conclusion that the burden of total and out-of-pocket expenses for CSHCN is concentrated among a small group of families.

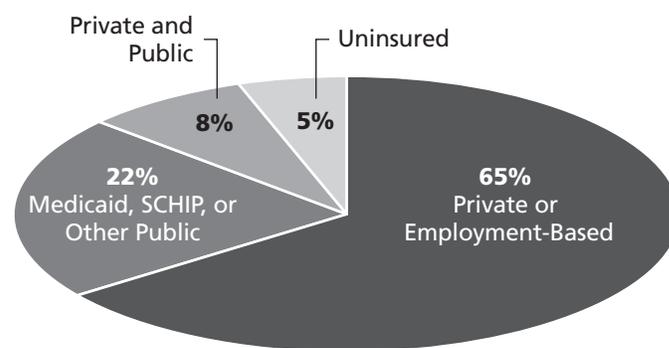
CSHCN and Health Insurance

Insurance coverage improves access to care and reduces out-of-pocket expenditures. Compounding the incentives for families with CSHCN to acquire insurance is the multitude of medical services often needed and the magnitude of out-of-pocket expenses families would face without coverage. Most CSHCN have health insurance. The distribution of coverage by type of insurance differs between CSHCN and other children. Using the 2000 and 2001 National Health Interview Survey (NHIS), researcher Amy Davidoff found that, in comparison to other children, “CSHCN have higher rates of public insurance (29.8 percent versus 18.5 percent), lower rates of private insurance (62.5 percent versus 69.1 percent), and a smaller percentage without insurance (8.1 percent versus 11.5 percent).”¹⁴

From a big picture perspective, one could conclude that CSHCN have adequate access to insurance. Almost 95 percent of families with CSHCN report having some form of health insurance in the 2001 National Survey of Children with Special Health Care Needs, with 65 percent reporting coverage through private or employment-based insurance. Source of insurance is affected by income (Figure 3). Across all income groups, 22 percent of families with CSHCN report coverage through public insurance (for example, Medicaid, SCHIP); among families in poverty, this figure climbs to more than 66 percent. Private or employer-based insurance covers approximately 65 percent across all income groups and 80 percent for CSCHN in families with incomes above 200 percent of the FPL.¹⁵

For low-income families with CSHCN, access to insurance remains a problem. Special needs children from low-income families are more than twice as

FIGURE 3
Percentage of Types of Insurance Coverage for CSHCN, 2001



Source: Maternal Child Health Bureau (MCHB), National Survey of Children with Special Health Care Needs: Chartbook 2001, Health Resources and Services Administration, U.S. Department of Health and Human Services, 2004.

likely to be uninsured for some or all of the year than those with family incomes at or above 200 percent of the FPL (Table 2).¹⁶ Davidoff found that over 13 percent of CSHCN in families with incomes less than 200 percent of the FPL are uninsured compared with 4 percent of CSHCN in families with incomes greater than 200 percent of the FPL.¹⁷ There are large differences between CSHCN and other children with respect to employer-sponsored insurance coverage and other private insurance coverage as well.

For low-income CSHCN who are not eligible for public insurance, access to private insurance can be limited. Most workers have access to group insurance through an employer, and most CSHCN have a working parent in the home. However, a smaller percentage of parents of CSHCN work full time compared with other parents, and part-time workers are less likely to be eligible for employer-sponsored coverage.¹⁸ Coverage for CSHCN families employed in small firms may be subject to underwriting, reducing the likelihood that an employer would offer coverage at all or with a premium that is affordable. Private nongroup insurance often proves to be unaffordable for many families with CSHCN.

Newacheck *et al.* found that the high cost of health insurance was the reason most cited for lack of insurance by three out of four families with uninsured CSHCN.¹⁹ Job loss, layoff, or other employment concerns was the next most common reason (cited by one out of ten families) for lack of insurance.²⁰

Unable to afford private coverage but too “wealthy” to qualify for public insurance coverage, these families may find themselves falling through the gap between the public and private insurance systems. In the media, cases have been reported in which families, unable to afford private insurance coverage, take extreme measures to qualify for public insurance coverage. These measures include moving to states with more generous Medicaid income eligibility requirements, adoption and foster care placement of a special needs child, institutionalization of the child, and deliberate impoverishment of families to meet financial eligibility requirements. A Brandeis University and Family Voices study found that 64 percent of families with severely disabled children interviewed say they are turning down jobs, promotions, and overtime pay, to keep family incomes low enough to qualify for or maintain public health coverage.

TABLE 2
Percentage of Types of Insurance Coverage for CSHCN, 2000-2001, by Income

Insurance Type	All Income	Income <200% FPL	Income >200% FPL
Any Private	62.5%	33.5%	84.6%
Employer-Sponsored	61.6	32.6	83.7
Nongroup	3.4	2.8	3.9
Any Public*	29.8	54.9	10.7
Multiple Coverage	7.5	6.3	8.4
Uninsured	8.1	13.2	4.2

* Excluding Medicare

Source: 2000, 2001 National Health Interview Survey, as cited in Amy J. Davidoff “Insurance for Children with Special Health Care Needs: Patterns of Coverage and Burden on Families to Provide Adequate Insurance,” *Pediatrics*, 114, no. 2, (August 2004): 394–403.

CSHCN Have More Unmet Needs

Access to insurance does not remove all barriers to needed services. Quality of coverage in terms of benefits, provider networks, and specialist availability is a critical component of “adequate” insurance for CSHCN. Noninsurance issues such as transportation, provider competence, and language barriers also affect access to services, as well as whether needs are met.

CSHCN require a variety of services, both medical (such as hospital and physician services) and nonmedical (such as counseling, therapy, and social services). Insurance plans vary tremendously in their scope of covered services and the level of coverage for such services. Access to adequate insurance and a medical home are important factors for meeting the various needs of CSHCN. CSHCN have higher levels of unmet need for medical services than other children (5.3 percent versus 1.6 percent), and children with more severe conditions are more likely to have unmet medical needs than other CSHCN.²¹ CSHCN in poverty or near poverty are more likely to report lack of insurance and lack of a medical home. Davidoff’s study of the 2000 and 2001 National Health Interview Survey found that almost 20 percent of low-income CSHCN experienced some form of unmet need.²²

Children most affected by their disability or condition to “do what other children do” are more likely to find their insurance coverage inadequate to meet their variety of needs. In the National Survey of Children with Special Health Care Needs, 44 percent of families with children who are affected “usually, always, or a great deal” by their conditions report that their plan does not meet all their needs compared with 26 percent of families with children whose condition “never affects their abilities.”

Unmet needs for specialty care occurs more frequently than unmet needs for routine care. Almost three-quarters of all CSHCN report needing routine care, and over half report needing subspecialty physician care. Of the children needing routine services, 3.2 percent are unable to obtain these services. Of the children needing specialty services, 7.2 percent report not being able to obtain all needed specialty care.²³ The availability of pediatric subspecialty care may be a contributing factor to this. Low reimbursement rates may keep provider subspecialists from participating in plans. This is particularly a concern regarding mental health service providers. A review of Medicaid claims data found that children with a variety of chronic conditions relied on generalists for their medical care, raising the question of whether access to pediatric subspecialty care is adequate.²⁴

With its broader coverage and reduced out-of-pocket burden, it would be reasonable to expect public insurance to provide more adequate coverage than private insurance for low-income children, but there is little evidence that public insurance does a better (or worse) job in meeting the needs of CSHCN compared with privately insured children.²⁵ According to the

National Survey of Children with Special Health Care Needs, families with CSHCN in public insurance programs are more likely to report problems with coverage than privately insured families (37 percent versus 32 percent); however, this difference is not found to be statistically significant.²⁶

Private Insurance: Higher Costs for CSHCN

Nearly two-thirds of children with special needs are insured through private or commercial employer-based health insurance. Families with CSHCN with private insurance often face high out-of-pocket costs for deductibles, additional cost sharing for covered services, exclusion of particular benefits, use of a medical necessity standard that does not reflect the developmental needs of children, and annual or lifetime benefit limits. The CSHCN population represents a small proportion of children enrolled in commercial plans and a disproportionate share of total costs.

A review of administrative and claims data (1999–2001) for children enrolled in two employer-sponsored UnitedHealth plans shows that CSHCN represent 12 percent of all enrolled children and almost half the total costs of care for all children in these plans.²⁷ Their per member–per month (PMPM) expenses are nearly four times higher than those of other children. In addition, the costs of CSHCN are highly variable. CSHCN with catastrophic conditions (for example, leukemia, cystic fibrosis, spina bifida) had average PMPM costs of \$2,867, whereas children with a single minor chronic condition such as Attention Deficit Hyperactivity Disorder (ADHD) have average PMPM costs of \$159.²⁸

Adequacy of private insurance coverage for CSHCN and risk of out-of-pocket expenditures varies by service. A review of contract documents for the most commonly sold health maintenance organization (HMO) and preferred provider organization (PPO) products in 1998 found that the plans “covered most basic medical services—physician services, and inpatient and outpatient hospital services...and nearly all covered preventive care and immunizations.”²⁹ This study, by the Maternal and Child Health (MCH) Policy Research Center, found that “almost all (plans) covered most behavioral health services including inpatient and outpatient mental health and substance abuse treatment.”³⁰

However, the same study notes that coverage of specialized services varied greatly, with “half or fewer offering audiology and optometry services, nutritional counseling and medical supplies.” Ancillary therapy and mental health services were benefits least likely to be available in the amounts considered necessary by medical experts. This is predominately due to access restrictions and narrow definitions of medical necessity. Coverage for behavioral health and specialized services was “usually subject to visit or monetary limits and usually condition or treatment exclusions as well.” In

The CSHCN population represents a small proportion of children enrolled in commercial plans and a disproportionate share of total costs.

addition, behavioral health services were found to have the highest cost-sharing charges, and certain goods and services—namely eyeglasses, hearing aids, all substance abuse services, medical equipment, and home health services—were most likely to be subject to annual or lifetime dollar limits. Furthermore, coverage for other services such as cognitive testing, residential treatment, and partial hospitalization were excluded from some plan contracts. Prescription drugs were not covered in about 20 percent of the plans examined.

Study authors Fox, McManus, and Reichman concluded that “children requiring ancillary therapy and behavioral health services, as well as those requiring home health care, were least likely to have their service needs met” by the most commonly sold HMO and PPO products.³¹ “Benefit amounts were typically less than what was recommended, and a variety of restrictive provisions, such as exclusions of treatment for developmental disabilities or behavioral conditions, often impeded these children’s access to otherwise available coverage.”³²

Enrollee experiences with such benefits under UnitedHealth employer-sponsored plans appear to be in line with these findings. CSHCN families in the UnitedHealth plans covered proportionally more of the costs for mental health visits (30.8 percent) compared with all other service categories.³³ In addition, CSHCN enrollees paid over 25 percent of their total prescription drug costs.

Benefit restrictions, condition and treatment exclusions, and high cost-sharing requirements for certain services disproportionately affect CSHCN in need of mental health services. Thirty-seven percent of the CSHCN enrolled in UnitedHealth plans had emotional or behavioral disorders.³⁴ Prescription medications accounted for the largest proportion (22 percent) of the total PMPM costs, and mental health visits accounted for 11 percent of the total costs for this segment of the CSHCN population.³⁵ They paid more in copayments and deductibles than other CSHCN families. In short, families with children with emotional or behavioral disorders under these plans pay for a substantial portion of the costs of the services that their children use frequently, namely mental health services and prescription drugs.

PUBLIC PROGRAMS: CRITICAL TO FAMILIES

Historically, public programs have been a particularly important source of insurance and health services for CSHCN. The three federally funded public health care programs serving CSHCN—Title V, of which 85 percent of funds go to the Maternal and Child Health Services Block Grant; Medicaid; and the State Children’s Health Insurance Program (SCHIP)—play unique roles in the public health care delivery system. Each is a federal and state matching program. Title V is a source of federal funds for states to develop and support primary and specialty care services, whereas Medicaid and SCHIP cover services for children of low-income families.³⁶

In FY 2004, approximately \$730 million in federal funds was appropriated to Title V. The vastly larger Medicaid program's federal spending reached \$177 billion, whereas SCHIP received a federal allotment of \$3 billion that year.

Together, these programs provide many CSHCN with a comprehensive safety net of insurance and specialty care services. However, financing limitations and state discretion with respect to benefit design, financing, eligibility, and administrative rules can prevent enrollment of some CSCHN in any of these programs and leave others who are enrolled with limited or no access to certain needed services. Coordination among the programs can help fill certain coverage gaps; however, this does not always occur. Although coordination between Title V and Medicaid is required as a condition for funding under their respective statutes, there is no similar language with regard to SCHIP. The SCHIP statute contains only broad requirements for states to describe procedures used to coordinate with "other sources of health benefits coverage for children, and relevant child health programs."

Title V and the Maternal and Child Health Services Block Grant

Title V is one of the nation's oldest health programs and a cornerstone of maternal and child health policy. Part of the 1935 Social Security Act, Title V funds programs that serve more than 27 million women, infants, and children every year, including 1.1 million children with special health care needs.

Title V has three components: the Maternal and Child Health Service Block Grants to states; a set-aside for special projects of regional and national significance (SPRANS); and another set-aside for the community integrated services systems (CISS) program. Eighty-five percent of the Title V appropriation is allocated to the state block grants according to a formula based on the number of low-income children in a state and on each state's historical levels of funding for the various Maternal and Child Health (MCH) programs that were combined into the block grant under Title V in 1981.

Services for special needs children is one of the original purposes of Title V. Initially, the special needs component of Title V was designed to assist states in the development of services for children with polio, commonly referred to as the "crippled children's program." Congress has amended the program over the years, expanding and restating its goals to reflect current concerns regarding child health. The focus of Title V services for CSHCN, however, has remained rooted in care for children with physical disabilities.

The MCH block grant component of Title V is a discretionary federal grant program. States direct block grant funds to local health clinics, health centers, and hospitals. The federal funds, along with a state matching

The focus of Title V services for CSHCN remains rooted in care for children with physical disabilities.

contribution (three state dollars for every four federal dollars), are used to provide access to maternal and child health care, especially for low-income women and children, and to support services that help families access care, including health education, case management, transportation, translation, and home visiting services.

Direct health care services provided under Title V programs are intended to be supplemental to fill in coverage gaps. For CSHCN, these include medical and surgical subspecialty services, occupational therapy, physical therapy, speech, hearing and language services, respiratory services, durable medical equipment and supplies, home health care, nutrition services, care coordination, and early intervention services.³⁷ Thirty percent of Title V block grant funds are reserved for family-centered, community-based programs for children with special health needs.

A handful of states have used their Title V programs to attempt to fill the gaps in coverage for CSHCN.³⁸ Even in states with coordination between Title V and SCHIP, families with children with extensive behavioral health needs find it difficult to navigate the system, and once they do, they still face gaps in coverage.³⁹ The majority of Title V agencies exclude coverage for inpatient and outpatient mental health services.⁴⁰

State Title V program services and expenditures vary from state to state. Beyond broad federal expenditure rules (for example, 30 percent for CSHCN), states determine the actual services provided under the block grant, as well as determine eligibility criteria. State investment in direct health services, the largest component of expenditures under the block grant, is affected by the comprehensiveness of Medicaid and SCHIP benefit packages offered by the state, the percentage of uninsured women and children in the state, and the perceived need for providing services excluded from the Medicaid and SCHIP programs.⁴¹

Medicaid and CSHCN

Medicaid is the single largest source of health insurance—public or private—for children with special health care needs. With its unique package of benefits designed for chronic and long-term care needs, Medicaid has the capability to address the various needs of CSHCN. In comparison to private insurance plans, Medicaid usually offers a more comprehensive benefit package with little to no cost sharing. Most state Medicaid programs offer a wide array of therapies and services, including those important to CSHCN such as mental health benefits, customized durable medical equipment, occupational therapy, physical therapy, speech therapy, rehabilitative services, and case management services that are designed to assist beneficiaries in getting medical, social, educational, and other services. Medicaid also provides personal care services (that is, assistance with basic daily activities such as bathing and dressing). Through waivers, states can offer respite care benefits as well, which provide relief to a primary caregiver for a disabled beneficiary.

As discussed, private insurance plans often restrict access to and payment for certain services valued by CSHCN (for example, mental health services, various therapies). State Medicaid programs may also have limits on benefits and services. However, Medicaid offers children a unique benefit in the form of mandatory Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services to help ensure children receive medically necessary services.

EPSDT provides children with a special entitlement to health care. Established in 1967 and expanded by Congress several times since the mid-1980s, the EPSDT benefit is designed to screen Medicaid children

at periodic intervals to detect, diagnose, and treat physical and mental health problems. This preventive role of EPSDT was conceived to diagnose and treat conditions before they became functionally limiting and costly. The treatment component of this service, mandated by Congress in the Omnibus Budget Reconciliation Act (OBRA) of 1989, requires states to cover any service or item that is medically necessary to “correct or ameliorate defects and physical and mental illnesses and conditions, regardless of whether the service or item is covered under the state Medicaid program”.⁴² This treatment requirement provides children with “wraparound services,” such as coverage for eyeglasses, home nursing, dental services, etc. As a result, Medicaid can provide CSHCN with a scope of benefits that is generally not matched in the private sector. This makes Medicaid attractive to families with CSHCN.

There are several paths to Medicaid eligibility for CSHCN. Some are mandated by federal statute; however, most are optional for state Medicaid programs. The four primary paths to Medicaid coverage for CSHCN are SSI, medically needy programs, Katie Beckett programs, and Home and Community Based Services Waivers. These particular pathways to eligibility are driven by disability status and medical need. CSHCN can also qualify for Medicaid under standard rules that are based on income and resources alone. Although Medicaid offers CSHCN several pathways to eligibility, families with CSHCN nevertheless face challenges obtaining and maintaining Medicaid eligibility and services.

Supplemental Security Income (SSI) — Eligibility for SSI, an income support program administered by the SSA, is the most common path to Medicaid for CSHCN. Approximately 18 percent of the CSHCN population receives SSI benefits. SSI was created in 1972 to federalize financial support to the elderly, blind, and disabled. In order to qualify for SSI, an individual must meet a federal definition for disability as well as strict thresholds regarding income and assets. A child is considered disabled under SSI if he or she has a physical or mental condition (or a combination of conditions) that results in “marked and severe functional limitations.”⁴³ The condition must be expected to last 12 months or be expected to result in death.

Medicaid offers children a unique benefit in the form of mandatory Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services to help ensure children receive any medically necessary service.

By the end of 2003, approximately 960,000 children were receiving SSI payments that averaged \$486 per month.⁴⁴ Most states provide automatic Medicaid eligibility to individuals entitled to SSI.

Loss of SSI generally means loss of Medicaid. Children in families experiencing an increase in income that exceeds the strict eligibility thresholds established under SSI are removed from SSI rolls and therefore lose their Medicaid coverage, unless they qualify for Medicaid through another eligibility path. In addition, SSI eligibility rules can create incentives for families not able to afford the financial and medical needs of a child with special needs to institutionalize that child in order for him or her to be eligible for Medicaid. SSI does not count parent income and resources toward eligibility once a child is in an institution for 30 days.

Medically needy programs — States have the option to extend Medicaid eligibility to individuals not qualifying for Medicaid because their income is too high. By deducting medical expenses from income, individuals can “spend down” to state-defined income thresholds that qualify them for Medicaid. This program mostly serves adults and individuals in nursing homes; however, some families with CSHCN can qualify for Medicaid through this program.

Medically needy eligibility can result in episodic Medicaid coverage because eligibility is tied directly to medical need expenditures. If expenses vary greatly, such as with conditions like acute asthma, children may move on and off Medicaid with regular frequency. This can disrupt a CSCHN’s medical home and access to continuous care.

Katie Beckett programs — The Katie Beckett option, created under the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982, allows states to cover home and community-based services for children who would otherwise need to be cared for in a medical institution. Children qualifying for Medicaid eligibility under the Katie Beckett option are entitled to the full array of Medicaid services. Eligibility is based on the child’s disability and care needs without regard to family income and resources. In order to be eligible, the child must meet the federal definition for disability under SSI; they must need the level of care normally provided in a hospital, nursing home, or Intermediate Care Facility for Mental Retardation (ICF-MR) and be able to be cared for at home instead of in the institution. In addition, the cost of care in the community cannot be more than the estimated cost of the institutional care.

States are provided flexibility to extend Medicaid services to CSHCN populations under the Katie Beckett option; however, not many are taking full advantage of the statutory flexibility to serve all CSHCN. Twenty states use the Katie Beckett option for programs that expand Medicaid eligibility for CSHCN. Children with behavioral or emotional disorders, however, often find the Katie Beckett option is not available to them: only half of the Katie Beckett states include children who qualified under the option as a result of a mental or emotional disorder. This may be due to lack of awareness by

families about the existence of the option in their state. It may also be due to inappropriate or inadequate state rules that either exclude children with mental and emotional disorders or discourage their inclusion. Regardless of the cause, federal Medicaid policy requires that states provide access to the Katie Beckett option for children with mental disorders.

Home and Community Based Services Waiver programs — Under Home and Community Based Services (HCBS) Waivers, authorized under section 1915(c) of the federal Medicaid statute, state Medicaid programs are permitted to offer expanded home and community-based services to children or adults with physical or mental disabilities as an alternative to institutional care. Under these waivers, states have the flexibility to extend coverage to people who otherwise would be ineligible for Medicaid, due to income and resources, and to offer an expanded array of services. Federal law specifies that a child require care in a medical institution (for example, a hospital, nursing home, or institution for mental retardation—not a residential treatment center) and that home and community-based services be an appropriate option. Furthermore, 1915(c) waiver programs must be budget neutral, meaning the cost of care in the community cannot exceed the cost of care in an institution.

Children receiving services under a 1915(c) waiver are only eligible for the services offered under the waiver and therefore are not entitled to all Medicaid services. In addition, states can impose restrictions on their 1915(c) waivers, such as targeting certain populations and/or geographic areas for services and limiting the number of children the waiver may cover.

Currently, children with mental or emotional disorders find that participation in 1915(c) waivers is not an option for them: only three states have 1915(c) waivers to cover services for these children.⁴⁵ In comparison, 49 states have waivers for people with developmental disabilities.⁴⁶ This is predominately due to the federal definition of “medical institution.” Residential treatment facilities are not currently referenced in the federal definition of medical institution; therefore, states cannot divert children from these facilities to community-based care.

Currently, children with mental or emotional disorders find that participation in HCBS waivers is not an option for them.

SCHIP Services for CSHCN

The primary goal of SCHIP is to extend health insurance coverage to the estimated 10 million uninsured low-income children in America. This capped entitlement to states is designed to serve low-income children not eligible for Medicaid. States can choose to expand their existing Medicaid programs or design a different insurance program within certain parameters. SCHIP presents an opportunity to provide insurance to CSHCN. Approximately 17 percent of low-income uninsured children have disabilities and chronic conditions; these children also represent roughly one of every six children eligible under SCHIP.⁴⁷

Little is known about CSHCN enrolled in SCHIP. A review of a few state SCHIP programs under the Child Health Insurance Research Initiative (CHIRI) found that Florida, New York, Kansas, and Indiana were successful in enrolling CSHCN.⁴⁸ In these states, the prevalence of CSHCN in SCHIP was equal to or greater than that of the general population.⁴⁹ In these states, CSHCN appeared to be more connected to the health care system before SCHIP enrollment than other children, but CSHCN had more unmet health care needs—most commonly mental health, specialty care, and prescription medications.⁵⁰

Separate SCHIP programs (that is, not Medicaid expansions) typically provide less extensive benefits and services than state Medicaid programs.⁵¹ Rosenbaum *et al.* found the majority of the 35 separate SCHIP programs have early childhood preventive and developmental services that are considerably less comprehensive than the standard of coverage under Medicaid.⁵² SCHIP coverage is often described as “much better” than typical private coverage; however, benefit designs in most original SCHIP programs did not focus on CSHCN.⁵³

An assessment of program benefit and cost-sharing information by the MCH Policy Research Center concluded that separate SCHIP programs “generally cover a broad range of services and generally provide excellent coverage for children with a wide variety of special health care needs.”⁵⁴ The assessment also determined, however, that limits on mental health coverage, such as outpatient mental health and substance abuse services, lack of coverage for residential treatment, lack of coverage for partial hospitalization, and lack of coverage for family therapy, are common barriers to access for children with mental health or developmental health conditions. The assessment also found that a significant number of states charge copayments for outpatient mental health therapy, outpatient substance abuse therapy, and occupational therapy.

THE FAMILY OPPORTUNITY ACT

The Family Opportunity Act (S.622), first introduced in 2000, addresses some of the gaps in the Medicaid program for low-income families with CSHCN. This bill would allow state Medicaid programs to cover children under the age of 18 who meet the SSI definition of disability but do not meet the income or asset restrictions. Families with incomes below a state-defined threshold less of than 250 percent of the FPL (that is, \$48,375 for a family of four in 2005) would be permitted to buy into Medicaid with a premium based on their income. These families would be required to purchase private health insurance through their employer if the employer-sponsored plan offers family coverage and subsidizes at least 50 percent of the cost of premiums. From the states’ perspective, these premium and employer insurance wraparound aspects make this proposed option an appealing alternative to waivers because states can implement the buy-in option without having to file waiver applications, wait for federal approval and/or renewal, or adhere to certain federal requirements.

As a result of this bill, Medicaid would be expanded to include higher income groups without insurance as well as wrap around employer-sponsored insurance coverage for families with CSHCN for whom insurance is available. The Congressional Budget Office (CBO) estimates that during the first year enrollment in Medicaid would increase by about 90,000. Enrollment would continue to increase between 140,000 and 150,000 new enrollees annually as more states implement the new option. CBO estimates that 65 percent of the additional enrollees would have private health insurance from an employer that pays at least 50 percent of the premium costs. Another 15 percent of those newly eligible would have employer-sponsored insurance with less than 50 percent of premium costs covered by the employer. The remaining 20 percent otherwise would be uninsured.

Other provisions designed to assist families with CSHCN include permitting states to allow children from residential treatment facilities to participate in 1915(c) HCBS waiver programs and expanding the Family to Family Health Information Centers (F2FHICs) program. F2FHICs are designed to be information and outreach centers for families with CSHCN navigating the private and public health care systems. These family-run centers were established to assist families with CSHCN to promote good treatment decisions, cost-effectiveness, and improved health outcomes. In addition, F2FHICs are charged with identifying successful delivery models, providing information on the health care needs and resources available, and encouraging collaboration between families with CSHCN and health care professionals.⁵⁵ Currently, 16 F2FHICs are financed through federal demonstration programs funded by HRSA and CMS. The Family Opportunity Act would permanently authorize funding for F2FHICs under the Maternal and Child Services Block Grant.

The Family Opportunity Act has stalled in Congress. Although it has passed the Senate twice—due largely to the strong support of Senator Grassley (R-IA), a sponsor of the bill and chairman of the Senate Committee on Finance—the bill has failed to pass the House primarily due to cost and financing mechanisms. CBO estimates the cost of the bill would be more than \$7 billion over 10 years. In addition to the cost, some lawmakers are concerned about expanding the Medicaid program. Some believe the bill would distort Medicaid's original mission of serving the nation's neediest. Others, however, emphasize that the bill helps keep families with CSHCN together and employed, allowing them to be independent and productive. Congress has created a reserve fund in the fiscal year 2006 budget resolution. This allows for funding for the Family Opportunity Act in 2006 as long as it does not affect the deficit. Funding cuts from other federal programs are needed.

CBO estimates the cost of the Family Opportunity Act would be more than \$7 billion over 10 years.

CONCLUSION

The challenges to families caring for CSHCN are great, and access to adequate health care is critical. There is a wide range of comprehensive services available to CSHCN, many of whom have had success in accessing them. However, the cost of caring for CSHCN falls unevenly among families. Low-income families with CSHCN face barriers to insurance coverage and high out-of-pocket costs, whereas children with behavioral and emotional disorders may find benefit limits and high cost-sharing requirements. The Family Opportunity Act proposes to address these issues through a buy-in approach to Medicaid. However, the current budgetary climate indicates such an expansion is problematic at this time.

As budget negotiations and possible Medicaid reform discussions get under way, it is important that CSHCN and the gaps in the current private and public health care delivery systems are carefully considered. Ensuring consistent access to a wide range of health care services necessary to meet the often complex needs of CSHCN may be difficult and expensive. However, if a measure of a society's success is how well it cares for its children, then the provision of health care services to children with special health care needs is a critical marker by which to measure that success.⁵⁶

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