One measure of a society’s goodness is how well it cares for its children. This standard has particular importance for vulnerable groups of children, such as those facing special health challenges. Thus, the level of care that children with special needs receive through public programs could be seen as a critical marker of the success of the nation’s publicly funded health insurance programs. This article reviews the characteristics of children with special health care needs, the types of publicly funded programs that serve them, and the challenges and opportunities involved with providing them with quality health care. It concludes by offering suggestions for improvement, such as enhancing outreach strategies and fostering collaboration across programs.

Who Are Children with Special Health Care Needs?

The term “special health care needs” (SHCNs) has been defined in a number of ways. In general, the children in this category tend to have a high need for services with correspondingly high health care costs. They also rely heavily on special care and ancillary services. In addition, they are especially vulnerable to adverse health outcomes. (See Box 1 for a profile of this group of children.) To plan and evaluate health care coverage for children with SHCNs, policymakers and administrators require information about the size and needs of this population. Yet, no uniformity exists in the way different states or programs identify children with SHCNs.

The number of children who meet the criteria for having SHCNs varies with the definition and the strategy used to identify them. In the past, providers limited their definition to children with specific diagnoses (for example, cystic fibrosis), clear impairments in functioning (for example, blindness), or severe limitations in daily activities. More recently, both the definition of children with SCHNs and the role of programs that serve them have been broadened.1 By current definition, children with SCHNs are those who have (or are at increased 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,” according to the Maternal and Child Health Bureau (MCHB). The broader definition includes children with chronic physical, mental, developmental, and behavioral needs. It also encompasses services not traditionally considered part of the domain of “health care” such as early intervention, school and developmental programs, mental health, social and home care services, and other programs that support families in their caregiving.

Different strategies for identifying children with SHCNs also contribute to varying estimates of the size of this population. In order to aggregate data on this population at the state level, state Medicaid programs

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generally apply their state’s definition to readily available administrative data sets with information on children (such as diagnosis and use of services). To estimate how many children are affected nationwide, surveys or interviews with parents are often used. Two studies examined parent responses from a national survey in light of the broad federal MCHB definition of SHCNs, and estimated that from 14.8% to 18.2% of children had special needs. Other approaches tend to identify fewer children. For example, examining insurance plan administrative data or lists of children enrolled in special programs identifies a lower prevalence rate of children with SHCNs.

Reaching a consensus about defining and identifying the population of children with SHCNs would be helpful in designing publicly financed programs to meet their needs, and assessing the quality of care they are provided. Defining this population in a similar manner across states and publicly financed programs is crucial in order to allow program comparisons and trend analyses. In addition, this information would make possible a...
...the variety of public programs and delivery systems for children with SHCNs poses a difficult challenge in evaluating the overall care of this population.

national effort for broader coverage of children with SHCNs with an adequate benefit structure and services. However, such standardization appears unlikely.15

Key Indicators of Program Quality

Beyond identifying the population, a useful strategy for assessing how well publicly funded insurance programs work for children with SHCNs is to examine key indicators of program quality that are unique to these children. Program performance can be assessed in terms of structural characteristics (such as the adequacy of benefit packages, availability of providers, and funding mechanisms), process indicators (such as the level and quality of primary and specialty care provided, and the level of care coordination), and outcome measures (such as the level of health outcomes, and levels of family and provider satisfaction). At the same time, the variety of public programs and delivery systems for children with SHCNs poses a difficult challenge in evaluating the overall care of this population. More study is needed in terms of the impact of different programs, especially the newer State Children’s Health Insurance Programs (SCHIP), on the quality of care and health outcomes for these children.

Structural Characteristics

A key indicator of program quality is the structure of the program itself: the type of program and benefits it offers, the providers it makes available, and the way it is funded. Each of these three structural characteristics has important implications for the quality of care provided children with SHCNs.

Type of Program and Benefits

With few exceptions, no universal entitlement program is available for children with SHCNs.16,17 Instead, a variety of federal, state, and local programs cover these children, including Medicaid, SCHIP, and Social Security Insurance (SSI).18 (See Box 2.) Such publicly funded programs are an important resource: More than one-third of all U.S. children with SHCNs are likely to be covered by them.19,20 Even more are likely to be eligible for coverage, but not enrolled. While the number of children with SHCNs enrolled in Medicaid managed care and SCHIP managed care plans increased dramatically in the 1990s, many more children are eligible.21 Several studies have examined the adequacy and breadth of the benefit structure of public health insurance programs with respect to children with SHCNs.22–25 Studies of Medicaid managed care suggest that these programs can improve children’s access to a medical home and facilitate tracking of enrollees, but may also limit needed services by constraining benefits, restricting referrals, and creating disincentives for primary care providers to accept children with SHCNs or to manage them optimally.26 Nevertheless, overall, Medicaid offers the most comprehensive benefit package for these children.

Every state Medicaid program—including every Medicaid expansion SCHIP program—is required to offer Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) health services that cover “medically necessary” diagnostic and treatment services for chronic conditions, and “optional” Medicaid services as long as medical screening deems the services necessary. The latter include wraparound services such as dental care, physical and occupational therapy, prescription drugs, eyeglasses, rehabilitation, social work, and home nursing.27 While many groups have opposed the wide scope of mandated services under Medicaid, the comprehensive benefit package is beneficial to children with SHCNs. States tend to interpret the “medically necessary” standard broadly, and have provided specifications regarding coverage and service delivery in their managed care contracts.28 For example, Pennsylvania required Medicaid managed care plans to cover any service that “is reasonably expected to prevent the onset of an illness…or is reasonably expected to reduce or ameliorate the physical, mental, or developmental effects of an illness, condition, injury, or disability.”29

By contrast, the benefit packages offered by separate SCHIP programs are more limited (see the article by Wysen, Pernice, and Riley on program design in this journal issue). Benefit packages through SCHIP often
Box 2

Publicly Funded Programs Available for Children with Special Health Care Needs

Medicaid: By far the largest public health insurance program with the most comprehensive benefit package for children with SHCNs. In fact, the benefit package in the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program was designed with children with SHCNs in mind. Medicaid covers children with SHCNs who are institutionalized and includes coverage of much durable medical equipment and many ancillary services.

SCHIP (or Title XXI): Covers many children with SHCNs now, but benefits vary by the type of program. Medicaid expansion programs have more comprehensive benefit packages for children with SHCNs than programs modeled after commercial insurance plans. Four models of SCHIP that cover children are:

- Traditional Approaches: Programs that rely on the basic SCHIP program to serve children with and without special needs.
- Wraparound Approaches: Programs that offer supplementary coverage (such as care coordination) and a benefit package that often mirrors Medicaid benefits for children with SHCNs identified by providers.
- Service Carve-Outs: Programs that enroll children with special needs in both a SCHIP managed care program and the state Title V (or other special needs) program, so that the oversight, financing, and programmatic responsibilities no longer reside with the managed care plan providing SCHIP coverage.
- Specialized Systems of Care: Programs that automatically enroll children in a special state program that is funded and managed separately from the SCHIP managed care plan and is specially designed for them.

Title V of the Social Security Act (via the Maternal and Child Health Services Block Grant): Provides money to states to develop community-based programs for mothers and children. At least 30% of Title V funds must be used for children with SHCNs. Services include case management, coordination of care, home visitation, and family support. States must match three dollars for every four dollars received by Title V, a higher level of state match than required for SCHIP or Medicaid. Some states match even larger amounts, but states vary greatly in their use of Title V funding and covered services.

Supplemental Security Income (SSI): Provides cash assistance to help families meet some expenses related to disabilities, qualifies children for Medicaid, and ensures that children receiving SSI are referred into the state’s Title V programs. Children must demonstrate both disability and financial need. Welfare reform legislation of 1996 tightened the definition of “disability,” particularly for children with behavioral problems. Children must fulfill two requirements for SSI: They must have (1) a physical or mental impairment that results in “marked and severe functional limitations” and (2) a condition that is expected to last for more than one year or to cause death within a year. The level of disability must be substantial to qualify for SSI. In addition, this benefit is not available to middle-income families, although in most states the income-eligibility requirements for SSI are more liberal than even the SCHIP income limits.

Katie Beckett Waivers: Since 1982, states have applied to the Department of Health and Human Services for state-specific Medicaid waivers (called “Katie Beckett waivers” and “1115 waivers”) to apply federal and state funds to cover health care for people with SHCNs who would otherwise be institutionalized or forgo needed care. The waivers vary by state, often involve demonstration projects, and usually include wraparound services.

References:

Children with Special Health Care Needs

exclude services that are important to some children with special health care needs such as case management, rehabilitative services, and behavioral health services. In many cases, uncertainty exists regarding the source of payment for certain services. For example, some SCHIP programs consider speech therapy for a child with autism a medical necessity, while others consider it an educational intervention. Similarly, the source of payment for a child who requires a nurse to accompany him to school may be unclear. Nonetheless, public program benefit plans—including both Medicaid and SCHIP programs—are often more comprehensive than the benefit packages of typical commercial plans in the same regions.

Availability of Providers

A key structural aspect of quality of care involves availability of primary care, specialty care, or ancillary health providers for children with SHCNs. As described below, four broad categories of health care providers serve children with special needs. Children with SHCNs may seek services from any of these categories regardless of the type of health insurance coverage they have.

- **Primary Care Providers (Medical Home):** A major goal of health care is for all children with SHCNs to receive comprehensive care within a “medical home,” where health care services are “accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent.” Most often, a primary care practice serves as a medical home.

- **Specialty Providers:** Many children with SHCNs require specialty care and rely on multiple pediatric subspecialists and surgical specialists. The amount of service varies widely depending on the child’s diagnosis, and some children with major handicapping conditions require extensive specialty care that is extremely costly.

- **Community-Based and Ancillary Providers:** The needs of children with SHCNs often extend beyond traditional primary care and include a wide range of allied health services such as nursing, physical and occupational therapy, speech and developmental supports, and durable medical equipment. In addition, many children with SHCNs have special educational needs, and school-based providers become exceedingly important. Often these services are not funded through the health care system, but through special educational programs mandated by federal law.

- **Safety Net Providers:** A range of academic medical centers, neighborhood health centers, public health clinics, school-based health centers, and other organizations serve low-income populations, offering both ambulatory and inpatient care for no fee to the patient. Because safety net providers rely largely on Medicaid revenues and many—particularly those within academic medical centers—offer specialized services for children with SHCNs, they often provide the actual primary and specialty care for children with SHCNs that are covered by publicly funded programs.

National studies have found that more than 90% of children with SHCNs do have a usual source of care, including children with SHCNs enrolled in Medicaid. Recent studies of prototype state insurance programs that were initiated prior to SCHIP also found that more than 90% of children with chronic conditions such as asthma had a usual source of care. Although having
a usual source of care is only a first step toward having a “medical home,” it is a necessary one. At the same time, children with SHCNs in public programs do not fare as well with respect to the availability of personnel for care coordination and access to specialty care, as further discussed below. Overall, too few specialists are available to serve children covered by Medicaid or SCHIP. Moreover, Medicaid managed care plans often have limited provider networks and require prior authorization for out-of-plan referrals, both of which may hinder access to appropriate specialty care.39–44

**Funding Mechanisms**

Children with special needs who are in publicly funded programs such as Medicaid or SCHIP may be covered by three major funding mechanisms: fee-for-service, managed care, and blended models. Each funding mechanism has both advantages and disadvantages for children with SHCNs, who tend to have a high need for costly services and specialty care.

**Fee-for-service:** A fee-for-service system pays providers, hospitals, and other health care services a fee based on patient use of services, with more use resulting in greater payments. Sometimes the payments for specific services are negotiated beforehand. Traditional Medicaid is an example of this funding mechanism. A major advantage of fee-for-service arrangements with respect to children with SHCNs, who consume more costly health care services than typical children, is that this arrangement minimizes the incentive toward limiting needed services. However, the system may reward the provision of unnecessary care.

**Managed care:** This broad term encompasses a variety of funding arrangements. In general, a defined

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**Box 3**

**Importance of a Medical Home for Children with SHCNs**

A medical home is not a specific site, but rather a comprehensive approach to providing optimal health care in partnership with children and their parents. Providers at the medical home assist children and families in obtaining comprehensive and other educational and community-based services that are:

- **Accessible**
  - Care is provided in the child’s community and available 24 hours a day, 7 days a week.
  - All insurance, including Medicaid, is accepted, and changes are accommodated.

- **Family-Centered**
  - Recognition that the family is the principal caregiver and the center of strength and support for children.
  - Unbiased and complete information is shared on an ongoing basis.

- **Continuous**
  - The same primary pediatric health care professionals are available from infancy through adolescence.
  - Assistance with transitions (to school, home, and adult services) is provided.

- **Comprehensive**
  - Preventive, primary, and tertiary care needs are addressed.

- **Coordinated**
  - Families are linked to support, educational, and community-based services.

- **Compassionate**
  - Concern for the well-being of child and family is expressed and demonstrated.

- **Culturally Effective**
  - The family’s cultural background is recognized, valued, and respected.

population is assigned a primary care provider who acts as a gatekeeper responsible for care coordination. Providers can be paid a discounted fee-for-service rate (they may negotiate to receive more if the managed care organization achieves a level of financial success), or they can receive a set amount per patient irrespective of the amount of services used (this is called capitation). An advantage of capitation is the incentive to use only efficient and effective care that results in cost savings. A potential disadvantage, particularly for children with SHCNs, is a tendency to deny needed services and to fail to enroll high-cost patients.

**Blended models:** A number of programs have experimented with “carve-outs” (see Box 2) that usually include fee-for-service payments for certain components of care (such as prescription medications or mental health services), while applying capitation for other components (such as primary care). Blended models try to incorporate different incentives for providers and patients to reduce the disadvantages of capitation (for example, denial of appropriate services or refusal to care for the chronically ill) and those of fee-for-service arrangements (for example, potential for excessive care).

Currently, although some findings exist, insufficient research evidence makes it difficult to characterize the performance of these different funding mechanisms for the population of children with special needs. One consistent finding, however, is that Medicaid reimbursement for providers has been substantially lower than reimbursement by commercial insurers, making many providers reluctant to care for this population when covered by Medicaid. To determine the best types of financing strategies for children with SHCNs, more research is needed.

**Process Indicators: Access and Coordination of Care**

The promise of a comprehensive benefit package does not necessarily translate into the reality of access to appropriate services. Thus, evaluating the process of providing care for children with SHCNs is critical. Several studies have addressed the quality of the processes by which children with SHCNs secure health care, mostly focusing on access to primary and specialty care, and on the continuity and coordination of care.

**Access to Care**

All publicly and privately funded programs based on current identification methods face the challenge of enrolling eligible children with SHCNs, leading some to perform targeted outreach. The effectiveness of such outreach programs is difficult to judge except to note that fewer children with SHCNs are enrolled in publicly funded programs than expected based on their prevalence within the population. One reason is that these children are expensive and difficult to treat, and while program managers want to provide care for eligible children, there are also disincentives to enrolling more children because of the added expense.

An initial step in a program’s ability to care for SHCNs is its capability and process of identifying the population. Unfortunately, neither Medicaid nor SCHIP programs tend to utilize special means to identify the population; instead they rely on the existing health care system to identify the population through children’s enrollment in programs like Title V or SSI, identification by providers, or via a list of chronic conditions. Barriers to identification include the lack of a commonly accepted definition and inconsistent use of screening tools to determine whether children meet the definition’s criteria. A qualitative study of different models of Medicaid managed care programs for children with SHCNs in eight states noted that fee-for-service programs were the least able to identify these children.

Nevertheless, it appears that the publicly financed health care system is performing relatively well for children with SHCNs on overall markers for quality of care, although publicly insured programs perform slightly worse than privately insured programs in certain measures. For example, one national study found that the proportion of children with SHCNs who had a usual source of care was the same for publicly and privately insured children, and that the proportion of publicly insured children with SHCNs who missed or delayed medical, dental, or mental health care was similar to privately insured children with SHCNs. At the same time, the study also found that publicly insured children fared worse on other measures of quality such as parental satisfaction with at least one aspect of their child’s primary care. However, this finding of less parent satisfaction in public programs may be due to the fact that children with SHCNs who are also poor
have even more complex and significant needs than do privately insured children (who are less often poor).

In addition, some evidence suggests that children with a variety of chronic conditions who are in Medicaid use more services than children with similar diagnoses who are covered by private insurance, including outpatient, emergency services, and home health services. This may be in part due to greater severity of illness among publicly financed children with SHCNs, and does not necessarily reflect better or worse care. In other words, there is no simple answer to the question about whether publicly financed children with SHCNs receive better or worse access to care than privately financed children with SHCNs.

**Continuity and Coordination of Care**

Two dimensions of quality are particularly important for children with SHCNs: continuity and coordination of care. Research indicates that the provision of comprehensive case management for children with serious chronic conditions can reduce rates of hospitalization and lower overall health care costs. Yet, several studies have demonstrated that many children with SHCNs in both publicly and privately funded programs experience discontinuities in care, insufficient primary care or coordination of care, and gaps in services especially with respect to specialty providers.

Continuity of care is important for children with SHCNs because they often have chronic needs for costly services. But inadequate attention has been given to the barriers to continuity of care within publicly funded programs. For example, a significant factor contributing to discontinuity of care is the mandatory waiting period for SCHIP enrollment. Many SCHIP programs have mandatory waiting periods of two to six months during which a child must be uninsured prior to being able to enroll. These waiting periods could present hardships for children with SHCNs because of gaps in services during uninsured months, or because these children may have been previously covered by commercial insurance and therefore would not be eligible for SCHIP because of a lack of an uninsured period. A recent evaluation of the design of SCHIP programs in 15 states found that some states tried to address such potential problems associated with mandatory waiting periods. Six states specifically exempted the waiting period policy depending on whether the medical costs for families were greater than a certain amount. For example, Connecticut waived a six-month waiting period if families paid greater than 5% of their gross income for their prior insurance plan coverage. Other states focused exemptions directly on children with SHCNs. For example, at one time North Carolina waived its two-month waiting-period requirement for families of children with SHCNs, if the prior coverage did not cover the special need (more recently, in October 2001, North Carolina eliminated its requirement of a 60-day period of uninsurance).

Coordination of care is also important to children with SHCNs because of their frequent need for specialty care. A major recent improvement to the coordination of care has been the promotion of providing a medical home for children with SHCNs, with specialists and ancillary providers used as needed. Yet, several studies have found that while most children with SHCNs have a usual source of care, there was evidence of insufficient coordination between primary and specialty care. For example, a recent four-state study of children covered by Medicaid with serious chronic conditions found that most failed to receive care from a subspecialist, even though most of their conditions warranted such
visits annually. This confirms earlier studies noting barriers to specialty care among children with SHCNs in publicly financed programs. At the same time, a recent study of children with SHCNs within the Oregon Health Plan managed care program suggests that enrollment in SSI may have facilitated access to specialty care. Also, only a small proportion of children with SHCN failed to receive needed care because of either cost barriers or other reasons.

If primary care providers are to serve children with SHCNs who are in publicly funded programs, they must participate in publicly funded programs, and have adequate personnel to coordinate the children’s care. Although the majority of practicing pediatricians participate in Medicaid and SCHIP, low reimbursement rates and high levels of paperwork discourage some from participation. While providers report high levels of organization and coordination of care for children with SHCNs and frequent use of family-centered approaches, care coordination within pediatric practices is often limited by lack of time and resources.

Outcome Measures
Measuring health outcomes and the quality of care for children with SHCNs is challenging. Individual programs must develop goals and outcomes specifically tailored to the needs of particular populations. One set of performance measures, recommended by the MCHB, is listed in Box 4. Another promising strategy for monitoring the quality of publicly financed care for children with SHCNs involves using the Health Plan Employer Data and Information Set (HEDIS), a set of standardized performance measures developed by the National Committee on Quality Assurance (NCQA). Other techniques for monitoring health outcomes and the quality of care include provider surveys, consumer surveys, administrative data, surveys tailored for children with SHCNs, and commissioned research studies.

Overall, health outcomes of children with SHCNs are clearly lower than outcomes of normal children due to their chronic diseases. Outcomes for children with SHCNs covered by Medicaid may be lower than for children with SHCNs covered by private insurance, although factors other than the performance of Medic-

**Box 4**

**Six Core Outcomes to Measure Successful Care of Children with SHCNs**

To improve care for this large population of children and families, the Maternal and Child Health Bureau developed six core outcomes to guide efforts to address the needs of children with SHCNs:

- All children with special health care needs will receive coordinated ongoing comprehensive care within a medical home;
- All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need;
- All children will be screened early and continuously for special health care needs;
- Services for children with special health care needs and their families will be organized in ways that families can use them easily;
- Families of children with special health care needs will partner in decision making at all levels, and will be satisfied with the services they receive;
- All youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence.

Two dimensions of quality are particularly important for children with SHCNs: continuity and coordination of care.

Program success also can be evaluated from the point of view of the key partners: parents and patients, providers, and the public programs.83 According to recent surveys, satisfaction by parents of children with SHCNs in general appears to be relatively high.84–86 For example, a 1998 survey of families of children with SHCNs found that most parents were satisfied with the overall care by their physicians.87 However, those covered by Medicaid plans were more satisfied than families of children in private managed care plans (perhaps because of Medicaid’s broader coverage). Major problems identified by families in both public and private plans included insufficient care coordination, limited specialty care due to approval requirements by the plan, and difficulty accessing mental health, behavioral health, and home health services.88 In addition, pediatricians are often dissatisfied by the lack of available subspecialists, obstacles to referrals, and the lack of personnel within primary care practices to perform case management for children with SHCNs.89–92

In sum, recent changes in the publicly financed health care system appear to have produced better access to primary care for children with SHCNs, although insufficient access to subspecialty care persists in many cases. Coordination of care remains suboptimal because of inadequate financing and personnel. Standardized instruments and measurement strategies are just now being incorporated and will hopefully be able to better measure the level and quality of care for children with SHCNs. There is an old saying that “what gets measured gets done.” Measuring the quality of care for children with SHCNs in publicly financed programs will enable planners, providers, and consumers to make services more efficient and effective, and ensure that the job is done well.

**Improving the System of Publicly Funded Programs for Children with SHCNs**

While many aspects of the publicly funded system work well for children with SHCNs, improvements could lead to a better quality of care and ultimately to improved health for children with SHCNs. Suggestions for strengthening these programs are outlined briefly below.

1. **Enhance outreach.** Outreach strategies should be enhanced to enroll children with SHCNs in appropriate health insurance programs. While new outreach efforts for Medicaid and SCHIP seem to have increased enrollment, state SCHIP outreach programs have not specifically targeted children with SHCNs for enrollment.93 The 10-year plan by the MCHB94 calls for managed care plans and health care programs to incorporate a systematic process for identifying their children with SHCNs and for tracking and monitoring their care. Having a systematic process for identifying these children is the first step toward effectively managing their care.95,96

2. **Include wraparound services.** State separate SCHIP programs that offer a more restricted benefit package for children with SHCNs compared to Medicaid’s should broaden their coverage to include wraparound services that are critical for children with SHCNs, such as dental care, physical and occupational therapy, prescription drugs, eyeglasses, rehabilitation, social work, and home nursing.
(3) **Improve provider networks.** State Medicaid and SCHIP programs should develop effective strategies to ensure the adequacy of provider networks to serve children with SHCNs. State programs should monitor the availability of primary care, specialty care, and subspecialty providers. Public programs should increase access to primary care medical homes, and improve access to subspecialty providers for children with SHCNs by reexamining referral and medical authorization requirements and broadening the provider network. Increased training will also help primary care providers to understand the concept of comprehensive medical homes to ensure that primary care sites meet the criteria for a true medical home.

(4) **Apply appropriate financial incentives.** Programs should consider risk adjustment strategies and carve-outs to more appropriately compensate for the cost of serving the children that have the most severe conditions. Because 10% of children with severe chronic conditions utilize 70% to 80% of children’s health expenditures,97 the financial pressures for publicly financed managed care plans are to avoid these high-cost patients. Risk adjustment strategies offer a solution to the lack of incentives for caring for this expensive population by more appropriately reimbursing plans or providers.98 These techniques, which are still early in their development for children, incorporate demographic, health status, and diagnostic information to classify individuals in terms of risk of health care expenditures, and to adjust capitation rates,99 raising reimbursements. If used in conjunction with rigorous quality-assurance monitoring techniques,100 they may help to develop more appropriate payment strategies for children with SHCNs.

Several state Medicaid programs (for example, Colorado, Maryland, New Jersey, Oregon, and Washington) have already adopted payment systems that vary based on health status of enrollees.101–103 These systems provide increased payments to Medicaid managed care plans for enrollees who are classified as having serious chronic illness. Increased use of risk adjustment systems is needed, and newer systems are being developed that will better focus on children with SHCNs.104

(5) **Support case management.** Publicly financed programs should help with case management and care coordination at the provider level. For instance, they could assist providers with arranging services, provide information to case managers about children’s utilization of recommended care (such as filling of prescriptions and follow-up with mental health or subspecialty providers), and increase their funding for case management activities that both improve the functional status of children with SHCNs and reduce the occurrence of complications of chronic conditions that are often costly to treat.105

(6) **Develop and disseminate best practices.** Professional organizations and perhaps states should develop “best practices” for serving children with SHCNs among Medicaid, SCHIP, and Title V programs. Descriptions of innovative solutions and program components that appear to work could be disseminated to other states and programs via publications, workshops,106 and other communications.

(7) **Cross program collaboration.** States should increase collaboration across different funding programs used by children with SHCNs. Stronger ties between state Medicaid programs, SCHIP programs, and Title V programs could enhance identification of children with SHCNs and tracking of their health care.107 Such coordination, while not specific to children with SHCNs, could particularly benefit this vulnerable population. For instance, increased collaboration across programs at the community level might enhance patient access to specialty care and to wraparound services (two areas that have been problematic for children with SHCNs). Programs could also work with other key child services such as educational and social services.

(8) **Monitor care.** States should monitor the care provided to children with SHCNs to ensure that they are receiving appropriate services through publicly financed programs. Monitoring should include prevalence of these children in the insurance program, access to and use of services, quality of care, presence of unmet needs, satisfaction and health outcomes, costs, and program per-
formance. Monitoring children with SHCNs separately will require a systematic means to define and identify the population of children with SHCNs (including uniform coding mechanisms and definitions of children with SHCNs) and routine assessment of health measures that are critical to children with SHCNs.108,109

Conclusion

Children with special health care needs represent an important and large subgroup of children with chronic disorders who are at high risk for suffering adverse outcomes. Although precisely defining this subgroup of children is difficult, around 14.8% to 18.2% of all children face special health challenges. Just as it is critical for health insurance programs to evaluate how successfully they serve adults with chronic conditions such as heart disease and diabetes, so too is it critical to evaluate the success of publicly financed programs in serving the needs of children with SHCNs.

Overall, the publicly funded insurance programs seem to work well for children with SHCNs, who often need wraparound services and subspecialty care. The comprehensive benefit coverage under Medicaid is particularly critical for these children, and separate state SCHIP programs often offer broader benefit coverage than is available under many commercial plans (though not as extensive as under Medicaid). Families with children having SHCNs are generally satisfied with their children’s care under public programs. While health outcomes of children with SHCNs tend to be poorer than outcomes of other children, determining the degree to which this gap can be narrowed by the improved performance of insurance programs is difficult because children with SHCNs have underlying chronic conditions that lead to poor outcomes.

Nonetheless, a number of improvements in publicly financed insurance programs could be made to address such issues as the frequent unavailability of specialty providers and lack of coverage for certain services. Possible improvements include more effective outreach to enroll children with SHCNs, better provision of wraparound services, improved provider networks, use of appropriate financial incentives, better support for case management, development and dissemination of best practices for SHCNs, and monitoring care. Continuously monitoring the quality of care for children with SHCNs within publicly financed programs is essential to ensure that they are receiving the services they need. Primary care providers within a medical home need to help coordinate the care for children with SHCNs because these children often require ancillary services. Public programs can assist providers in this care coordination by offering appropriate provider networks, comprehensive benefit packages, monitoring, and coordination of care.

If a measure of society’s goodness is how well it cares for its children, and one marker is how well insurance and public programs serve children with SHCNs, then there is still substantial room for improvement before we can feel satisfied that we are doing all we can to help some of our nation’s most vulnerable children.

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E N D N O T E S


4. These methods include: (a) specific diagnoses, (b) above average use of services (for example, 1 or 2 standard deviations above the mean use of services by the child population), (c) cost-based approaches (for example, expenditures over $5,000 or $10,000 during the past year), or (d) enrollment in a special program for children with SHCNs such as Supplemental Security Income (SSI). Neever and not widely used administrative data based methods involve “classification systems” that use a combination of diagnostic information from claims or encounters to group children into meaningful categories, some of which include children with SHCNs.

5. These methods more closely follow the definition in Box 1, and several excellent instruments are now available. Although this approach is time consuming and most publicly financed health insurance programs have not yet widely adopted it, some programs such as Medicaid programs in Florida and Texas have started using such surveys to identify children with SHCNs.


12. See note 5, Shenkman and Wegener.


14. A direct comparison of administrative data from several publicly funded health insurance programs versus parent surveys found that nearly one-third of children with SHCNs identified by surveys were missed by using administrative data alone. See note 3, Shenkman and Wegener; note 13, Hill, et al.

15. The Centers for Medicare and Medicaid Services (CMS, formerly HCFA) is currently considering revising the final criteria that it uses to evaluate mandatory managed care waivers, allowing states to develop their own definition of special populations. This will allow states to choose one of several definitions for children with SHCNs, and it is likely that different definitions will continue to be used throughout the United States.

16. However, Medicare covers children with SHCNs with end stage kidney disease.

17. An important caveat is that many adolescents lose coverage under these programs as they transition to adulthood. See the article by Brindis, Morreale, and English in this journal issue for a more complete discussion of health insurance and adolescents.


20. See the article by Mann, Rowland, and Garfield in this journal issue.

21. Of note, a small percentage of children are covered by both public and private insurance, and many privately insured children still receive some services through public programs such as school programs.

22. See note 2, Fox, et al.


27. See note 19, Kaiser Commission on Medicaid and the Uninsured.

28. See note 25, Center for Health Services Research and Policy.

29. See note 9, Carmen, et al.

30. See note 13, Hill, et al.

31. See note 13, Hill, et al.

33. See previous journal issue on special education for students with disabilities, The Future of Children (Spring 1996) 6(1).

34. See note 14, A Comparison of Administrative Data.

35. They also rely to a lesser extent on Medicare, SSI, and Title V funds.


39. See note 23, Horowitz and Stein.


49. See note 3, Shenkman and Wegener.


51. See note 19, Kaiser Commission on Medicaid and the Uninsured.

52. See note 50, Schwalberg, et al.


54. See note 36, Newacheck, et al.


58. See note 26, Szilagyi.


61. The purpose of the waiting periods is to prevent “crowd-out,” where public programs replace or substitute for existing private coverage.


66. See note 13, Hill, et al.


69. See note 46, Yudkowsky, et al.


72. In the past, HEDIS surveys have not measured quality of care specifically for the children with SHCNs population, but NCQA recently approved using a 5-item set of questions to identify chil-
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dren with special health care needs, and a 31-item set of questions regarding various areas of care for them. These questions may be incorporated into HEDIS in the near future, and can be used in conjunction with another major nationwide survey (The National Children with SHCN Survey) that measures the child's general quality of health care. Such standardized measurement will be able to assess variability across plans, trends over time, and overall quality of care for children with SHCNs.


77. See note 7, Stein and Silver.

78. See note 11, Newacheck, et al.

79. See note 18, Stein.


84. See note 36, Newacheck, et al.

85. See note 38, Szilagyi, et al.

86. See note 65, Kuhlthau, et al.

87. See note 76, Family Voices.

88. See note 76, Family Voices.

89. See note 46, Yudkowsky, et al.

90. See note 70, American Academy of Pediatrics.

91. See note 23, Horowitz and Stein.

92. See note 40, Cartland and Yudkowsky.

93. See note 13, Hill, et al.


98. See note 97, Neff and Anderson.


105. See note 57, Liptak, et al.


107. Managed Care Best Practices. Improving preventive care services for children: A best clinical and administrative workshop for Medicaid/SCHIP plans. Available online at http://www.chic.org/ManagedCare/bcapworkshop.htm. Center for Health Care Strategies, Inc. Accessed December 31, 2001. Since two-thirds of states have either a separate SCHIP program or combination of programs, most children with special needs in SCHIP likely have less comprehensive coverage than they would under Medicaid. An exception is SCHIP programs that are Title XXI Medicaid expansions. They meet the more comprehensive EPSDT standard that is mandatory for Medicaid, but do not provide the entitlement to benefits that Medicaid provides.
