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## Developing a Monitoring and Quality Assurance System for Connecticut's Children with Special Health Care Needs Program

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# CHAPTER I

## Background and Overview

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Increasingly, public health agencies and programs are being forced to reconsider their roles as providers of direct health care services. Budget reductions and a renewed emphasis on the core public health functions of assessment, policy development, and assurance are requiring these agencies to curtail their roles as direct providers and payers of personal health services and focus on monitoring and oversight of services provided and managed through the private sector.

The Connecticut Bureau of Community Health is experiencing precisely this transformation. In early 1996, the state's Commissioner of Health required that the Bureau's Children with Special Health Care Needs (CSHCN) program cease to serve as a provider and payer of direct services, providing instead monitoring and oversight of services provided by contractors. Previously, the program had provided case management and payment for medical services to approximately 1,000 eligible children; an additional 8,000 children received specialty clinic-based services under contractual arrangements with 17 community-based providers. Providers' invoices were authorized and reimbursed by the state CSHCN program. CSHCN program staff conducted eligibility determination, authorization of and payment for services, administrative case management, and contract management, while a separate office within the Department handled the payment of providers.

The 1996 decision changed the program's role dramatically. Under the new structure, the program would no longer be responsible for direct services, including eligibility determination, case management, and authorization of services. Beginning in 1997, these services would be provided by two community-based tertiary regional centers under contract with the state, with a plan for each provider to receive a single annual contract awarded for the care of a defined population of children. In early 1997, contracts for these services were let to two providers:

Connecticut Children’s Medical Center (CCMC) and The Children’s Hospital at Yale/New Haven (YNH). Each of these sites was assigned a service area, representing approximately half of the state, for which it is responsible for outreach, eligibility determination, and case management for all children meeting the program’s eligibility criteria. In addition, CCMC was allotted a common pool of funding with which to reimburse providers for direct medical services provided to children eligible for the program whose care will be managed at either site.

Under this plan, the role of the state CSHCN program will shift from that of direct provision of case management and reimbursement for discrete services to one of contract management, oversight, and quality monitoring for these activities. Although the state will no longer be responsible for the provision and payment of direct services, the CSHCN program will retain its responsibility for assuring the appropriateness and quality of services provided with Title V funds. Thus, a system was needed through which to gather and analyze data from the contracted providers in order to develop indicators of the quality of care provided and the use of contract funds.

## A. HSR TA Process

In October 1994, Health Systems Research, Inc. (HSR) began to provide technical assistance to Connecticut’s CHSCN program under a contract with the federal Maternal and Child Health Bureau (MCHB). Two MCHB contracts with HSR support the provision of technical assistance to all 50 states and three territories over a five-year period.

Connecticut’s original technical assistance request concerned the need for an automated data system for the CHSCN program. Traditionally, the program had kept all of its eligibility, case management, and service authorization information on paper, and billing records were maintained in another division. Thus, program staff were unable to monitor the use or the cost of services used by its enrollees. Colleen Monahan, DC, MPH of the University of Illinois at Chicago Division of Specialized Care for Children was engaged as a consultant for this assignment. Over the first year of the project, Dr. Monahan developed an automated record-

keeping system for the CSHCN program, basing her database program on Epi-Info, a DOS-based freeware application developed for the Centers for Disease Control and Prevention.

As the role of the CSHCN program changed, however, the program's data collection and analysis needs changed as well. Dr. Monahan's focus turned to the development of a data collection and analysis system that could be used to monitor the use of funds and quality of care provided by the program's two contractors.

## **B. Overview of Report**

This document presents a summary of the monitoring and oversight system developed by Dr. Monahan for Connecticut's CSHCN program. The next chapter presents the types of data to be collected through a variety of sources, including quarterly contractor reports, family surveys, application forms, and site visit reports. The final chapter presents indicators to be derived from these data sources and discusses how to use these quality indicators to improve the care provided to children with special health care needs in Connecticut.

## CHAPTER II

### Data Collection Tools and Database Structure

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To develop the monitoring system, the infrastructure was first developed through which to collect and analyze the data submitted by the contractors. Then, specific data collection tools were developed through which to collect these data. These structures and systems are described below.

#### A. Developing the Capacity to Collect and Analyze Data

For the monitoring system to be successful, both the two contractors and the CSHCN program required data systems to consistently collect and analyze program data. As described earlier, an automated system had been developed for the CSHCN program that used Epi-Info to enter and analyze client records. For this monitoring system, however, it was decided that a database application be used that would be compatible both with the databases used by the contractors and with those used in other DPH programs, most of which used DOS- or Windows-based databases. Visual FoxPro 3.0 was selected as the system's database engine. The currently-available Windows version of this program requires the use of the Windows 95 operating environment; therefore, this system was installed on two workstations within the CSHCN program, with the expectation that the entire Department would make this transition over the coming years.

The two contractors also needed systems with which to gather and submit data to the CSHCN program. Before these contracts began, neither site had databases that were capable of reporting information on the CSHCN clients they had traditionally served. To test their systems, the contractors were asked to produce all electronic data available on each of their CSHCN program clients. After a two-week period, each site reported that no data were

retrievable; clients were identified as CSHCN-eligible on hard copy charts, but were not identifiable as eligible for the program on any clinical data system known to information systems staff. Since Microsoft Access was the database in use by the staff at these sites, this software package was selected as the database engine for the contractors. Databases developed in Access can be saved and submitted in a format that can be read in FoxPro.

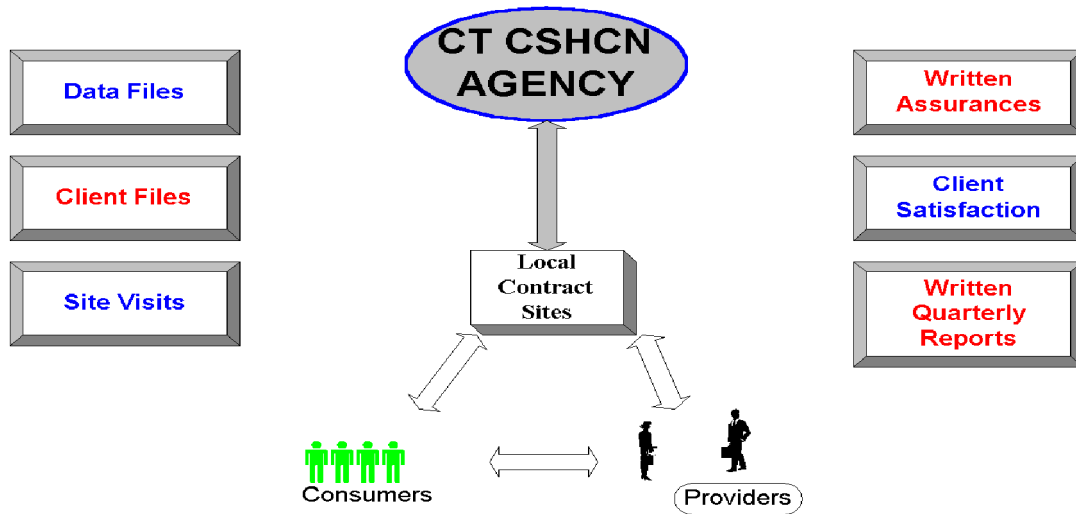
## B. Data Collection Tools

A number of tools were then developed to gather data from providers and families. Figure 1 shows a diagram of the components of the quality assurance and monitoring system, including the following data sources:

- Family application forms;
- A CSHCN worksheet completed annually for each enrolled child;
- Quarterly written activity reports from the two contractors;
- Data on the contractors' expenditures for services;
- Annual family surveys;
- Reports of annual monitoring site visits conducted by CSHCN program staff;  
and
- Written assurances from the contractors.

Each of these is discussed in more detail below.

Figure 1.



## 1. Family Application

This form is to be completed when a child enrolls in the CSHCN program and annually thereafter when the child's eligibility is recertified. It will collect demographic information and financial information to be used in determining income eligibility for the program; it also includes a space for staff to enter information about the child's primary diagnosis. The demographic and diagnostic information included in the form will be entered into the database by each contractor and reported to the state CSHCN program. These data will be entered for all applicants to the CSHCN program, including those who are determined to be ineligible; thus, information will be available with which to assess unmet needs and potential gaps in the program.

## 2. CHSCN Worksheet

This form was designed to gather information about each CSHCN enrollee that may not necessarily be available at the time of eligibility determination. The worksheet will be used by the two contractors to provide information about clients enrolled in foster care, ineligibility for the CSHCN program, disenrollment in the CHSCN program, acuity level, and immunization status. The worksheet will be completed annually for each child at the time of recertification.

### 3. Quarterly Activity Reports

Each quarter, each contractor will be required to provide a standard set of aggregate data on a written form. The data to be reported include the following:

- Total number of children served in the quarter;
- Number of children by town, age, gender, and race/ethnicity;
- Number of visits provided;
- Number of active records during the quarter;
- Number of records opened;
- Number of records closed;
- Description of problems and concerns families have with payment for goods or services;
- Number and type of grievances filed;
- Number, type, and location of outreach activities;
- Availability of the following services in the communities served:
  - Respite care;
  - Special recreation services;
  - Special transportation services;
  - Mental health services;
  - Physical, occupational, and speech therapy;
  - Child care for CSHCN; and
  - Nutrition services
- For each clinic conducted during the quarter, the number of patients seen, the number of CSHCN-eligible patients seen, and the number of encounters;
- Other services needed by CSHCN that are unavailable or hard to obtain;

- Vulnerable groups of CSHCN not currently eligible for the program;
- Community linkages needed to enhance the comprehensiveness of services; and
- For each service to which clients are referred, the number of clients referred to (or from) the program.

In addition, several additional items may be added to the quarterly activity reports in future years. These include the following:

- The number of children enrolled by type of health insurance;
- The number of children enrolled in managed care plans;
- The number of clients referred to services who received those services; and
- The number of care plans developed.

#### 4. Expenditure Data

Each quarter and at the end of each year, the contractors will be required to submit a data file containing information on expenditures made on behalf of each client over the reporting period.

The data elements to be submitted in this file include the following:

- The client's identification number, insurance status, enrollment status in the state's Birth to Three (Part H) program and SSI;
- The family's gross income and family size;
- Total CSHCN program funds (Title V dollars) expended on behalf of the client for each of the following services:
  - Hospitalizations;
  - Emergency room services;
  - Ambulatory surgery;
  - Pharmacy services;
  - X-rays;

- Durable medical equipment;
- Laboratory services;
- Care coordination;
- Office visits;
- Therapies;
- Nursing services;
- Dental services and orthodontia;
- Other tests (EEGs, EKGs, etc.);
- Orthotics and prosthetics;
- Hearing devices;
- Medical supplies; and
- Other services (with an explanation of these services).

In future years, the database may also be augmented to include any other payers available for these services, such as foundations or charities.

## 5. Family Survey

Families of enrolled children will be asked to complete the Family Survey at enrollment and annually thereafter. This survey will cover information typically included in a client satisfaction survey, including the number of services used, the appropriateness of these services, and the family's perception of and satisfaction with their child's care.

## 6. Site Visit Reports

Site visits will be made at least annually to each contractor by CSHCN program staff. In addition to speaking with clients and families, observing service delivery, and reviewing the data system, during each visit, staff will review a sample of client charts, selected to represent children with a range of ages and diagnoses. These chart reviews will address such standards as the presence of care plans, the immunization status of enrolled children, the coordination of care, and the coordination of benefits. Concomitantly, the policies and protocols of the contractor will be reviewed.

## 7. Written Assurances

Prior to the end of each contract period, a set of assurances is required by DPH as part of an application for continued funding. These assurances include the following:

- Assurance of the existence of a policy to inform parents about health supervision guidelines;
- Assurance of a written grievance procedure policy;
- Assurance of the existence of a policy to disseminate information on the availability of services, if this information is known to the contractor; and
- Assurance that services are delivered in a comprehensive, coordinated, family-centered, community-based, and culturally competent manner.

## C. Database Structure

Information from the application forms, family surveys, CSHCN worksheets, and the contractors' expenditure information will be entered into tables to form the Visual FoxPro database. Table 1 below presents the databases into which the data from each source will be entered.

<b>Table 1. Data Sources and Database Tables</b>	
<i>Data Source</i>	<i>Database Files</i>
Family Application	CTDEMO.DBF; DIAGNOSE.DBF
CSHCN Worksheet	WORKSHEET.DBF
Expenditure Data	FINANCE.DBF
Family Survey	FAMSURV.DBF

These tables will be created by the contractors in Microsoft Access; however, they will be required to provide the tables in database format (that is, as \*.dbf files), to be read into Visual FoxPro by CSHCN program staff. This database will then be analyzed to create the reports on quality indicators described in the next chapter.

## CHAPTER III

### Quality Monitoring Indicators

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Using the data sources described in Chapter II, indicators were developed to monitor the quality of care provided by the CSHCN program contractors. Indicators were developed in the following domains:

- Membership;
- Utilization of services;
- Quality of services and health status of enrollees;
- Access to care;
- Clinical management; and
- Finance.

These were adapted from the domains used in the Health Plan Employer Data and Information Set (HEDIS) for Medicaid, developed by the National Committee for Quality Assurance. The indicators used in each domain, as well as the data sources used to develop each measure, are presented below. The denominator of many of these indicators is the total number of program clients enrolled in the contractor's site. This may be taken from the contractors' quarterly reports, which will be submitted in paper form, or by summing the number of records included in the database files submitted by the contractors.

#### A. Membership

This indicator compares the actual number of children enrolled in each contract site with the expected target population, as determined by state program staff. By monitoring the proportion

of the target population that is served, program staff will be able to monitor the effectiveness of contractors' outreach efforts and assure the provision of services to all children in need. The development of this indicator is presented in Table 2 below.

<b>Table 2. Membership Indicator</b>		
<i>Indicator</i>	<i>Measurement</i>	<i>Data Sources</i>
Proportion of the expected target population of CSHCN served by the contractor.	Numerator: the total number of clients served by the site in each quarter  Denominator: expected target population of CSHCN in each service area, as estimated by the Connecticut CSHCN program	The Connecticut CSHCN program and contractors' quarterly reports (or database files)

## B. Service Utilization

The eight indicators in this domain are designed to provide information on the utilization of services and the program's approach to allocating services to meet its clients' needs. In general, utilization indicators may simply measure the number of services provided in order to assure that services are being provided in accordance with the contract. The eight indicators presented here focus on several main areas. First, they include measures of the level of care provided, including rates of hospitalization and emergency room use. A measure of appropriateness of care is included, measuring the rate of hospitalization for conditions for which consistent outpatient care can help reduce the need for inpatient care; these conditions include asthma, bacterial pneumonia, diabetes, cellulitis, dehydration, immunization-preventable conditions, kidney and urinary tract infections, failure to thrive, and tuberculosis. Measures are also included of compliance with standards of care, such as immunization rates and the proportion of children receiving an annual dental visit. These indicators are presented in Table 3 on the next page.

**Table 3.  
Utilization Indicators**

<i>Indicators</i>	<i>Measurement</i>	<i>Data Sources</i>
Rate of hospitalizations for eligible diagnosis.	Numerator: the number of hospitalizations for the conditions that qualify the child for the CSHCN program.  Denominator: total number of clients served.	The Family Survey data and quarterly reports.(or database files)
Rate of hospitalizations for ambulatory care sensitive conditions (ACSC)	Numerator: the number of hospitalizations for ACSC.  Denominator: the total number of clients served.	The Family Survey data and quarterly reports (or database files)
Proportion of visits to a physician's office that are acute in nature.	Numerator: the number of physician visits that are acute in nature.  Denominator: the total number of physician visits.	The Family Survey data and quarterly reports (or database files)
Rate of unplanned hospitalizations for child's eligible condition.	Numerator: the number of unplanned hospitalizations for eligible conditions.  Denominator: the total number of clients served  (Alternatively, the denominator could be the total number of hospitalizations for enrolled children.)	The Family Survey data and quarterly reports (or database files)
Proportion of children served with at least one unplanned visit to ER for primary condition.	Numerator: the number of children with at least one unplanned visit to ER for the qualifying condition.  Denominator: the total number of clients served.	The Family Survey data and quarterly reports (or database files)
Proportion of children who had one preventive dental care visit in the last year.	Numerator: the number of children who had one preventive dental care visit in the last year.  Denominator: the total number of clients served.	The Family Survey data and quarterly reports (or database files)

**Table 3. (cont.)  
Utilization Indicators**

<i>Indicators</i>	<i>Measurement</i>	<i>Data Sources</i>
Proportion of children up to date on their immunizations at program entry.	Numerator: the number of children fully immunized at program entry.  Denominator: the total number of clients served.	The CSHCN Worksheet data and quarterly reports (or database files)
Proportion of children up to date on their immunizations (annual review).	Numerator: the number of children up to date on their immunizations at the end of the year.  Denominator: the total number of clients served	The CSHCN Worksheet data (or database files)

## C. Quality of Care and Health Status

Four indicators have been developed to monitor the health status of enrolled children, using information from the Family Survey on parents' reports of their children's health and functional status. These indicators, which identify parents' perception of the health of their children and the change in their children's health status, may be used to monitor the quality of care provided by the contractors by examining changes in these indicators over time. The specific indicators of health status are presented in Table 4 below.

<b>Table 4. Indicators of Quality of Care and Health Status</b>		
<i>Indicator</i>	<i>Measurement</i>	<i>Data Sources</i>
Proportion of parents reporting that the care provided to the child is good or excellent.	Numerator: the number of parents reporting care provided to their child is good or excellent.  Denominator: total number of clients served.	Family Survey data and quarterly reports (or database files)
Proportion of parents reporting that the child's health status has improved in the last year.	Numerator: the number of parents that their child's health status has improved in the last year.  Denominator: total number of clients served.	Family Survey data and quarterly reports (or database files)
Proportion of parents who believe their child's condition adversely affects their child's activity status.	Numerator: the number of parents reporting that their child's condition adversely affects their child's activity status.  the total number of clients served.	Family Survey data and quarterly reports (or database files)
Proportion of parents who perceive that the child's activity status is below that expected for a child with the condition.	Numerator: the number of parents who perceive that child's activity status is below that expected for a child with the condition.  Denominator: total number of clients served.	Family Survey data and quarterly reports (or database files)

## D. Access

These seven indicators are designed to reflect the degree to which individuals and groups are able to obtain needed services from the medical care system. These indicators measure logistical and linguistic access, and monitor the proportion of children covered by various forms

of insurance in order to monitor their overall access to medical and health services. These indicators are presented in Table 5 below.

<b>Table 5. Indicators of Access to Care</b>		
<i>Indicator</i>	<i>Measurement</i>	<i>Data Sources</i>
Proportion of children referred to services that received those services.	Numerator: the number of children referred to services that received those services.  Denominator: the total number of clients referred for services.	The quarterly reports.
Proportion of children by type of insurance (commercial, Medicaid, CHAMPUS, etc.).	Numerator: the number of children enrolled by insurance type.  Denominator: the total number of clients.	The Family Application and quarterly reports (or database files)
Proportion of children with any type of health insurance.	Numerator: the number of children with any insurance.  Denominator: the total number of clients.	The Family Application and quarterly reports (or database files)
Proportion of children in a managed care plan.	Numerator: the number of children in a managed care plan.  Denominator: the total number of clients.	The Family Application and quarterly reports (or database files)
Proportion of parents reporting that their providers communicate with each other to coordinate their child's care.	Numerator: the number of parents reporting that their providers communicate with each other.  Denominator: the total number of survey respondents.	The Family Survey
Proportion of children who have a named primary care provider.	Numerator: the number of children with a named provider.  Denominator: the total number of clients.	The CSHCN Worksheet and quarterly reports (or database files)
Proportion of parents reporting their culture is respected by their health care providers.	Numerator: the number of parents reporting their culture is respected by their health care provider.  Denominator: the total number of survey respondents	The Family Survey

## E. Clinical Management Systems

These four indicators will provide information on the degree to which each site monitors the plan of care for the CHSCN enrolled, include families in decision-making, and inform families of their rights. These indicators are presented in Table 6 below. The analysis of one measure, the proportion of parents who have been informed of the components of health supervision, will not be collected for the contracts' first year, and CSHCN program staff have not yet determined how this information will be given to parents.

<b>Table 6. Indicators of Clinical Management Systems</b>		
<i>Indicator</i>	<i>Measurement</i>	<i>Data Sources</i>
Proportion of children for whom a care plan was developed.	Numerator: the number of children for whom a care plan was developed  Denominator: the total number of clients	The Site Visit Checklist and quarterly reports (or database files)
Proportion of children whose families were included in the development of the care plan.	Numerator: the number of families included in the development of a care plan  Denominator: the total number of clients	The Family Survey and quarterly reports (or database files)
Proportion of parents who have been informed of the components of health supervision.*	Numerator: the number of informed of components of health supervision  Denominator: the total number of clients	The CSHCN Worksheet and quarterly reports (or database files)
Proportion of parents who have knowledge of program's grievance procedures and due process.	Numerator: the number of parents who have knowledge of program's grievance procedures and due process  Denominator: the total number of survey respondents	The Family Survey and database files
Proportion of parents who filed formal complaints or grievances.	Numerator: the number of parents who filed formal complaints or grievances  Denominator: the total number of clients	Quarterly reports
*This measure is on hold for the first year.		

## F. Finance

Monitoring the contractors' and families' expenditures will help to manage and control the cost of care to the family and the funding agency. Title V expenditures will be monitored using the expenditure information submitted by the contractors in their database files. Because the state CSHCN program has no historical cost information against which to compare the contractors' experience, the indicators of contractors' expenditures to be examined have not yet been determined. However, a number of indicators of the use of Title V funds may be developed from the expenditure information collected, including the following:

- Average quarterly and annual expenditure per enrollee for services;
- Average quarterly and annual expenditure per enrollee for services, by primary qualifying diagnosis; and
- Average quarterly and annual expenditure per user of each type of service.

## G. Review of Quality Assurance Data

After all of these data have been collected and analyzed, the staff of the Connecticut CSHCN program will review the results with the staff of each contracting agency and develop goals and objectives for quality improvement in each site. This process is illustrated in Figure 2 below. The data collected after the contract's first year will provide a baseline against which to compare the following years' indicators, so as to track the changes in the accessibility and quality of services provided to CSHCN in Connecticut.

**Figure 2.**

