# Managed Care and Children with Special Health Care Needs: Strategies for Monitoring the Quality of Care

Prepared for:

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# CHAPTER I

# Introduction and Background

More states than ever before are implementing fully capitated Medicaid managed care programs and moving greater proportions of their Medicaid populations into managed care arrangements. Included in these expansions are children with special health care needs (CSHCN) who traditionally have been served through Title V/CSHCN programs, community-based systems, and by private fee-for-service providers and institutions.

Like many state health departments across the country, the North Carolina Department of Environment, Health, and Natural Resources (DEHNR) is aware of the challenges involved with serving CSHCN in managed care systems and is concerned about the impact that these new delivery systems will have on the quality of care provided to them. As a proactive effort to promote high-quality care, the Department's Division of Maternal and Child Health (DMCH) is currently working to develop strategies for monitoring and assuring quality of care for CSHCN served in Medicaid managed care systems.

To assist North Carolina with this effort, Health Systems Research, Inc. (HSR) was invited to provide DMCH officials with technical assistance (TA). This assistance is supported by a contract between HSR and the federal Maternal and Child Health Bureau (MCHB), under which HSR has provided TA to Title V/Maternal and Child Health programs in all 50 states, the District of Columbia, the U.S. Virgin Islands, and Puerto Rico in support of their development of comprehensive systems of care for children and their families.

## A. Technical Assistance to Date

The technical assistance process in the State of North Carolina began in January 1996 when DEHNR officials, specifically those of the Children and Youth Section (CYS) of DMCH, asked for help in designing quality assurance systems for CSHCN served in managed care. With the state Medicaid agency planning the increased use of managed care delivery systems, health department officials expressed the need for help in developing quality assurance strategies to promote high-quality care and measure how CSHCN will be affected.

In May 1996, HSR Project Director Ian Hill and Senior Associate Vivian Gabor conducted an initial site visit to Raleigh to meet with health department officials and with the members of the Children's Special Health Services (CSHS) Medical Advisory Committee's Subcommittee on Outcome Measures. They were accompanied by James Perrin, M.D., Director of the Division of General Pediatrics at the Massachusetts General Hospital, Harvard Medical School, who was retained as a consultant for this assignment because of his extensive experience with quality assurance issues for children with chronic illnesses and disabilities. During this site visit, Dr. Perrin made presentations before each of these groups on the subject of children with disabilities and managed care, and the consultant team facilitated discussions with the goal of identifying a specific workplan for the TA effort.

At the conclusion of the site visit, it was decided that HSR would develop two reports for the state. The first, submitted in November 1996, was a compendium of available clinical standards and practice guidelines for the ten most common and costly conditions affecting CSHCN in North Carolina; the state is currently reviewing these guidelines and standards with its Medical Advisory Committee for CSHCN and will begin discussions with managed care organizations to reach consensus on the practice standards that will be used by them in serving CSHCN. This document is the second report requested by CYS—an analytical report on strategies for measuring and assuring quality of care for CSHCN in risk-based managed care.

To provide a context for the discussion of alternative approaches to assuring quality of care for CSHCN under managed care, the following section presents background information on Medicaid managed care systems and the potential benefits and risks they hold for CSHCN.

## B. Background on Managed Care and Children with Special Health Care Needs

Health care delivery and financing systems are rapidly moving toward increased reliance on risk-based managed care[1] in both the private health care marketplace and in public programs. The main goal of managed care arrangements is to control health care costs while assuring access to high-quality care for enrollees. Risk-based managed care plans achieve these goals by altering the traditional fee-for-service administration, organization, and financing of health care. Care is paid for on a capitated basis. Referrals to specialty services must be made or preauthorized by a primary care provider in order to be covered by the plan, and this referral process is coordinated for patients by a case manager or this primary care gatekeeper. Managed care plans also can offer an array of services in one or more centralized community sites.

Until recently, children with disabilities or chronic illnesses were typically exempted ("carved out") from most Medicaid managed care plans and received their health care services in traditional fee-for-service delivery systems. However, state Medicaid programs are increasingly enrolling various high-risk and high-cost populations into managed care arrangements, including CSHCN who are enrolled in the Supplemental Security Income (SSI) program. According to the Office of Managed Care at the federal Health Care Financing Administration, as of the Spring of 1996, 23 states were providing Medicaid services to some or all of their SSI populations through managed care waivers. Three states had statewide managed care programs for their SSI population (through Section 1115 waivers of the Social Security Act) and 20 had programmatic Section

[1] Risk-based managed care refers to an arrangement in which a health plan receives a fixed monthly payment per enrollee (from a private or public insurer) in return for providing or arranging for the provision of an agreed-upon set of health and medical care services to that enrollee. This definition applies to any type of plan that accepts risks and contracts on a prepayment basis such as a health maintenance organization (HMO), a prepaid health plan, etc.

1915(b) waivers of the statute to serve this population under managed care in portions of their states.

As the numbers of CSHCN enrolled in managed care plans continue to grow, the need to understand the potential benefits and risks associated with managed care enrollment for these children and their families must be recognized. Potential benefits for these children include a better guarantee of access to adequate primary care services compared to fee-for-service practices. In some organized systems of managed care, families may also gain access to a broader array of ancillary preventive health-related services, such as social work and nutrition counseling. Plans also have financial incentives to coordinate care and to improve patient amenities to attract and keep enrollees. Similar incentives also exist to provide more care in offices and other community-based settings rather than in hospitals and emergency rooms. Families also typically have lower out-of-pocket costs in managed care plans compared to fee-for-service and thus face fewer financial disincentives to seeking care when it is needed.

On the other hand, families of children with disabilities also face potential loss of benefits or inadequate services from managed care. First, in capitated managed care arrangements, plans have the incentive to discourage enrollment of high-cost patients, especially if capitation rates are not risk adjusted. Similarly, once such persons are enrolled, plans have little incentive to provide multiple and complex specialized services or to organize multidisciplinary programs for children with disabilities, both because of the cost implications and because developing a reputation as a plan that is responsive to the needs of CSHCN would enhance the likelihood that more such children would enroll. Furthermore, it is widely acknowledged that many managed care organizations have limited experience caring for persons with disabilities in general and for CSHCN in particular. As a result, they often lack the providers and clinical expertise needed to meet the specialized need of this population. Physician specialists working with the plans are more likely to be trained in adult, rather than pediatric, subspecialties, thus increasing the likelihood that CSHCN will not receive the appropriate care they need to reach their potential. Additionally, most plans are not likely to include in their networks the full range of specialized ancillary services that CSHCN often need, such as physical, speech-language, and occupational

therapy, nor are they likely to have had much experience providing durable medical equipment that is adapted for children.

In sum, the operational and financial structures of managed care organizations have the potential to improve access to primary care, as well as continuity and coordination of services for CSHCN who depend on an array of providers for their care. At the same time, the financial incentives to underserve these children and the limited specialized providers and services available in most networks may counteract these advantages. Thus, close monitoring is needed to assure that CSHCN are able to take advantage of managed care's potential benefits without succumbing to its risks.

## C. Purpose and Organization of This Report

As noted above, this report is designed to assist North Carolina officials and other readers in developing strategies for assuring and monitoring the provision of high-quality services to CSHCN through managed care delivery systems. The next chapter sets the framework for state officials to develop a quality assurance and monitoring system for CSHCN. Approaches are discussed for assuring quality of care through prospective structural standards and retrospective measures that monitor the structure, process, and outcomes of care received by CSHCN. Chapter III makes recommendations for specific steps North Carolina officials should take in designing a quality assurance and monitoring system for CSHCN, including choosing specific structural standards and measures, process indicators and measures, and tools and indicators useful in monitoring the health status and outcomes of care for CSHCN and their families.

# CHAPTER II

# Approaches to Assuring Quality of Care

Assuring the quality of care provided to CSHCN under managed care can be approached from two perspectives: prospectively, by assuring that a managed care plan is appropriately structured to address these children's needs, and retrospectively, by monitoring the care that a plan provides. Prospective quality assurance measures may focus on the *structure* through which care is provided; that is, on the extent and qualifications of the network of physicians and other providers in the plan, the degree of access to care the plan affords, and the range of benefits covered. Retrospective quality assurance mechanisms may monitor compliance with structural standards and may also measure the quality of care using measures of the *process* of care (including the continuity of care, the degree to which services provided are appropriate, and the degree of coordination of care) and the *outcome* of care (using measures of health and functional status). The following sections present a framework for considering each of these approaches to quality assurance.

## A. Structure

As mentioned above, the structure of managed care plans' provisions for children with disabilities can be assured both from the outset, through appropriate contract provisions, and retrospectively, with careful monitoring of plans to assure compliance with their contracts. A number of areas in which contract provisions, and subsequent monitoring, may help to improve the quality of care provided to CSHCN are described below.

- Population Identification. Plans must have a consistent mechanism for identifying children with special health needs in order to assure that these children are referred to appropriate types and sources of care. Therefore, the state may include in its contract a requirement that plans screen their enrollees on enrollment and annually thereafter to identify CSHCN. In addition, if a state is to implement a

monitoring system to assess the quality of care provided to these children, a consistent definition and screening tool must be implemented by all participating plans, to assure that the indicators reported by each plan are comparable. Thus, it may be preferable for the state to require that a specific screening form be used.

- Provider Networks. Children with special health needs require a comprehensive and coordinated system of health care that links community-based primary care with sub-acute and tertiary care. Clarity in contracts regarding the make-up of the provider networks is essential for ensuring that CSHCN have access to the appropriate primary, specialty, therapeutic, and support services needed to meet their diverse, and often complex and intensive, needs.

- Access Standards. Like other children, CSHCN require services that are accessible in both time and distance. In addition, children with physical disabilities require services to be free of physical barriers.

- Benefit Packages. For children with special health care needs, adequate access to certain services is vitally important. These services include, in addition to basic primary and specialty medical care, specialized therapies, durable medical equipment, home-based care, and family support services such as case management, respite care, health education and health promotion, and nutritional counseling for treatment and management of acute and chronic disease.

- Grievance and Appeals Processes. A process through which enrollees or their families may file grievances against a managed care plan or appeal the decisions of the plan or its providers are important protections for all managed care consumers. For CSHCN and their families, it is important that these processes be accessible, that they operate with sufficient speed that situations may be resolved before a child's condition deteriorates, and that families be informed and included in all stages of the grievance and appeals process.

- Quality Assurance Mechanisms. In addition to the quality monitoring systems used by the state Medicaid program, internal quality assurance programs may be required to assess whether the health care services provided to enrollees meets professionally recognized standards. However, standard quality assurance tools such as the Health Care Financing Administration's Health Care Quality Improvement System (HCQIS) were not designed and do not have the capacity to assist plans in assuring the quality of care provided to CSHCN or other populations with special needs. Therefore, the state could require that additional quality monitoring efforts be undertaken for this population, including detailed family satisfaction surveys.

Plans' compliance with the structural requirements of their contracts may be monitored through annual on-site audits or standard reporting mechanisms. These will be discussed further in Chapter III.

## B. Process

Process of care indicators may be used to assess the quality of care provided by measuring certain aspects of enrollees' use of care and comparing these indicators to accepted standards (such as the American Academy of Pediatrics' periodicity schedules for preventive care for children) or goals (such as the U.S. Public Health Service's *Healthy People 2000*). The process of care provided by managed care plans can be monitored only after the fact, using indicators developed from data collected from managed care plans. These indicators may be divided into a range of areas, or domains, each addressing an important aspect of the quality of care provided under managed care. Several potential domains that may be used to assess the care received by CSHCN are described below.

- Access to Care. The domain of access may be seen as a structural measure, addressing the physical accessibility of facilities and services, and a process measure. The process of gaining access to care may be monitored using indicators such as the average waiting time for an appointment, the average amount of time spent in waiting rooms, and the average amount of travel time required to see primary and specialty care providers. For children with special health care needs, these measures should be applied not only to primary care and specialist physicians but also to therapists and providers of durable medical equipment.

- Utilization of Care. One of the most straightforward measures of the process of care provided in a plan is the average number of services used per enrollee. For children with special health care needs, it is particularly important that the standards to which these utilization rates are compared take into account the extent and variety of services that these children require. Services for which utilization may be monitored include primary care (including immunizations, routine supervisory care, and acute care); specialty medical care (including both physician and hospital services); specialized therapies (including ancillary therapies, mental health services, and home health services); family support services (including family counseling and education, care coordination, respite, and transition services for adolescents); and durable medical equipment.

- Appropriateness of Care. Beyond the mere number of services used by a plan's enrollees, the state may monitor the appropriateness of the timing and targeting of

those services. For children with special health needs, measures of appropriateness may include the accuracy and sensitivity of screening mechanisms to identify CSHCN; the degree to which services are family centered; the use of multidisciplinary approaches to serving children with complex needs; the degree of coordination among medical, educational, and support services; and the coordination of primary, specialty, and emergency care.

- Health Care Expenditures. Changes in expenditures for services provided to CSHCN, within the public sector, the private sector, and in total, may be of interest as this population is enrolled in managed care. Measures of interest may include the effect of managed care on total expenditures, changes in families' out-of-pocket costs as new systems are implemented, and shifts in expenditures across systems as access standards change. However, monitoring the cost of care provided under managed care can be difficult, as payments are related not to particular services but to individual enrollees. Because the expenditure per capita is predetermined, data on the per-capita cost of individual categories of service (such as inpatient hospital care or specialty care) may be unavailable. However, plans may be able to document their internal expenditures in each service area and report their cost per capita for the population of children with disabilities. Families may also be surveyed regarding their out-of-pocket costs.

- Consumer Satisfaction. Satisfaction surveys of consumers and their families may be used as a measure of both the process and the outcome of care. Measures of consumer satisfaction with the process of care include the degree of choice of providers enrollees are given, the accessibility of providers, the amount of time they spend with their patients, the attention they give to follow-up, and their knowledge of the child's health history and needs.

The development of indicators within these domains will depend largely upon the availability of data from managed care plans; some may prove to be more challenging than others to operationalize and implement. Several of the domains, including the utilization of care and the appropriateness of care, can be monitored using encounter data that may be collected from plans. Other domains, such as consumer satisfaction and access to care, may require extensive surveys of enrollees and their families. The sources of data for indicators within each domain will be discussed in more detail in Chapter III.

## C. Outcomes

The assessment and measurement of health outcomes for any population is complex, and to attribute specific health status measures or outcomes to the particular interventions of a managed care plan is extremely difficult. A number of other factors, including the care a child receives at home and at school, affect the child's health and functional status. For the population of CSHCN, these problems are complicated by the fact that many children's conditions are unlikely to improve, even with the best care, and some children's health may inevitably decline. In addition, the small number of children with chronic diseases and disabilities in many managed care plans makes the development of stable, meaningful, plan-level indicators close to impossible. Therefore, although many state agencies would ideally like to be able to measure the effect of managed care on the health of CSHCN, this may be, at least for the present, an unattainable goal.

An additional problem in monitoring health outcomes for children with special health care needs, as with all children, is determining the time span over which outcomes are measured. Short-term outcomes may more accurately measure the immediate effects of medical interventions on a child's health. However, examination of long-term outcomes may be more meaningful in determining the effectiveness and cost-effectiveness of treatment strategies. In addition, the development of outcome measures specifically tailored to address children's health is complex, as the development and manifestations of children's conditions are affected by the stage of the child's development. Therefore, not only are outcome measures developed for adults often inapplicable to children, those developed with the pediatric population in mind may not be consistently applicable to children at all ages and stages of development.

That said, a number of domains do exist in which children's health may be measured and monitored. Indeed, the various aspects of a child's health and development may be divided along a number of different axes to create a variety of types of domains. A sample group of domains describing children's health status is presented below.

- Global Health. A child's overall health status may be measured using indicators such as the child's and parent's assessment of the child's health.

- Physiology. This domain measures the existence of conditions that affect the body's physiological function, such as those causing inflammation or infection.

- Physical Function. Children's level of physical function may be measured using indicators such as mobility and motor function and age-appropriate limitations in activities of daily living.

- Social Function. Measures of children's function in the social arena include social role limitations, degree of limitation, number of days out of school for illness, number of days spent in bed, and peer relations.

- Cognitive Function. Indicators of health and development in this area include ability to reason, ability to concentrate, and ability to perform in school.

- Behavioral or Emotional Status. This may be monitored using measures of anxiety, depression, withdrawal, hostility, coping, and self-esteem.

In addition to monitoring the health status of an individual child, measures of the health and functional status of the child's family may be particularly useful for the families of CSHCN. Measures of family function may include sibling health and adaptation, family interaction and support levels, and the effect on parental health of a child's condition.

Finally, the development of indicators of children's health status will again depend on the availability of the necessary data. Sources of these data may include reviews of individual children's records, surveys of parents regarding their children's health or of children regarding their own health, or the administration of assessment tools aimed at measuring specific aspects of children's health and development. The types of tools available to measure children's health in the domains described above, as well as sample indicators within these domains, are presented in Chapter III.

# CHAPTER III

# Sample Indicators of the Quality of Care

The previous chapter presented an overview of the domains in which the structure, process, and outcome of care provided to CSHCN may be monitored. In this chapter, we present sample indicators in each of these domains, including the specific data elements to be collected to develop these indicators and potential sources for these data. The sample indicators presented here are culled from a variety of sources. A number of recent efforts have been undertaken to develop quality monitoring systems to assess the care provided to CSHCN under managed care systems. These include the following:

- HEDIS. The National Committee for Quality Assurance (NCQA) has developed several versions of the Health Plan Employer Data and Information Set (HEDIS), the most recent of which combines indicators developed for the general population enrolled in managed care with those developed specifically for the Medicaid-eligible population (NCQA, 1996). Although few of these indicators specifically address issues of concern for CSHCN, several of them may be applicable to this population. In addition, it has been suggested that indicators of the quality of care provided to all children (such as immunization rates) be calculated separately for children with chronic illnesses and disabilities, so as to assess the use of primary care for this special population.

- Quality Community Managed Care. Researchers from the University of Illinois at Chicago, with funding from the federal Maternal and Child Health Bureau, have developed a quality assurance system for CSHCN using selected HEDIS indicators as well as original indicators specific to this population (Monahan, et al., 1996). The system includes indicators in six domains, presenting definitions of the numerator and denominator for each indicator and identifying sources for these data.

- Enhancing Quality. New England SERVE, a consortium of CSHCN programs in the six New England states, has developed a set of quality standards for programs serving CSHCN (New England SERVE, 1989). Although these standards are not developed specifically for monitoring the quality of care provided in managed care systems, many of the standards are applicable to these systems. The *Enhancing*

*Quality* workbook provides a comprehensive list of quality standards, but does not provide information about operationalization of the standards or about the necessary sources of data.

- Pediatric Excellence in Health Delivery Systems. This document, developed by the National Association of Children's Hospitals and Related Institutions (NACHRI), also presents a set of standards for the care of children with chronic illness, covering the areas of primary care, acute care, chronic care, and system-wide standards (NACHRI, 1996). This document provides criteria against which to evaluate health care systems, including managed care systems, and measures to use to apply these criteria, but does not operationalize the measures or provide potential sources of data.

- Monitoring and Evaluating Managed Care for Children with Chronic Illnesses and Disabilities. This article, published in *Pediatrics* in 1996, presents an outline for a monitoring system for CSHCN enrolled in managed care, along with standards of care in seven domains (Newacheck, et al., 1996). These standards are not operationalized, nor are sources of data discussed.

- Family-Centered Service Delivery Scale. The Beach Center on Families and Disability has developed this survey instrument to assess the family-centeredness of services provided to CSHCN (Beach Center, 1994). This survey, which includes both English and Spanish versions, comprises 32 questions in which families are asked to rate, on a scale of 1 to 5, the quality of care provided by a staff member in a particular agency. The survey questions may be applied to a range of types of services, including health, mental health, early intervention, child welfare, or employment services.

- Health Status Measurement Tools. A variety of researchers have developed and tested tools that assess the health status and function of children and families in the physical, behavioral, functional, and psychological domains. These will be described in detail later in this chapter.

The following sections present recommendations for monitoring the quality of care in four areas:

- Identifying children with special health care needs in managed care plans,
- Assuring the quality of the structure of care,
- Monitoring the process of care, and
- Measuring the outcomes of care.

Drawing upon the sources described above, this chapter provides examples of indicators and tools that may be used in each of these areas.

## A. Population Identification

The first step in developing a quality assurance and monitoring system for CSHCN in managed care systems is the identification of these children among all plan enrollees. To accomplish this task, the state should provide MCOs participating in quality monitoring for CSHCN with a common definition of CSHCN and an agreed-upon, standard screening tool to identify children who meet this definition. To identify CSHCN, the standard screening tool should be administered by plans to all children, both at the time of enrollment and on a periodic basis to assure that children who later develop special health care needs are identified. The population of children identified through this process provides the basis for monitoring the quality of care for CSHCN.

Several methods have been discussed for the identification of CSHCN. Some are more effective than others. One approach is to use a child's participation in a public program serving CSHCN as a proxy definition. Plans would then be required to screen all children regarding their enrollment in a particular program. As such a proxy definition, one could use participation in the State's Title V Maternal and Child Health program for special needs children, the Supplemental Security Income (SSI) program, or in the Individual with Disabilities Education Act (IDEA) Part H Early Intervention or Part B Special Education programs. However, each of these proxy definitions would be limited as explained below.

- Participation in Title V Maternal and Child Health Program for Special Needs Children. Using Title V participation as a proxy definition of CSHCN primarily emphasizes children with specific physical disabilities and some with developmental disabilities. On the other hand, this definition would generally omit children with mental retardation who do not have substantial associated physical problems or children with primary mental health conditions.

- SSI. Using SSI participation as the identifier of CSHCN would generally include children with only severe disabilities, though it would include children with a broader range of disabling conditions than using Title V program participation.

- IDEA Programs. A definition based on eligibility for the Part H Early Intervention program for preschool children and Part B Special Education program for school-age children would primarily identify only those children with conditions that may interfere with cognitive development, such as developmental delays and behavioral disorders.

A second approach defines children as CSHCN based solely on their diagnosis. Under this approach, the state would agree upon a list of diagnoses to define CSHCN and require plans to use this list as their screening tool to identify CSHCN for monitoring purposes. Although this approach will not capture all children with impairments which the state may want to monitor, it is likely the easiest for managed care plans to implement and operationalize.

The state could develop a list of qualifying diagnoses from a variety of sources. Three potential options for lists of diagnoses that a state can use to identify the population of CSHCN within managed care plans are described below:

- A typology, such as that being developed by the National Association of Children's Hospitals and Related Institutions, could be created based on the identification of ICD-9 codes that are associated with high rates of utilization (Neff and Anderson, 1995).

- The ICD-9 codes used by the Research Consortium on Chronic Illness in Childhood in their research could be adopted (Gortmaker, et al., 1993a; Gortmaker, et al., 1993b).

A third approach to identifying CSHCN is to use the definition of CSHCN developed by the federal Maternal and Child Health Bureau. The Bureau's definition, included below, is not dependent on specific diagnoses; instead its uses a combination of diagnostic, functional, and service criteria to identify CSHCN and would include a broad spectrum of children with established conditions, as well as those at risk for developing certain conditions.

- The MCH Bureau's Definition of CSHCN: "Children with special health care needs 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."

This definition is likely more difficult to operationalize at the managed care plan level because of the broad terminology of "increased risk" and of service needs "beyond that required by children generally." However, excluding the at-risk population, Paul Newacheck and colleagues are currently developing a method for operationalizing the MCHB definition using items from the Disability Supplement to 1995 National Health Interview Survey (U.S. Department of Health and Human Services, 1996). Newacheck's method has been used to determine prevalence of CSHCN nationwide and if developed into a screening tool could potentially be a means for managed care plans to identify children with a history of both high rate of service use and functional disabilities.

A fourth approach, developed by Ruth Stein and her colleagues at Albert Einstein School of Medicine, is the administration of a questionnaire to screen children and identify those with chronic conditions. Stein and her colleagues have developed a questionnaire, called the "Questionnaire for Identifying Children with Chronic Conditions" (QuiCCC), that can be administered to parents of children as a screening tool to identify CSHCN. The QuiCCC includes a series of questions designed to identify children with chronic conditions who meet a a combination of diagnostic and functional standards. Children are identified as having a "chronic condition" if their condition meets the following three criteria (Stein, et al., 1993):

- The condition has a biologic, psychologic, or cognitive basis;
- The condition that has lasted more than one year or is anticipated to last more than one year; and
- The condition has one or more of the following consequences for the child:
  - Limitation of function, activities or social role;
  - Dependency on medication, special diet, medical technology, assistive devices, or personal assistance to compensate for or minimize their limitations; or
  - Need for medical care or related services, psychologic services or education services over and above the usual for the child's age or for special ongoing treatments, interventions or accommodations at home or in school.

The QuiCCC has recently been tested and found to be a valid instrument (Stein, et al., in press). It is a relatively short questionnaire, taking an average of eight minutes to complete for each child, and can be administered by non-physician staff at an MCO.

Given the strengths and limitations of the current definitions of CSHCN and available screening tools, it is recommended that a state planning a quality monitoring effort for CSHCN choose either the QuiCCC instrument or a specific list of pediatric diagnoses as the screening tool. Specific state contract standards for MCOs, which follow from this recommendation, are listed below:

- Plans must screen all children at intake and on a periodic basis after enrollment, using a specific, standard screening tool.
- Plans must provide information to the state on the total number and percentage of children identified as CSHCN, the primary diagnoses of these children, and the number of CSHCN with each diagnosis. This information should be collected and tracked, using the standard screening tool and, if required to confirm diagnoses, the medical record.

## B. Structural Standards

As discussed in Chapter II, a key step in assuring quality care for CSHCN in managed care is the establishment of standards for the structure of care. Structural standards tailored to this population of children are needed because CSHCN often require a broad range of specialty services and an increased emphasis on coordination of their care plans with multiple providers and with the family.

Structural standards can play two important roles. First, as contract language between state Medicaid agencies and managed care organizations (MCOs), structural standards specifically designed to meet the needs of CSHCN act as state requirements regarding MCOs' infrastructure, the content of care, and the accessibility of care for this population. Structural standards can also be used as part of ongoing quality assurance monitoring systems to monitor the MCOs' compliance with the contract standards.

This section recommends a set of structural standards for state agencies to use with managed care organizations that provide services to CSHCN. The recommended standards in this section are organized according to five domains of quality for structural standards discussed in Chapter II:

- Provider networks,
- Benefit coverage,
- Appropriateness of care,
- Access standards, and
- Grievances and appeals processes.

In addition to the standards that are recommended below, many overarching structural standards can be applied to the care of all children in managed care. These include such pediatric standards as the availability of preventive primary care services and providers, the presence of pediatric-specific internal quality assurance standards, coordination with school health services, and convenience of the plan's hours of operations for families, among others. It should be noted that the recommendations in this section are limited to those that focus on the particular concerns of CSHCN and their families.

Except where otherwise noted, each of the recommended standards below can be included both in state Medicaid agencies' contracts with MCOs and in ongoing quality assurance surveys as a monitoring requirement. In either case, the standards are designed to document compliance with a structural standard. Many of the standards require MCOs to simply provide documented assurances that they have the systems, the care, and the standards to adequately serve CSHCN and their families. Other standards require the MCOs to describe their systems, care, or standards for this population. For these latter group of standards, it is assumed that the state would evaluate the adequacy of plans' descriptions in meeting the needs of CSHCN. Standards requiring lists or narrative descriptions standards are recommended in several areas, including referrals, family involvement, multidisciplinary teams, case coordination, and waiting times.

The structural standards recommended below are adapted from published papers and reports by national organizations on quality assurance for CSHCN served in managed care settings. The sources are noted following each of the recommended standards.

## 1. Provider Networks

The recommended structural standards regarding provider networks are designed to assure that MCOs possess the appropriate mix of primary, specialty, and ancillary providers to meet the multiple needs of CSHCN. Children with special health care needs have complex medical and related service needs. Quality of care for these children depends in large part on the availability of specialty pediatric providers and on the knowledge and training of providers in the MCO network who serve these children.

The suggested structural standards for this domain focus on the capacity and adequacy of the provider network. Specifically, the standards fall into three areas: 1) composition of the provider network, 2) knowledge and training of plan physicians, and 3) continuing education for physicians and staff.

- **Provider Network Composition**

  - ✓ Plan is able to refer within its network, or through arrangements with out-of-network providers, to pediatric physician subspecialists, including subspecialists in the following areas: allergy/asthma, cardiology, child and adolescent psychiatry, developmental/behavioral pediatrics, endocrinology/diabetes, ear, nose and throat, gastroenterology, hematology/oncology, hemophilia, HIV/AIDS, neonatology, nephrology, neurology, oro-facial anomalies, orthopedics, pulmonary/cystic fibrosis, rheumatology, and sickle cell disease (New England SERVE, 1995).

  - ✓ Plan is able to refer within its network, or through arrangements with out-of network providers, to ancillary services and ancillary providers with pediatric expertise, including the following: adaptive equipment, durable medical equipment, home nursing services, hospice services, personal care, nutritional counseling, physical therapy, occupational therapy, speech therapy, respiratory therapy, psychology, and social work (New England SERVE, 1995).

- **Pediatric Specialty Training and Knowledge of Providers**

- ✓ Plan tracks the number of physicians who have completed residency training and/or are board certified in a pediatric subspecialty (NCQA, 1996).

- ✓ Plan tracks the percentage of its specialty care physicians who report they have adequate knowledge to provide care to CSHCN (Monahan, et al., 1996).

- ✓ Plan tracks the percentage of its primary care physicians who report they have adequate knowledge to provide care to CSHCN (Monahan, et al., 1996).

- ✓ Plan tracks the number and describes types of mental health providers specially trained to treat children and adolescents (NCQA, 1996).

- Continuing Education for Providers

  - ✓ Plan physicians and other staff receive annual continuing medical education about the medical needs of CSHCN (NACHRI, 1996).

  - ✓ The plan informs physicians and other staff about the use and location/availability of the following services for CSHCN and their families: respite services, special recreation services, special transportation services, mental health services, ancillary therapies, and child care (Monahan, et al., 1996).

### 2. Benefit Coverage

In the Medicaid program, the Early and Periodic Screening, Diagnosis, and Treatment program (EPDST) is a comprehensive standard of benefit coverage for all children. EPDST rules recognize that health care services for CSHCN must include prevention, treatment for illnesses, and care for children with chronic conditions that may not be curable. Specifically, the EPDST program rules require states to conduct periodic EPDST screens on all members under age 21 to identify health and developmental problems, and to provide the following diagnostic and treatment services:

> ...such other necessary health care, diagnostic services, treatment, and other measures...to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the state plan. (42 U.S.C. § 1905(r))

To assure that CSHCN in Medicaid managed care plans are covered by the plans for the full range of benefits envisioned by the EPDST program, the first recommended structural standard in this domain is to require MCOs to adhere to the letter and intent of the Medicaid law as it relates to EPDST.

A second structural standard is recommended to require that plans document the benefits they offer to their pediatric enrollees. Note that not all of these services need to be included in the MCO's scope of service; however, the standard requires that covered services be specifically listed by the MCO in its contract and in its annual reporting to the state. For those services that are not in the MCO's scope of service, the standard requires that the MCO contract should describe the systems for referral to and follow-up with providers of these services.

A third structural standard is recommended to promote formal referral arrangements between MCOs and the public health, education, and social service entities who provide services and develop care plans for CSHCN.

- ✓ The plan agrees to provide the full range of periodic early and periodic screening, diagnosis and treatment services to all eligible children up to age 21, in accordance with the federal Medicaid EPDST law and the intent of the law (Health Systems Research, 1996).

- ✓ The plan's benefit package includes the following services and equipment (Health Systems Research, 1996; New England SERVE, 1995; and Newacheck, et al., 1996):

    - Primary and specialty medical services (in- and out-patient);
    - Specialized nursing and support services;
    - Mental health services;
    - Durable medical equipment (e.g., wheelchairs and braces) adapted for children;
    - Adaptive equipment (e.g., orthotic devices and communication devices);
    - Occupational and physical therapy;

- Speech, language and hearing services;
- Home health care;
- Hospice services;
- Nutritional counseling and services;
- Health education and health promotion, and
- Medications

✓ The plan describes the arrangements it has with individual public health, education and other agencies serving CSHCN (NCQA, 1996 and Newacheck, et al., 1996).

### 3. Appropriateness of Care

Due to the complex, long-term and sometimes intensive care needs of CSHCN, the appropriateness of the care provided to them—i.e., the arrangements and delivery systems for care—are as important as the provider networks and benefits available. Managed care organizations must have appropriate arrangements and delivery systems to ensure that these children can receive the full range of services they require in a timely fashion. In addition, it is critically important that a system be in place to coordinate the child's care and the family's needs across multiple providers and services in outpatient medical settings, in tertiary care settings, in the home and in the community. Further, for all children and particularly for CSHCN, the system must be structured so that families can play a pivotal role in planning and carrying out their children's care plan.

Seven structural standards of appropriateness of care are recommended below. These standards address the following operational aspects of the care system: referrals, multidisciplinary teams, case coordination/case management, and family involvement and education.

#### ■ Referrals

✓ Plan provides a description of its system for referring new enrollees to a primary care provider with experience serving CSHCN, and in some cases directly to a pediatric specialist if he/she is trained in general pediatrics and

able to monitor the child's receipt of preventive and primary care services (NACHRI, 1996).

✓ Plan provides a description of its system for primary care physicians to refer CSHCN to pediatric subspecialists as well as to ancillary therapies, if needed, both within and out of plan (NACHRI, 1996; New England SERVE, 1995).

- Multidisciplinary Teams

✓ Plan describes the multidisciplinary care teams available to serve CSHCN whose purpose is to evaluate, plan, and provide comprehensive health care services (Health Systems Research, 1996; NACHRI, 1996; New England SERVE, 1989; Newacheck, et al., 1996).

- Case Coordination/Case Management

✓ Plan describes its care coordination/case management system to assure coordination and continuity of health and related services for CSHCN (New England SERVE, 1995).

- Family Involvement and Education

✓ Plan describes how families are included in the development of care plans for CSHCN (New England SERVE, 1989 and 1995; Newacheck, et al., 1996).

✓ Plan describes any special targeted efforts to educate and orient the families of new Medicaid CSHCN enrollees on appropriately accessing and utilizing plan services (NCQA, 1996).

✓ Plan provides written information to parents of CSHCN on the plan's services and the providers trained and available for their children (New England SERVE, 1995 and Newacheck, et al., 1996).

✓ The plan describes its system to inform and refer families of CSHCN to support services, such as support groups, family counseling, and respite care, that increase the family's capabilities to participate in the child's care (New England SERVE, 1995 and Newacheck, et al., 1996).

### 4. Access Standards

In order for CSHCN to utilize the managed care plan's available services, they must be available in a timely manner physically accessible to all children, including those with functional and physical disabilities. The first recommended structural standard below requires MCOs to document their standards and policies regarding appointment waiting times. The second standard requires MCOs to document their physical accommodations to the needs of children who are visually impaired, hearing impaired, and those who have physical disabilities.

- Waiting Times

  - ✓ Plans must document that their waiting time for routine specialist follow-up appointments is no longer than 30 days for CSHCN (Health Systems Research, 1996).

  - ✓ Plan must develop a process for monitoring the scheduling of appointments along with the actual time that enrollees must wait to be seen at the office or clinic. When the appointment scheduling or office waiting times are excessive, the plan must take appropriate action to ensure adequate service (Health Systems Research, 1996).

- Physical Access

  - ✓ Plan provides assurances that its facilities and services will be accessible to its visually and hearing impaired and physically disabled members of all ages, including children (Health Systems Research, 1996; Newacheck, et al., 1996).

  - ✓ Plan provides assurances that it will provide or arrange for special transportation of children with disabilities to medical care, when necessary (Health Systems Research, 1996).

### 5. Grievances and Appeals Processes

As noted in Chapter I and II, because closed-system capitated managed care is new to many CSHCN and their families and these children's complex health needs are generally new to managed care organizations, early on there are likely to be many concerns that families have with the care they receive in this system. The recommended standards below are designed to assure that MCOs have a system for hearing these family grievances and an appeals process for families

to contest denials of service, as well as a tracking system to document families' concerns and the solutions implemented as a result of these grievances.

- ✓ Plan describes its process for hearing and resolving member grievances and its appeals system, along with any specific characteristics of this system for CSHCN and their families (Newacheck, et al., 1996).

- ✓ Plan describes its system for monitoring the number and types of grievances, appeals and the corrective actions taken specific to the care of CSHCN (Health Systems Research, 1996).

## C. Process Measures

As discussed in Chapter II, the process of care provided to CSHCN may be monitored in a number of domains. Many of these may be directly tied to the structural indicators described above, as they address the use of providers and services whose availability is monitored through the indicators of structural quality. The major process domains to be addressed here include the following:

- Access to care,
- Utilization of care,
- Appropriateness/Quality of care,
- Health care expenditures, and
- Consumer satisfaction.

This section presents a selection of sample indicators in each of the six domains listed above. These examples are drawn from the quality monitoring systems and instruments described earlier in this chapter. In many cases, similar indicators are included in more than one of these sources, although the different systems may state or define an indicator slightly differently. In these cases, more than one source will be cited for an indicator. In other cases, the original sources present only a general standard, without a clear method for operationalizing it as a quality indicator. In these cases, HSR has developed specific indicators based on these standards. The six domains are discussed in turn below.

### 1. Access to Care

Access to care can be measured using indicators of the availability of providers (including provider-to-population ratios), actual waiting times for an appointment or in the waiting room, and the physical accessibility of services for children with physical disabilities. This information can be gathered through administrative data collected from plans or through surveys of clients or their parents. Other measures of access examine the use of certain services, such as primary care or Early Intervention, with the rationale that if services are used, they must be accessible. (Although some of these measures are designed for the population of children generally, the results should be analyzed separately for CSHCN, to assure that these children have access to appropriate primary and preventive services.)

Measures of access that are based on utilization of services may be developed using encounter data collected from managed care plans. In some cases, these data may be combined with information gathered from reviews of a sample of medical records. To develop those access measures that are based on clients' or families' perceptions of access, family surveys will be required. Examples of access measures included in several quality monitoring systems, including potential sources of data for each indicator, are presented in Table III-1 on the next page.

**Table III-1.**
**Sample Measures of Access to Care**

| *Measure* | *Numerator* | *Denominator* | *Source of Data* |
|---|---|---|---|
| Proportion of CSHCN who have one or more primary care visits in the year[*] [¶] | Number of CSHCN with one or more primary care visits | Number of CSHCN continuously enrolled | Plan encounter and enrollment data |
| Average waiting time for appointment[‡] | Total reported waiting time by CSHCN | Number of families of CSHCN surveyed | Client/family surveys |
| Average time spent in waiting room[‡] | Total reported waiting time by CSHCN | Number of families of CSHCN surveyed | Client/family surveys |
| Proportion of [primary care, dental, mental health] providers who serve children and are accepting new Medicaid child patients[†] | Number of providers who are accepting new Medicaid children | Number of providers who serve children | Provider survey, plan administrative information |
| Proportion of very low birth weight infants referred to Early Intervention at discharge[†] | Number of VLBW infants referred to Early Intervention | Number of VLBW infants | Medical record review; Vital Statistics |
| Proportion of CSHCN referred to services who received those services [† ¶ ‡ §] | Number of CSHCN who received services following a referral | Number of CSHCN referred to services | Plan encounter data, medical record review |
| Use of care coordination to support access to community-based services[§ ‡] | Number of CSHCN who have named care coordinators | Number of enrolled CSHCN | Medical record review; client/family surveys |
| Provision of information on services provided by the plan and resources for obtaining care not covered[§ ‡] | Number of CSHCN whose families report that they have received this information | Number of enrolled CSHCN | Medical record review; client/family surveys |

*NCQA, 1996 ‡Newacheck, et al., 1996 ¶NACHRI, 1996
†Monahan, et al., 1996 §New England SERVE, 1989

### 2. Utilization of Care

Process measures of utilization quantify the use of care, either by calculating the average number of visits of a certain type per enrollee (or per user of services) or by calculating the proportion of enrollees who used a service at least once (or more). Basic utilization measures may be applied to a wide range of service categories, including inpatient hospital care, ambulatory care, prescription drugs, durable medical equipment, mental health services, and substance abuse treatment services.

Measures of utilization may be tracked over time, compared to historical fee-for-service utilization patterns, or used to compare different managed care plans. These indicators may then be used to analyze the effect of managed care on utilization patterns or to compare how different plans manage the use of services by their enrollees.

Examples of utilization measures proposed in several monitoring systems are presented in Table III-2. Most of these measures were designed to apply to the general population, although many, such as the use of durable medical equipment, are particularly appropriate for monitoring the use of services by CSHCN. Other measures, such as the rate of unplanned hospitalizations among CSHCN, were specifically designed for the CSHCN population to take into account the distinction between predictable and unpredictable use of services. These measures are based largely on encounter data submitted by plans, with enrollment databases used to develop the measures' denominators.

### 3. Appropriateness/Quality of Care

Process measures of the appropriateness of care build on other measures of the structure and process of care by operationalizing standards of appropriate care for children. Some of these standards, including immunization rates and adherence to recommended schedules of well-child care, reflect the need to monitor these children's use of primary care, in addition to the specialty services they require. In addition, measures of the appropriateness of care provided to children with special health care needs can be designed to assess the degree to which care is community

**Table III-2.**
**Sample Measures of Utilization of Care**

| *Measure* | *Numerator* | *Denominator* | *Source of Data* |
|---|---|---|---|
| Frequency of selected procedures (e.g., tonsillectomy, myringotomy) per 1,000 member months[*] | Number of procedures performed, by age | Total number of Medicaid member months by age | Plan encounter and enrollment data |
| Number and rate of hospital discharges per 1,000 member months, by age[*‡] | Number of discharges by age | Number of Medicaid member months by age | Plan encounter and enrollment data |
| Average length of hospital stay per 1,000 member months, by age[*‡] | Number of inpatient care days by age | Number of Medicaid member months, by age | Plan encounter and enrollment data |
| Number and rate of ambulatory visits per 1,000 member months, by age[*‡] | Number of face-to-face encounters by age | Number of Medicaid member months by age | Plan encounter and enrollment data |
| Number and rate of ER visits per 1,000 member months[*] | Number of ER visits | Number of Medicaid member months | Plan encounter and enrollment data |
| Percentage admitted for specified mental health disorders who are readmitted within 90 or 365 days[*] | Number readmitted within 90 and 365 days, by age and sex | Number hospitalized for specified mental health disorders | Plan encounter data |
| Rate of hospitalization for ambulatory-care-sensitive conditions[†] | Number of children hospitalized for these conditions | Number of children enrolled | Plan encounter and enrollment data |
| Proportion of children's visits to a physician that are acute in nature[†] | Number of children's visits to physicians that are acute in nature | Number of visits to physicians made by children | Plan encounter data |
| Proportion of children who received any mental health service who received inpatient mental health services[†] | Number of children who received inpatient mental health care | Number of children who received mental health care | Plan encounter data |
| Rate of unplanned hospitalizations for CSHCN[†] | Number of unplanned hospitalizations for CSHCN | Number of CSHCN | Plan encounter and risk-screen data |

*NCQA, 1996 ‡Newacheck, et al., 1996 ¶NACHRI, 1996
†Monahan, et al., 1996 §New England SERVE, 1989

based, family centered, and comprehensive, attributes that are particularly important for children with complex needs. Most mainstream quality monitoring systems, however, have not developed operational definitions of these measures. The efforts of New England SERVE and the Beach Center on Families and Disability have been specifically directed toward the development of monitoring systems that assess systems' achievement of these goals.

Measures of the appropriateness of care that are based on accepted standards of care, such as immunization schedules, may be developed using encounter and enrollment data from plans. Those that assess more subjective qualities of care, such as family centeredness, may be developed using family surveys as well as information from the client's medical record. Examples are included in Table III-3 on the following page.

### 4. Health Care Expenditures

Few monitoring systems have developed detailed indicators of expenditures for the care of CSHCN. Under managed care, the amount spent per enrollee in a plan is generally constant unless capitation rates are risk-adjusted based on some criterion, such as an enrollee's health status. Therefore, measures of expenditures for care may focus on the cost to a plan of various types of services. These measures may also be construed broadly to include out-of-pocket expenditures and services financed through other systems, such as Title V CSHCN programs. However, sliding-scale fees charged by many programs may make it difficult to compare the amounts spent out of pocket by families at different income levels.

Measure of plans' expenditures for various types of care may be based on administrative data collected from the plans. Measures of expenditures from other sources will require data from those sources, including Title V and Part H Early Intervention programs. Surveys of families may be used to examine out-of-pocket expenditures, with the caveat that respondents may not accurately recall their expenses and that the amount families actually pay may not equal the actual cost of services. Despite the difficulty of measuring expenditures for care under managed

**Table III-3.**
**Sample Measures of Appropriateness of Care**

| *Measure* | *Numerator* | *Denominator* | *Source of Data* |
|---|---|---|---|
| Proportion of LBW/VLBW infants delivered at Level II/III hospitals[*] | Number of LBW/VLBW infants delivered at Level II or III hospitals | Total number of LBW/VLBW infants | Plan encounter data |
| Proportion of children receiving recommended schedule of well-child visits[*] and additional screens as required for certain conditions [¶] | Number of children receiving recommended schedule of well-child visits | Total number of children enrolled | Plan encounter and enrollment data |
| Vaccine-specific and combined immunization rates for two-year-olds[*¶] | Number of two-year-olds who have received full course of recommended vaccines | Total number of children enrolled | Plan encounter and enrollment data |
| Representation of CSHCN through family membership on the health care team[§#] | Number of CSHCN enrolled in plan with family member as member of health care team | Number of CSHCN enrolled in plan | Medical record review; family survey |
| Use of a comprehensive assessment process preceding and guiding the development of the health care plan[§ ¶] | Number of CSHCN enrolled for which a comprehensive assessment process is conducted | Number of CSHCN enrolled in plan | Medical record review |
| Development of a written health care plan to guide all treatment and therapeutic interventions[§ ¶] | Number of CSHCN enrolled for which a written health care plan is in the medical record | Number of CSHCN enrolled in plan | Medical record review |
| Proportion of CSHCN who had at least one preventive dental visit in the last year[†] | Number of CSHCN enrolled who had at least one preventive dental visit in the last year | Number of CSHCN enrolled in plan | Plan encounter and risk-screen data |
| Proportion of adolescents with special health care needs for whom a transition plan is developed [† § ¶] | Number of adolescents for whom a transition plan is developed | Number of adolescent CSHCN in plan | Medical record review and plan enrollment data |

*NCQA, 1996 ‡Newacheck, et al., 1996 ¶NACHRI, 1996
†Monahan, et al., 1996 §New England SERVE, 1989 # The Beach Center, 1994

care systems, several monitoring systems have proposed measures of expenditures for or the cost of care which may be applied to CSHCN services. These are presented in Table III-4.

**Table III-4.**
**Sample Measures of Expenditures for Care**

| *Measure* | *Calculation of Measure* | *Source of Data* |
|---|---|---|
| Changes in cost of care (rate trends)* | Percent change in per-member-per-month expenses, by payer | Plan administrative data |
| Average total expenditure for care, from all sources‡ | Average of capitation rate plus family expenditures | Plan administrative data and family survey |
| Average out-of-pocket expenditure for care‡ | Average family expenditures | Family survey |

* NCQA, 1996 ‡Newacheck, et al., 1996

### 5. Consumer and Family Satisfaction

A final, important area for monitoring is the satisfaction of users of care and their families with the plan in which they are enrolled. While this domain is important for all populations enrolled in managed care, it is particularly useful for CSHCN, whose families can be expected to be closely involved in and well informed about their children's care. Thus, a carefully designed survey of clients and their families can reveal much about the process of care employed by a particular plan. Examples of the types of measures of family satisfaction that may be developed using information about consumer and family satisfaction are presented in Table III-5 below; however, other information, such as data describing the outcomes of services provided by a plan, may be included in these surveys as well.

**Table III-5.**
**Sample Measures of Consumer and Family Satisfaction**

| *Measure* | *Numerator* | *Denominator* | *Source of Data* |
|---|---|---|---|
| Proportion of parents reporting that care provided to the child is appropriate † | Number of parents of CSHCN reporting that care is appropriate | Number of parents of CSHCN responding to survey | Client/family survey |
| Proportion of parents reporting that care provided to the child is good or excellent† | Number of parents of CSHCN reporting that care is good or excellent | Number of parents of CSHCN responding to survey | Client/family survey |
| Proportion of parents reporting that they are satisfied with their role in making decisions about their child's care†# | Number of parents of CSHCN reporting satisfaction with their role in making decisions | Number of parents of CSHCN responding to survey | Client/family survey |
| Proportion of parents who feel that they have adequate information to manage their child's care† ¶# | Number of parents of CSHCN reporting adequate information | Number of parents of CSHCN responding to survey | Client/family survey |
| Proportion of parents who filed formal complaints or grievances (or are in an appeal process) with the plan or program† ‡ | Number of parents who filed complaints on behalf of CSHCN | Number of CSHCN enrolled in plan | Plan administrative data |
| Proportion of parents reporting satisfaction with the choice of primary and specialty providers‡ | Number of parents of CSHCN reporting satisfaction with the choice of providers | Number of parents of CSHCN responding to survey | Client/family survey |
| Proportion of parents reporting satisfaction with the amount of time providers spend with the child‡ | Number of parents of CSHCN reporting satisfaction with time spent with child | Number of parents of CSHCN responding to survey | Client/family survey |
| Rate of voluntary disenrollment among CSHCN‡ | Number of CSHCN who disenroll in plan | Number of CSHCN enrolled in plan | Plan administrative data |

*NCQA, 1996 ‡Newacheck, et al., 1996 ¶NACHRI, 1996
†Monahan, et al., 1996 §New England SERVE, 1989 #Beach Center, 1994

## D. Health Status and Outcome Measures

As discussed in Chapter II, a set of measures related to the health status of children and the outcomes of the care they receive represents an additional, critical component of any quality assurance system designed to monitor the experiences of CSHCN enrolled in managed care. However, numerous complications relating to data availability, multiple domains within which to measure child health, time frames over which to measure outcomes, and the degree to which child health outcomes can be attributed to the particular services provided by a managed care plan make the measurement of outcomes extremely complex and difficult. Therefore, it is important for state officials not to place undue emphasis on outcome measures, at the expense of structure and process measures, when assessing the overall quality of care being provided to CSHCN in managed care arrangements.

Based on a comprehensive review of current research on outcomes measurement in child health and analysis of existing instruments designed to assess various aspects of child health and functional status, this section recommends that North Carolina officials focus their attention on two primary areas—child health status and parental health status—when considering the development of a quality assurance system. Each of these areas is discussed in more detail below.

### 1. Child Health Status

When measuring changes in child health status over time, one can choose to monitor general indicators of child health (covering several domains) or indicators directed toward specific realms, such as physical functioning, psychological status, or educational achievement. For measuring general child health status, two promising instruments exist: the Medical Outcome Study's SF-36 Health Survey (Landgraf, et al., in press); and the Functional Status Measure (FS-IIR) (Stein and Jessop, 1990). Each of these tools is described in more detail below.

- SF-36 Health Survey—Child Health Questionnaire. The SF-36 Health Survey was developed by the Health Institute at Tufts University. It provides practical and valid insights into health status and outcomes from the patient's point of view by measuring eight health concepts: limitations in physical activities due to

health problems, limitations in social activities because of physical or emotional problems, limitations in usual role activities because of physical health problems, bodily pain, mental health (psychological distress and well-being), limitations in usual role activities because of emotional problems, vitality (energy and fatigue), and general health perceptions.

While the general SF-36 has been widely tested and available since 1988, a new Child Health Questionnaire has recently been released and promises to be an effective means for assessing general child health status. The Child Health Questionnaire is a 50-item parent-completed form that assesses several key health concepts, including physical functioning, role and social limitations, general health perceptions, mental health, self-esteem, and effects of a child's condition on the household (such as limitations in family activities and family cohesion). The Questionnaire is intended for use with children ages 5 and older; a similar instrument can be directly filled out by children ages 10 and older. The Child Health Questionnaire also exists in a 28-item short form, which may be the one best suited for use in a monitoring system for managed care arrangements. The developers of the Child Health Questionnaire have been working on a tool for children ages 2 months to 5 years, but it has not yet been published nor is it available for general use.

Sample questions from the Child Health Questionnaire were not available for inclusion in this report; copies of the instrument can be directly obtained from the Health Institute at Tufts University.

- Functional Status II(R). The other main general health assessment instrument is the Functional Status II(R) developed by Stein and colleagues. The FS II(R) attempts to measure child health status by assessing child behavior compared to normal roles and functions at various ages. The tool assesses fewer specific health domains than the Child Health Questionnaire, but focuses mainly on the impact of illness on the usual daily activities of the child. In the instrument, each question has two parts. Part 1 asks whether the child performs various activities (including eating well, sleeping well, communicating what they want, concentrating or paying attention for a given period of time, acting nervous and tense, getting involved in games and other play) "never or rarely," "some of the time," or "almost always." Part 2, which is administered after the completion of the entire list of Part 1 items, probes those Part 1 items that reflect poor functioning to determine whether a given functional impairment is due "fully," "partly," or "not at all" to a health problem.

  The FS II(R) has both a long (43-item) and short (14-item) version. Importantly, research indicates that the instrument appears to be valid for use with children of all ages.

Moving beyond measurement of general health status, North Carolina officials may consider instruments designed specifically to measure particular health and functional domains, such as psychological and physical functioning of children. For measuring psychological function, two instruments have been frequently used among children with chronic health conditions—the Child Behavioral Checklist (CBCL) and the Personal and Role Skills Scale (PARS III). For measuring physical functioning, the Functional Independence Measure for Children (WeeFIM) may be the most reasonable choice. Each of these measurement instruments is summarized below.

- Child Behavioral Checklist (CBCL). The Child Behavioral Checklist has been used extensively in multiple studies, although mainly for research purposes and for clinical evaluation. The instrument is designed to distinguish between children with and children without psychiatric conditions. It also distinguishes between types of behavioral problems and provides a relatively good assessment of the likelihood of attentional or impulsive disorders.

  Different sections of the CBCL explore issues related to the activities that the child engages in (e.g., sports they are most likely to take part in, favorite hobbies and games, membership in organizations and clubs); the child's relationships (e.g., number of "close" friends, ability to get along with brothers and sisters, other children, etc.); and school performance (e.g., in reading, writing, arithmetic, and spelling). In another section, the CBCL asks parents to assess their children on more than 100 behaviors by indicating whether the listed activity is "very or often true," "somewhat or sometimes true," or "not true." Examples of the activities listed include acting too young for his/her age, arguing a lot, seeming confused or in a fog, being cruel to animals or other children, being disobedient at school, feeling he/she has to be perfect, seeming nervous and high strung, overeating, exhibiting sudden mood changes, and seeming too concerned with neatness. (Achenbach and Edelbrock, 1981).

  The CBCL exists in several forms, but has mainly been used to assess psychological status in children of school age and adolescents. There is, however, a form for younger children and a youth self-report form that can be applied to children ages 7 and older. There is also a teacher report available. A shorter revision of the CBCL has been incorporated into behavioral problems measures associated with the National Health Interview Survey Child Health Supplement of 1988.

  Although providing substantial amounts of information, the CBCL requires roughly 20 minutes of respondent time. This fact may make it less feasible for application in a state quality assurance system. A further problem with the CBCL is that several questions that are scored as indicative of a behavioral

problem are ones that many children with chronic conditions would normally respond to positively, as an appropriate indicator of their common symptomatology (e.g., difficulty breathing) (Perrin, et al.,1991).

- PARS III. The PARS III appears to be a particularly appropriate assessment instrument for measuring the psychological functioning of children with chronic illnesses. It is a 28-item tool that measures functioning in six domains that are associated with patterns of maladjustment in children—peer relations, dependency, hostility, productivity, anxiety-depression, and withdrawal—and can easily be used in either an interview or a self-report format. Survey questions explore whether children "never or rarely," "sometimes," "often," or "always" engage is such activities as spending time with friends, making friends without difficulty, being unable to decide things alone, doing things for attention even though he/she would be punished for it, becoming upset if others do not agree with him/her, lying, doing work without being pushed or punished, seeming restless or tense, seeming sad, acting afraid or apprehensive, and seeming unaware of things going on around him/her.

  The PARS III, compared to the CBCL, has the advantages of including no apparent confounders with chronic health conditions and of being somewhat shorter. However, the tool is also mainly intended to evaluate children ages 5 through 18 (Walker, et al., 1990).

- WeeFIM. For tracking and monitoring the physical functioning of children with disabilities, the Functional Independence Measure for Children (WeeFIM) offers a valid and well-tested measure. The WeeFIM is an 18-item, 7-level instrument used to assess a child's typical and consistent performance in self care (e.g., eating, grooming, bathing); sphincter control (e.g., bladder and bowel management); transfers (e.g., to and from chairs, toilets, tubs); locomotion (e.g., walking, crawling, stairs); communication (e.g., comprehension, verbal and nonverbal expression); and social cognition (e.g., social interaction, problem solving, memory). Scoring is designed to determine whether a child is independent, somewhat dependent, or completely dependent on others for his or her functioning. Studies have used the WeeFIM to assess children with a broad range of disabilities, including limb deficiency, Down's syndrome, spina bifida, cerebral palsy, and extreme prematurity, and has been used for both preschool and school-age children (Msall, et al., 1994).

- PEDI. The Pediatric Evaluation of Disability Inventory (PEDI) has both disability and functioning scales for children ages 6 months to 7 1/2 years, thus a similar age range as the WeeFIM (Haley, et al., 1992). The disability scales assess what a child can do, the amount of caregiving needed, and equipment modifications needed. The functional scales assess mobility, self-care, and social functioning. The developers of the PEDI are currently working to extend the age range to which it applies (Campbell, 1996). Although its upper limit is 7 1/2

years, it can also be used for older children whose disability places them functionally at younger levels of development. While the PEDI provides information on a wider variety of performance measures, this instrument requires somewhat more time to administer than does the WeeFIM.

### 2. Parental Health Status

The central role of parents or other family caregivers in affecting the health and outcomes of children with special health care needs suggests that it may also be important to employ some measure of parental health status along with measures of child health status. Two valid, well-tested instruments are available for this purpose, one that assesses both adult physical and mental health status and one that particularly focuses on parental mental health. Each of these is described below.

- SF-36 Health Survey. As discussed above, the adult version of the Medical Outcome Study's SF-36 is by far the most commonly used instrument to assess adult health status, describing both physical and mental health. Once again, the tool measures health status in eight areas and is designed to identify limitations in physical and social activities and usual roles due to health and emotional problems, bodily pain, mental health problems, and lack of vitality (Ware, 1993; McHorney, 1993).

- Center for Epidemiologic Studies-Depression (CES-D). Increasingly, many investigations have demonstrated the impact of parental mental health on the growth, development, and health status of their children (Walker, et al., 1989 Jessop, et al., 1988). Thus, several investigators recommend the use of specific measures of parental depression, rather than the broader SF-36. Among the most common of such scales is the Center for Epidemiologic Studies-Depression (CES-D) scale, a 20-item measure that determines depressive symptoms. Using a self-report format, respondents are asked to indicate how frequently they have experienced a range of depressive symptoms, including whether they were bothered by things that usually don't bother them, not feeling like eating, not feeling like they were as good as other people, feeling like everything was an effort, experiencing restless sleep, feeling lonely, having crying spells, feeling sad, etc. Respondents are asked to identify the number of times they felt these feelings—"rarely or not at all, some or a little of the time, occasionally, or most or all of the time"—during the previous week.

  Although the scale does not directly diagnose depression, it provides substantial information on depressive symptoms among parents, and scores above 20 on this measure are highly indicative of substantial clinical depression (Radloff, 1977; Orme, et al., 1986).

Although many other measures of adult health status and functioning exist, these two represent the most useful in the context of monitoring the status of parents of children with special health care needs.

### 3. Implementation Issues

In implementing the outcomes measures portion of its quality monitoring system, North Carolina officials will need to find the appropriate balance between obtaining sufficient and high-quality information regarding the health and functional status of its children with special health care needs and their parents and not imposing an unreasonable data collection burden on either managed care plans or their enrollees. Therefore, it is recommended that serious consideration be given to assessment instruments discussed above, and that state officials and members of the CSHS Medical Advisory Committee prioritize among the types of measurement data they would like to collect and select the combination of tools that best meets their information needs. For example, given the current state of the art in child health outcomes measurement, one reasonable course might be to use the FS II(R) for assessing general health and functional status for preschool children and the Child Health Questionnaire for children ages 5 and older. In addition, to monitor parental health status and especially their health in coping with the stresses of raising a child with special health care needs, it would be wise to utilize the SF-36 measure. Should the state have particular interest in parental mental health issues, the CES-D could be used instead.

With regard to timing issues, it will be critical for state officials (and managed care providers and administrators) to establish a baseline score on these various scales for each child so that changes over time can be measured. When a child is known to have a chronic illness or disability, therefore, it is suggested that managed care plans be required to administer the selected outcomes measures within a very short time after enrollment with the managed care plan (e.g., within 45 days). When an otherwise healthy child who is already enrolled in a plan develops a qualifying chronic condition, it is similarly suggested that plans be required to obtain baseline status information relatively soon after the onset of the condition. For ongoing monitoring and assessment, it is also suggested that plans be required to retest all children with

special health care needs and their parents on an annual basis so that providers, administrators, and state regulators can keep close track of changes in health and functional status over time.

## E. Conclusion

By focusing attention on the development of monitoring systems tailored to the needs of CSHCN, North Carolina officials have taken an important step. The needs of this population are complex, and their conditions make these children particularly vulnerable to the risks inherent in managed care. As the development of this monitoring system proceeds, state officials should carefully assess the progress of health services research for this population. State officials will have to select among the wealth of available structural standards for CSHCN in managed care, and choose process and outcome indicators and measurement tools that have been shown to be reliable and valid in the assessment of the effects of managed care on children's and families' health. States will also have to balance the need to monitor the structure, process, and outcome of care provided by managed care plans.

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