

**Using Data to Enhance Quality of Care
for Children with Special Needs:
The Role of Data Warehouses and Repositories**

A Technical Resource Brief

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INTRODUCTION

In the current health care marketplace, managing information effectively is central to assuring a competitive edge in providing care to populations with complex, chronic health conditions -- including children with special health care needs. Data warehouses can facilitate the capacity of managed care organizations (MCOs) to evaluate outcomes, calculate cost-benefit ratios, assess system performance and quality of care, respond to audits, profile enrollees and providers, and respond quickly to critical service delivery problems.

Our primary purpose in this technical brief is to describe how MCOs can use data warehouses and repositories to enhance their capacity to provide high quality of care to this population of children. Monitoring the care provided to children with chronic conditions is especially important because they need a wider range of health services and use a larger proportion of resources compared to children in general.

As a group, children with special health care needs receive services from a broad array of medical providers, ancillary community-based practitioners or programs, and different service systems (health, educational, social service), and may require these services over a long period of time. The diversity and duration of services provided to these children and their families lead to major challenges in creating a comprehensive record of encounters and costs. Meeting these challenges aggressively is essential because a coordinated data system provides the foundation for an efficient service system.

Data warehouses can include medical data or computer-based patient records, financial and service use data, demographic data on enrollees, and practice-related information on providers. Storing diverse data components in an integrated accessible environment has multiple benefits for MCOs, which are described in Section II. Unfortunately, sources of data on this population are usually scattered. Individual providers maintain health records on the children they see but payment histories reside in family records, government data files, or insurance company records. Claims, encounter, and payment data usually are stored separately from clinical and provider data.

Integrating data from diverse sources into a single location that is appropriately accessible by multiple users remains a formidable technical and conceptual challenge for most MCOs. Moreover, different types of MCOs have different strengths and weaknesses in relation to compiling, storing, and accessing integrated data. Nonetheless, all MCOs can enhance their management of information by developing better data warehouses and repositories. Failure to manage this task well will contribute to substantial administrative inefficiencies, serious threats to the quality of patient care, and increased probability of poor health outcomes.

OVERVIEW OF THE BRIEF

The purposes of this resource brief are to 1) describe the emerging role of data warehouses and repositories and 2) identify key approaches for using them to improve quality of care provided to children with special needs. We have designed the brief to be of use to a variety of audiences, including managed care administrators, providers, state Medicaid and Title V agencies, and families. In addition to providing critical background information, it illustrates how the current demand for quality of care measures can be addressed by integrated data.

SECTION I Who are children with special health care needs?

This sections briefly describes how this population has been defined, and implications of different definitions for data management purposes.

SECTION II Importance of data warehouses and repositories

This section identifies some of the potential uses of data warehouses for MCO administrators, providers, Title V and Medicaid agencies, and families.

SECTION III Gathering, storing, accessing, and linking data

Specific data sources are described, along with selected issues in linking and accessing warehoused data (e.g., confidentiality).

SECTION IV Using data warehouses and repositories to assess quality and improve program planning

Examples of analyses of data to assess costs and quality of care for this population of children are presented.

SECTION V Future applications

This section briefly identifies potential uses of data warehouses as they become more available.

This brief has emerged from a collaboration between The National Policy Center for Children with Special Health Care Needs and Health Services for Children with Special Needs, Inc.

(HSCSN). The Policy Center aims to promote comprehensive, family-centered systems of care for children with special health needs and their families. HSCSN, Inc. is a managed care organization based in Washington, D.C. and created under an 1115 Medicaid waiver in 1995. It provides comprehensive care to children receiving Supplemental Security Income from the District and has taken major strides towards creating data warehouses and repositories to enhance quality of care for children with special needs.

DEFINITION OF TERMS

Because the terms discussed in this brief are defined in different ways by various groups, it is important to set forth how they will be used within this text. The table below lists the definitions we use within this brief.

Term	Definition
Data Warehouses	large centralized databases utilized by MCOs or medical institutions that can house and integrate clinical, financial, utilization data; demographic information on enrollees; and provider data
Clinical Data Repositories (CDRs)	databases that contain medical data from various providers, departments, labs, and/or settings within a MCO or large medical institution
Claims Data	electronic records that document services provided and their charges as well as payments made by the insurer
Encounter Data	records that detail the services a client receives from a provider in one time period, contains more detailed information than claims data
Plan of Treatment Data	records that describe the medical, home health, case management, transportation services, etc. a child is to receive to meet specified treatment goals agreed to by parents or guardians, patients and providers
Computer-Based Patient Record	electronically maintained information about an individual’s lifetime health status and health care which replaces the paper medical record as the primary source of information for health care, meeting all clinical, legal and administrative requirements (Patient Records Institute updated version of 1991 IOM definition; Anderson & Bunschoten, 1996)
On-Line Analytic Processing (OLAP)	tools to study data in order to answer strategic questions or make clinical decisions, it involves combining and analyzing data according to multiple dimensions (Codd, Codd, & Salley, 1994; Gilbreath, 1995)
Standard Query Language (SQL)	a computer language for relational database systems utilizing specific command words that enable researchers to retrieve and utilize the data

SECTION I

WHO ARE CHILDREN WITH SPECIAL HEALTH CARE NEEDS?

The term “children with special needs” refers to a group of children with a broad range of conditions that may include:

- sensory, motor, or intellectual impairments (e.g., blindness, congenital malformations, or mental retardation),
- chronic medical conditions (e.g., leukemia, diabetes or asthma), and
- behavioral or emotional disorders (e.g., attention deficit disorder, autism).

Many children in each of these categories require a wide range of services, including medical care, habilitative and rehabilitative treatments, home-based care, and other ancillary individual and family support services. Substantial symptom heterogeneity characterizes all diagnostic groups; some children with diabetes, for example, will need many more services than other children with the same condition. In addition, many conditions co-exist with others in predictable patterns (e.g., children with Down syndrome are at high risk for heart conditions). The presence of multiple co-morbidities creates special classification challenges.

Methods for classifying a child as having “special needs” have varied widely, depending on particular policy or research issues. In the last several years, for example, the National Association of Children’s Hospitals and Related Institutions (NACHRI) has attempted to develop a classification scheme that is based primarily on ICD-9 codes. The purpose of this effort is to create a risk adjustment methodology pertaining to this population of children that will yield capitation payments appropriate for pediatric centers serving large numbers of these children (Muldoon, Neff, & Gay, 1997). The list of ICD-9 codes used in this classification scheme operationally defines the population of children with special needs.

Other classification methods rely on assessments of health or functional status. For example, the 1994-95 National Health Interview Survey included a wide range of items pertaining to children’s limitation in activity and other indices of functional status appropriate to children with chronic conditions. These items have been used by several investigative teams to estimate the prevalence in the general population of children with special needs. These studies typically begin with a conceptual definition of the population, which is then operationalized through data derived from questions asked to parents. Descriptions of these efforts can be found elsewhere (e.g., Newacheck & Halfon, 1998; Stein, Westbrook, & Bauman, 1997).

A third common approach is to identify a small group of specific conditions that serve as “markers” for the population overall. This approach has been used frequently in cost and utilization studies of this population (Ireys, Anderson, Shaffer, & Neff, 1997; Shatin, Levin, Ireys, & Haller, in press).

IMPLICATIONS FOR DATA WAREHOUSES

An extended discussion of definitional issues pertaining to this population of children is beyond the scope of this technical brief. However, several key points are noteworthy in relation to warehousing data related to this group of children.

First, in the adult population, there are about 10 chronic conditions (e.g., heart disease, arthritis, diabetes) that account for the large majority of long-term care needs. All of these conditions are relatively common. In contrast, there are over 200 chronic conditions of childhood and all of them, with the exception of asthma, are comparatively rare. Thus, the population of children with special needs is extremely heterogenous. Furthermore, many children have multiple conditions. Data warehouses, therefore, have to be structured to deal with large heterogeneity and multiple co-existing conditions within this class of children.

Second, administrative databases typically include ICD-9 codes but little data related to health or functional status. The functional status data, however, are often the most important for tracking indices of both process and outcome for this population of children. Part of the enormous potential for data warehousing is its capacity to link administrative databases (with their standard ICD-9 and encounter coding) to clinical records (with their information on functioning).

Third, recent studies indicate that children with selected chronic conditions have higher costs than children in general and that, within this population, a relatively few children account for the majority of costs (Ireys, Anderson, Shaffer, & Neff, 1997). In addition, service use appears to vary somewhat by population (commercial vs. Medicaid) and by plan (Shatin, Levin, Ireys, & Haller, in press). These studies underscore the need for capitation methods appropriate to this population. Current risk adjustment methods have serious problems in predicting costs for these children. Integrated databases are needed to develop strategies that account for the amount, diversity, and cost of services provided to this population.

Finally, work has only begun on conceptual frameworks pertaining to quality of care for children with special needs in managed care systems. Much work is needed to develop measures that assess the key dimensions of quality, including dimensions of (Ireys, Grason, & Guyer, 1996):

- access to care,
- developmental appropriateness of services,
- comprehensiveness and continuity of care,
- coordination of care,

- relation of health services to the community, and
- the degree to which services and the service system are family-centered.

As more sophisticated measurement strategies for these dimensions are developed, policymakers and consumer groups will increase demands on health plans for more detailed performance reports. Developing the data storage and integration systems discussed in the following pages of this brief will allow MCOs to meet these emerging demands.

SECTION II

IMPORTANCE OF DATA WAREHOUSES AND REPOSITORIES

Managed care organizations, state Title V and Medicaid agencies, and families will derive important benefits from centralized storage and integration of data in planning and assessing quality of care for children with special health care needs. Some specific uses of the warehouses and repositories for the various stakeholders are listed below.

Different data are relevant to and consequently collected by different parties. Families are interested in the health status of their children and the source of payment for services; providers want to know about the impact of treatments and payment rates; insurers need both cost and outcome information. If a child with a chronic condition uses the services of a primary care physician, pediatric specialist, home health agency, pharmacy, and hospital, the task of coordinating all the relevant information is exceedingly difficult. Families, providers, and managed care organizations all find themselves having to master not only health service delivery issues, but also information technology, contracting, claims processing, and encounter reporting. To enhance long-term outcomes and improve efficiency, the various parties also must share information with each other. Overall, management of information is central to assuring quality of care.

MCO Administrators

Managed care organizations increasingly need to monitor quality to be successful in the competitive health care marketplace. Data in warehouses can enable administrators to:

- compare the cost-effectiveness of treatments,
- compare actual vs. planned expenses,
- evaluate the predictive accuracy of risk adjustment methods and examine the adequacy of capitation rates,
- meet the increased demand from Medicaid contracts that require access to more data and increased flexibility to meet reporting requirements,
- participate in research studies on various treatment alternatives,
- compare their providers' treatments with clinical practice guidelines,
- examine compliance issues, and
- document services, which may be necessary for litigation in the event of a critical incident.

Providers

Providers benefit from research studies that can be conducted from the historical data within the warehouses. They can also benefit in their daily practice from the centralized patient data found within clinical repositories.

Such data can be used to (Safran & Chute, 1995):

- provide comprehensive information on a particular patient, which can be used for patient profiling (“results reporting”),
- respond to families’ requests to supply data to other providers (medical and nonmedical) and agencies,
- find data on a patient who is similar to one being treated (“case finding”),
- describe a group of patients who have at least one common characteristic, which could identify patients with common risk factors for a particular condition (“cohort description”), and
- analyze data patterns by trends or relationships (“predictive modeling”).

State Medicaid and Title V Agencies

State Title V and Medicaid agencies increasingly are playing a monitoring role and will need to support and help shape the development of data warehouses, which then can be used to:

- develop indicators of access to and quality of care,
- compare these indicators across differing communities and/or diagnostic groups,
- document additional services needed by children with special needs to be used for setting capitation rates or justifying service or population carve-outs, and
- follow trends over time in response to changes in contract regulations, Medicaid policies, etc.

Families

Depending on how data are made available, information found in warehouses will enable families to:

- compare actual services received with the child’s plan of treatment,
- compare different health care plans on quality indicators,
- learn of strengths and possible problems with a managed care organization’s service patterns,
- share information among relevant providers (schools, social agencies), and
- avoid duplication of services and tests.

SECTION III

GATHERING, STORING, ACCESSING, AND LINKING DATA

The information technology utilized in the creation of data repositories and warehouses is developing rapidly. New computing “platforms,” software programs, and strategies for linking data from different locations are being introduced into the market at a rate that is difficult to track. Moreover, different institutions have created data repositories and warehouses that suit their own particular needs, and few industry-wide standards are available.

Much information on warehouses and repositories is found within journals for health care management, where administrators and industry consultants present new models of data systems and recommendations for their development and implementation. In contrast, information on service use and costs of care for children with disabilities is located in journals of public health or pediatrics. The challenge is to bring these two bodies of information together by identifying relevant sources of data, storing them in ways that serve multiple purposes, and assuring appropriate access.

SOURCES OF DATA

Data warehouses and repositories store the data found in claims and encounter forms, plan of treatment records, clinical assessment, enrollment and provider databases. These financial, utilization and clinical data sources all have limitations in their reliability, accuracy and completeness. Despite these inherent limitations, each provides valuable information for managed care organizations’ planning and monitoring of quality. The table on the following page lists these sources of data and their strengths and weaknesses. The sections following discuss them in further depth.

Description of Data Sources

Name	Source of Information	Strengths	Weaknesses
Claims Data	claims records completed by provider	<ul style="list-style-type: none"> -largely available, inexpensive to utilize for studies, provide information for examining quality indicators such as access to care -provide information for risk adjustment and reinsurance systems 	<ul style="list-style-type: none"> -contain limited clinical data so not as useful for outcome studies, problems with accuracy and completeness, only contain information on enrolled children who actually receive services
Encounter Data	encounter record filled out by provider	<ul style="list-style-type: none"> -provide more detailed information than found on claims, useful for assessing utilization and access -allow for assessing care of small populations who get lost in aggregate reporting -provide information for risk adjustment and reinsurance systems and episodes of care 	<ul style="list-style-type: none"> -problems in gaining data from providers for encounter records -not all MCOs collect this information
Plan of Treatment Data	created by MCO providers, case managers, families	<ul style="list-style-type: none"> -provide information to the MCO on services to be covered and expected costs -allow for comparisons of planned and actual costs and services, so useful for modifying benefit packages and program planning 	<ul style="list-style-type: none"> -do not provide information on services actually received -technically complex to update and link to other data sources in real time
Enrollment Data	families and patients	<ul style="list-style-type: none"> -include information on demographics and health status of child and family -can include information on family preferences 	<ul style="list-style-type: none"> -subjective, single point-in-time data, potentially expensive to collect and enter
Provider Data	collected from providers by MCOs	<ul style="list-style-type: none"> -various provider databases contain extensive information for MCOs to assess the comprehensiveness of their network and conduct analyses of practice patterns, etc. 	<ul style="list-style-type: none"> -information is contained in separate databases which may need to be integrated for analyses
Computer-based Patient Records	medical information, test results, etc., input by providers, nurses or laboratory staff	<ul style="list-style-type: none"> -allow access to comprehensive information on individual patients 	<ul style="list-style-type: none"> -complex technology and ongoing training of physicians, nurses, staff may be required -needs to be extremely user-friendly to assure appropriate use
Satisfaction Data	families and patients	<ul style="list-style-type: none"> -direct evidence on whether different aspects of care are meeting user expectations 	<ul style="list-style-type: none"> -little experience to date in assessing satisfaction for this population of children

Claims Data

Claims data are electronic records that document services provided, associated charges, and actual payments. Claim records use diagnoses from the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) and procedures in the Current Procedure Terminology, Version 4 (CPT-4).

Virtually all MCOs, including those serving the Medicaid population, collect claims data. This wide availability is its primary advantage, and using claims data for studying quality indicators is much less expensive than most other methods. While claims analysis does not provide conclusive evidence on outcomes of care, it does allow for examining indicators, such as access to care, that are believed to promote positive outcomes.

The traditional fee-for-service health care system provided an incentive for providers to submit claims for individual services because those claims were the basis for reimbursement. These same incentives exist within IPA models of managed care that use discounted fee-for-service payment policies. In a fully capitated system of health care delivery, however, incentives to submit claims may be less powerful because physicians receive a predetermined amount per patient rather than per service.

Less incentive to record and submit accurate service information raises the question of the reliability and completeness of claims data. In any system--whether a negotiated fee-for-service system or a capitated system--appropriate incentives are needed to assure that claims data have sufficient and accurate detail to address important questions regarding performance and quality of care. Actual use of claims data in relation to quality should improve their reliability and accuracy over time.

Finally, claims data, as well as encounter data, only capture information on enrollees who actually receive services. This is important to consider when conducting studies that require a count of the entire enrolled population, whether or not services are used.

Encounter Data

An encounter is defined as the group of services a client receives from one provider in a particular time period (Howell, 1996). Encounter records detail more completely the health services that enrollees receive. Claims data, therefore, represent a subset or summary of the data included in encounter forms. While a claim form may report that a child received an intermediate office visit, an encounter record of that visit reveals what procedures (weight check, nutrition counseling) the provider actually performed. Claims are used for billing purposes; encounter data are used mainly for utilization reporting (Dresser et al., 1997).

Information on the provider and patients may also be found in the encounter record. National standards for core elements to be included on encounter forms are currently being constructed. Not all managed care organizations collect encounter records, however. Furthermore, encounter data are often incomplete because they are not required for payment purposes.

Encounter data allow MCOs to analyze utilization, access and quality measures for different subpopulations. This is important because merely utilizing the aggregate reports completed for the National Committee on Quality Assurance's HEDIS measures may allow service problems for particular subpopulations to be lost (Howell, 1996). Encounter level data also provide important information to refine risk adjustment models or to justify MCOs reinsurance claims (Howell, 1996).

Encounter data within large data sets can be used to construct episodes of care for specific conditions. Episodes of care describe "a block of one or more medical services received by an individual during a period of relatively continuous contact with one or more providers of service, in relation to a particular medical problem or situation" (Solon et al., 1967; Wingert et al., 1995/96). Examining episodes of care rather than individual services has several advantages for children with special needs, many of whom have multiple chronic conditions. For example, it allows for more comprehensive economic analyses by identifying how particular treatments fit into and affect other services needed during an episode. These analyses, however, are difficult for a heterogeneous population with numerous co-morbidities and the potential for multiple episodes. Much work remains to be done in constructing valid episodes of care for the population of children with special needs.

Plan of Treatment Data

One type of clinical information that may be found in CDRs is plan of treatment data. These data may include the medical, home health, case management, transportation and other services each enrollee is to receive. The services within the plan can be set to meet specified goals and can be agreed upon by parents or guardians, patients and providers. Linking this information with patient records or claims and encounter data enables families and plan administrators to compare the actual services received with those planned. For those MCOs whose CDRs also contain clinical practice guidelines, comparing the planned treatment with these standards is possible as well.

Enrollment Data

Along with the financial, utilization and clinical data sources, MCOs also may create enrollment databases. Within an enrollment file, for example, an MCO might store information on enrollee demographic characteristics or care manager and primary care physician assignments. The listing of siblings and contacts found in enrollment data also facilitate the outreach that MCOs

often are required to conduct under contracts with Medicaid. MCOs also may ask enrollees to complete a health assessment survey at the time of their enrollment which includes information on functional and health status. All of these data can be used to provide baseline data for subsequent studies on outcome.

Provider Data

Provider databases may contain the education, board certification, practice information, and contract information of plans' providers. These different components commonly reside in multiple unrelated databases. A centralized provider database enables MCOs to identify generalists vs. specialists, pediatric specialties not available in a network, the number of pediatric vs. adult providers, and in-network vs. out-of-network providers. MCO administrators can also conduct reviews on referral practices and analyze service patterns by practice type and location.

Computer-Based Patient Records

Computer-based patient records systems are being used increasingly in place of the paper medical chart. They contain clinical information, test results, medical alerts, etc. This clinical information can be housed within CDRs and then extracted by providers using the computer-based patient record system. Barriers to medical institutions or group practices implementing this new information storage system include software that is not user-friendly, reluctance on the part of physicians, and the lack of technology for institutions (in part due to cost) to be able to integrate the medical records from various locations within the medical system (Bazzoli, 1996; Anderson & Bunschoten, 1996). Institutions often start with the creation of clinical data repositories to store lab and diagnostic tests as a first step toward a computerized patient records system.

Satisfaction Surveys

As an indicator of quality, satisfaction surveys provide a direct assessment of whether services met user expectations. Most MCOs are familiar with administering satisfaction surveys, but linking assessments of satisfaction to other data elements for individual patients or groups of patients can pose major technical challenges. Moreover, satisfaction surveys appropriate to this population have been developed only in the last year or two. As a result, experience in assessing satisfaction with care for children with special needs is limited.

LINKING DATA

Integrating data from the various possible sources into a repository or warehouse requires an effective strategy for linking the bits of data associated with a particular patient. This is usually

done by developing master patient indexes that permit the tracking of services that a patient receives across different provider sites, and the payments for those services. These master patient indexes utilize relational database tables which pool the various identifiers patients receive from different service provider sites and assigns them a global identifier (Siwicki, 1996). The patient index should be able to identify the patients by their demographic information, with neither the patient nor the providers having to remember or use the identifying number (Bazzoli, 1996).

DATA STORAGE

Most *clinical data repositories (CDRs)* focus on providing timely information for clinical decision-making. Quickly accessing pertinent information and service history is especially important for individuals with chronic conditions who may receive services from a number of different providers, often in different settings. CDRs bring together a child's medical information from the various settings in which he or she receives services and so can include plan of treatment information, patient records, laboratory and diagnostic test results as well as clinical practice guidelines. In addition, the development of object-oriented technology enables audio and video images to be stored (for example, echocardiograms) and consequently enlarges the range of patient information that can be found in repositories. CDRs also can be mechanisms for ordering tests or reading information into the files in real time, as well as for transmitting data for consultation purposes. A unique identifier allows the patient's clinical information from diverse settings to be linked. Providers can use a stored Structured Query Language (SQL) statement to access data for decision-making.

Institutions can be thought of as existing along a continuum of ability to store and integrate data. While some MCOs may have CDRs that only store lab and diagnostic test results, others may be able to store and integrate a much larger amount of information. Some researchers utilize the terms CDRs and computer-based patient records interchangeably; others see CDRs as a part of a computer-based patient records system (Siwicki, 1996).

Data warehouses refer to centralized databases used by MCOs or medical institutions to house and integrate clinical, financial, utilization data, and demographic information on enrollees and provider data. Warehoused data are integrated from diverse sources and transformed into a compatible format and provide snapshots of data over a period of five to ten years or longer (Gilbreath, 1995). A warehouse can include multiple "levels" of data (Inmon, 1993; Gilbreath, 1995). One level may include archival data, i.e., historical data integrated from older records. Another level may be highly summarized data, i.e., numerous pieces of data that are aggregated into a few variables (e.g., many data, for example, may be aggregated into a composite variable of "health status"). Yet another level may be lightly summarized data, i.e., combinations of a few variables (e.g., data on school days missed and activity limitations may be combined to create an index of functional status).

No one structure exists for data warehouses. For example, data warehouses of insurance companies may differ fundamentally from those of hospitals. Insurance companies' warehouses contain claims and utilization data from patients seeing a number of providers. Provider warehouses, on the other hand, contain inpatient and outpatient claims and test results for patients at their own institutions but no information on the patients seen by other providers (Ruffin, 1994).

The warehouses' wealth of historical data makes them valuable tools for retrospective data analyses using OLAP or On-Line Analytic Processing (also called multidimensional data analysis). OLAP involves combining and analyzing data according to multiple dimensions (Codd, Codd, & Salley, 1994; Gilbreath, 1995) and can aid investigators in addressing critical research questions. The ability of the warehouse to serve as a common data source also increases the reliability of results for investigators as well as their ability to find relationships among variables that would have been obscured in small data sets.

A variation of the data warehouse are *data marts*. Data marts are compilations of information that are housed in several sites throughout an institution, rather than in one central location and are used by individual divisions for their own purposes. Organizations may start out with data marts prior to developing a single data warehouse. Data marts are used typically for research rather than operational purposes (Bazzoli, 1997).

ACCESS TO DATA & CONFIDENTIALITY

With the large amount of data found in warehouses and repositories, questions of who determines who can access specific data items and the limits on the types of data to be shared becomes critical (Kahn, 1997). Because of the potential greater availability of this electronic data, new security measures will be needed. The Institute of Medicine has described three different activities to protect patient confidentiality in regard to data. These include (Dick & Steen, 1991; Kahn, 1997)

- *system security*: measures aimed to ensure that computer-based information systems are protected from unauthorized access and other harm,
- *data security*: measures to protect data from accidental or intentional disclosure to unauthorized persons and from unauthorized alteration, and
- *data confidentiality*: measures taken to keep sensitive information from being revealed to unauthorized individuals.

It is beyond the scope of this technical brief to discuss specific strategies in relation to these activities. However, MCOs, purchasers, providers, and families must work together to identify concrete measures that will balance confidentiality with appropriate access.

SECTION IV

USING DATA WAREHOUSES AND REPOSITORIES TO

ASSESS QUALITY AND IMPROVE PROGRAM PLANNING

Numerous efforts are underway across the country to identify strategies for measuring quality of care for children with special health care needs (e.g. FACCT, NCQA, New England SERVE). Different conceptual frameworks support these efforts. For example, Donabedian's formulation of structure, process, and outcome has been used to identify and categorize measures of quality for this population. The Institute of Medicine's definition has also been valuable in conceptualizing measurement approaches (Lohr, 1990; Ireys, Grason, & Guyer, 1996). NCQA's ongoing development of HEDIS has attempted to bring standardization in measurement to managed care organizations' administrative procedures, process indicators, and effects on health outcomes.

Effective application of these approaches to assessing quality of care for children with special needs depends on the resolution of several major obstacles (McGlynn, Schuster, & Halfon, 1996; McGlynn, Halfon, & Leibowitz, 1995). These include:

- developing randomized controlled trials to construct clinical guidelines for both medical and health-related services,
- increasing the number of children participating in outcome studies to obtain adequate sample size and power,
- addressing developmental issues that affect children's functional status,
- devising longitudinal databases and analytic techniques needed for studying long-term developmental outcomes, and
- assessing how variation in environmental demands or characteristics influence the impact of a disability and subsequent outcomes.

Creative use of information in data warehouses will contribute significantly to solving some of these challenges. As a way of illustrating how data can be used to assess quality and inform program planning, we have constructed several scenarios using hypothetical data. These examples, however, emerge from actual questions that have arisen in the context of monitoring quality of care for children with special needs enrolled in a managed care organization. These presentations do not represent actual analyses, but rather provide a set of analytical examples.

UNDERSTANDING AND PREDICTING COSTS

Claims and payment data can be used to analyze the range of costs across diagnoses or other subgroups of children (defined, for example, by functional status). Initially, these analyses can be used to develop baselines for tracking cost or use data. Over time, they will provide a means for identifying major fluctuations that may be linked to changes in clinical or administrative policies.

In Figure 1, hypothetical data are used to identify mean costs and confidence intervals for children with three diagnoses enrolled in a managed care system. The data illustrate somewhat different patterns of costs. For example, school-aged children with sickle cell have the lowest mean costs with fairly wide confidence intervals, suggesting much variation within the group of children. Children with mental retardation have somewhat higher means costs, but a much narrower confidence interval. Children with cerebral palsy have the same mean costs as children with mental retardation but a very broad confidence interval, again suggesting large within-group variation in costs. Predicting how changes in treatment will affect costs may be more difficult under conditions of high within-group variability, depending partly on what factors are contributing to the variation (e.g., prevalence, access, socioeconomic status).

Figure 2 illustrates analyses from the same hypothetical data set. In this illustration, the subgroups of interest are based on measures of functional severity (e.g., reported limitations in activity and school days missed). As would be expected, this figure indicates that yearly mean costs are related to severity level. It also shows that confidence intervals are much smaller for the groups of children with mild and severe limitations, compared to the group with moderately severe limitations. These data suggest the need to understand more about factors affecting variation in the moderately limited group, since costs for this group might be much harder to predict.

Figure 1: Variance in Yearly Mean Costs for Specific Conditions in School-Aged Children

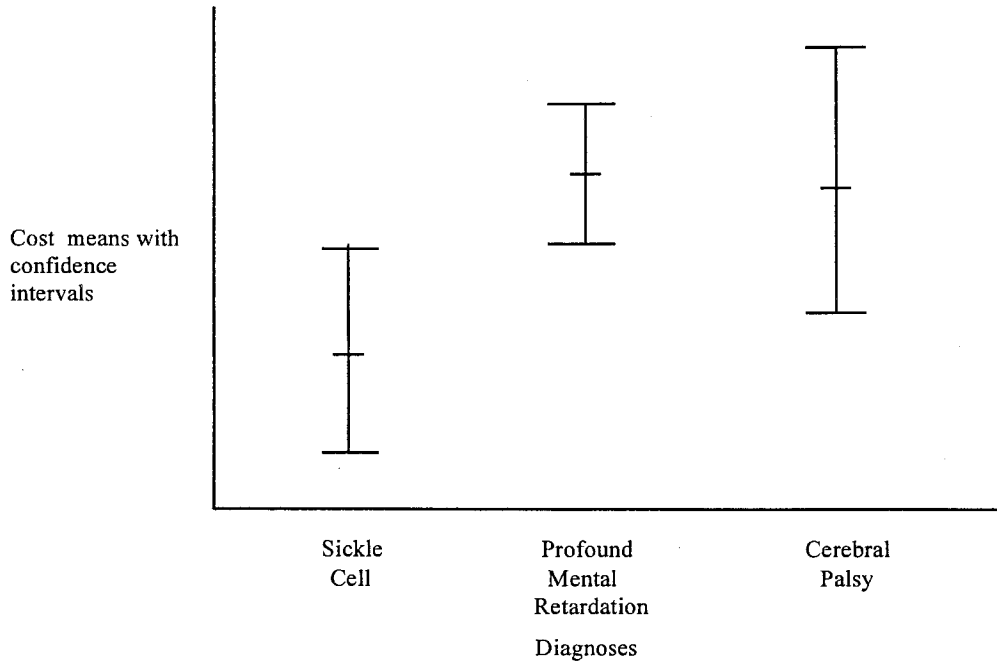
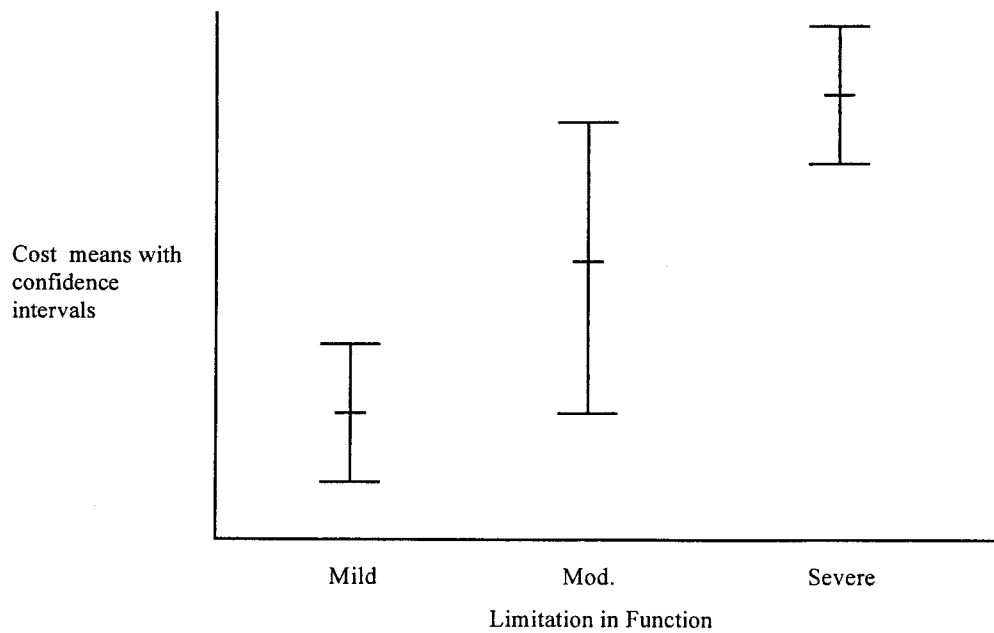


Figure 2: Variance in Yearly Mean Costs by Degrees of Limitation in Function in School-Aged Children



Other analyses could focus on how developmental stages affect costs, the relation between provider training and costs, the impact of new treatment protocols on costs, and whether satisfaction with different types of providers is related to cost patterns. Information from claims data can be combined with plan of treatment information to assess the deviation between planned and actual costs of care for a particular diagnostic group.

Cost analyses using claims data might include:

- reviewing the cost of particular services, such as home health vs hospitalization,
- tracking costs by episodic diagnoses and procedures,
- examining the cost implications of targeted services in terms of their effect on subsequent hospitalizations or overall service use,
- tracking costs to justify higher capitation rates for certain populations or services,
- tracking payments to providers,
- cost-effectiveness studies of clinical guidelines or critical pathways, and
- studies on the effect of targeted outreach on, for example, decreases in emergency room visits.

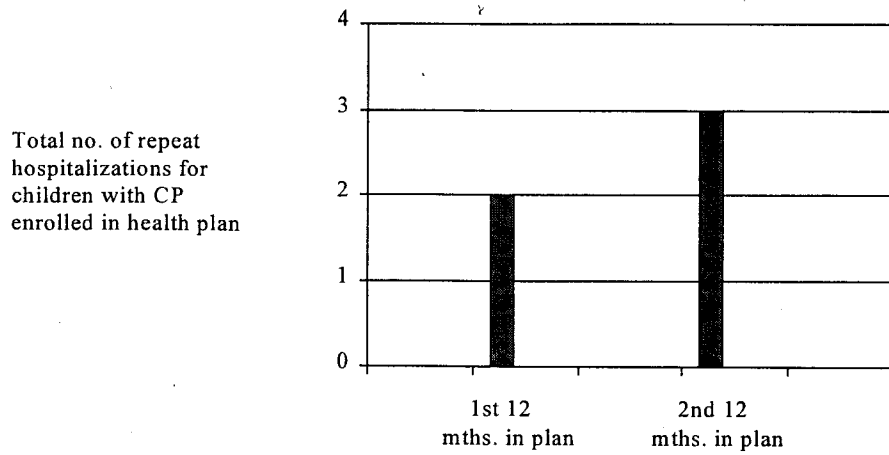
MODIFYING PROGRAM OPERATIONS

Information in data warehouses can be used to modify program operations to enhance quality of care. For example, Figure 3a illustrates analyses of hypothetical data relating to repeat hospitalizations for children with cerebral palsy. Data derived from claims files indicate that repeat hospitalizations increased in the second 12 months of enrollment for some of these children. This increase may well indicate poor ambulatory care management, or possibly the consequence of overly-restrictive limitations on approval for physical therapy treatments. Figure 3b shows analyses derived from treatment planning data and suggests that approval for aggressive (>25 visits) physical therapy is linked to lower repeat hospitalizations after adjusting for level of functional severity (as defined by data from intake surveys or clinical files). This conclusion would have obvious implications for breadth of benefit packages.

Another approach to using warehoused data to modify program operations is illustrated in Figure 4. Here the expected or planned number of hospitalizations (as derived from plan of treatment data) is compared with the actual number of hospitalizations for three diagnoses. The analyses suggest that the accuracy of treatment planning differed across the diagnoses. The actual total number of hospitalizations exceeded the anticipated number for children with asthma, equaled the anticipated number for sickle cell, and was less than the anticipated number for children with mental retardation. If based on real data, these analyses would underscore that predicting morbidity and service use is more difficult for some conditions than others.

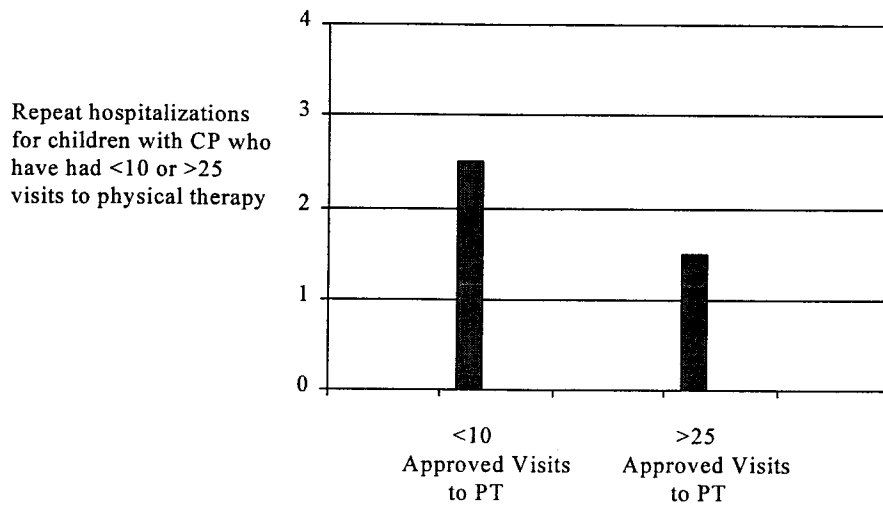
These analyses may be beyond current technical capacities of many managed care organizations. Nonetheless, the continued growth in data warehouses and repositories will permit increasingly sophisticated analyses with direct implications for policies and programs within managed care systems. Designating a person to take the lead in these analyses will yield critical data for corporate functioning.

Figure 3a: Repeat Hospitalizations for Children with Cerebral Palsy Over Time in Plan



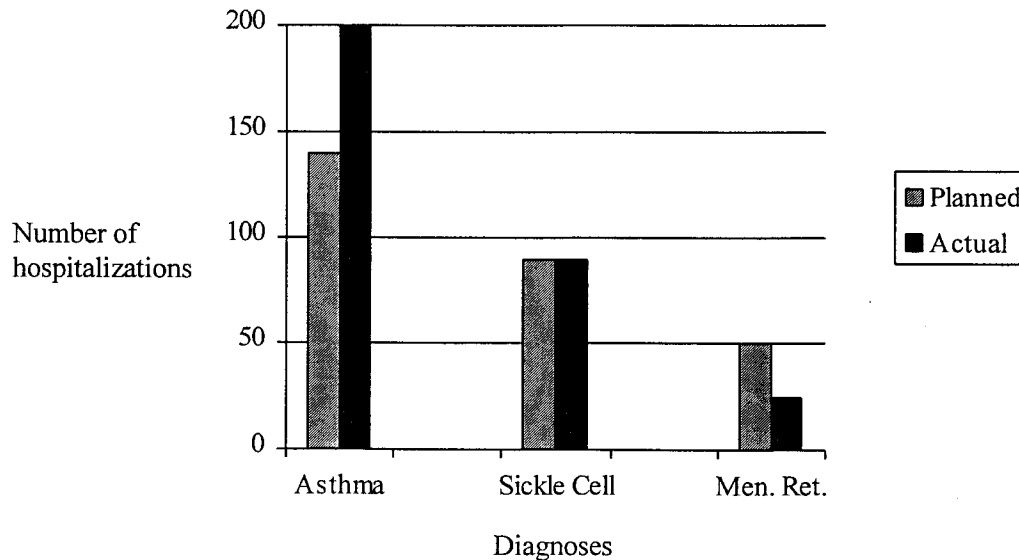
Note: Repeat Hospitalizations defined as hospitalizations within 6 weeks of a previous hospitalization

Figure 3b: Repeat Hospitalizations for Children with Cerebral Palsy by Physical Therapy Visits, Adjusted for Functional Severity



Note: Repeat Hospitalizations defined as hospitalizations within 6 weeks of a previous hospitalization

Figure 4: Planned vs. Actual Hospitalizations for Various Diagnoses Over Year One for Health Plan Enrollees



Further Examples of Applications

Even basic data from a single source can be used to address critical issues. The boxes below illustrate some of these applications.

Claims Data Applications:

- assessing quality indicators such as access to and continuity of care (over time and for various populations including Medicaid-managed care, employer-based managed care enrollees)
- comparing cost patterns and service use for these groups
- reviewing costs of particular services: e.g., home health care following discharge
- examining the cost-effectiveness of services (do they reduce hospitalizations or lower the overall cost of treatment, etc.)
- tracking costs to justify higher capitation rates for certain populations or services

Encounter Data Applications:

- reviewing how therapies or referrals are distributed across a group of children with a particular diagnosis by selected subgroups
- examining what subdiagnoses or co-morbidities may be associated with a primary diagnosis
- constructing episodes of care
- assessing referral rates for primary care providers (using the unique provider identifier on encounter forms and linking this information with practice demographics to investigate reasons for higher referral rates, etc.)

Plan of Treatment Data Applications:

- identifying services anticipated for selected subgroups of children with special health needs (within a plan or across different service agencies)
- understanding projected service needs for children with multiple chronic conditions
- comparing treatments by providers with clinical practice guidelines

TRACKING OUTCOMES

Parents, providers, and MCO administrators have a common interest in answering a single critical question: Does treatment promote health status? This question underlies virtually all approaches to assessing quality of care because no intervention could be considered of value in regard to cost and quality if it does not achieve its objectives, however those might be defined, or if it has unintended negative outcomes or effects. The simplicity of the question, however, belies the difficulty in answering it. "Health status" can be defined and measured from numerous perspectives (Starfield & Newacheck, 1990; Lewis et al., 1989), and tracking outcomes can involve repeated and extensive information-gathering efforts.

The problems of defining and measuring health status and tracking outcomes are especially challenging for the population of children with special health care needs because of its heterogeneity and the complex relationships between development and health status (Ireys, Grason, & Guyer, 1996). Tracking outcomes for this population is difficult for other reasons as well. First, the focus of the outcome can vary from biological processes (e.g., did the treatment remove diseased cells) to functional measures (e.g., did the treatment improve mobility) to more social or family aspects (e.g., did the treatment enhance social interaction) to levels of service use (e.g., did the intervention lessen need for hospitalization). Which outcome is most important?

Second, existing measures of health status of children (see Appendix A for a brief description of some of these measures) vary in their applicability to this group of children. At the present time, there are few widely-accepted measures that are valid and reliable for use in the population of children with special health care needs. Lack of adequate measurement tools impedes monitoring of outcomes.

Third, the heterogeneity of the population itself creates practical barriers to comprehensive assessment of outcomes. At high levels of generality (e.g., effect of treatment on subsequent service use), the same item or scale could be used regardless of the child's diagnosis. At the level of biological processes or even functionality, different measures are needed because of the varying biological processes across diagnostic groups. Developing a capacity to measure both general and specific effects requires considerable resources of both a technical and conceptual nature.

Illustrating all the possible approaches to tracking treatment outcomes is well beyond the scope of this brief. We have therefore elected to focus on one outcome measure: satisfaction with care. Satisfaction measures for this population are under development in several sites, and consequently, credible data are likely to be available through written and electronic means as health plans begin to adopt these measures.

Figure 5 illustrates the relationship between parents' overall satisfaction with a plan's benefit package and the presence of a specially designated care manager. This care manager, for example, might be an individual who monitors closely the needs of the family in relation to service use beyond the usual service coordination provided by a primary care physician. These hypothetical data indicate that the presence of a special care manager does not alter satisfaction for parents of children with low levels of functional severity, in part because satisfaction is already high. In contrast, the presence of a special care manager has dramatic effects for parents of children with high levels of functional impairments. Intermediate effects are shown for families of children with moderate levels of functional impairment. These hypothetical data suggest the value of special care managers rises with increases in severity of functional impairment.

Finally, Figures 6a and 6b present results of satisfaction analyses based on hypothetical warehoused data drawn from diverse sources. The analyses compare the relationship between satisfaction and functional severity over time for two different groups of providers: primary care providers and specialty physicians. The analyses indicate that satisfaction with primary care providers decreases over time for parents of children with severe limitations; in contrast, satisfaction with specialty providers increases over time for these parents. For parents of children with low to moderate levels of functional severity, satisfaction changes very little. These analyses underscore the importance of the family-specialist relationships for children with conditions that place severe limitations on their activity, and thus imply that health plan policies should support these relationships if the goal is to increase satisfaction levels.

Figure 5: Percent of Enrolled Families Satisfied with Plan's Benefit Package by Presence of a Care Manager

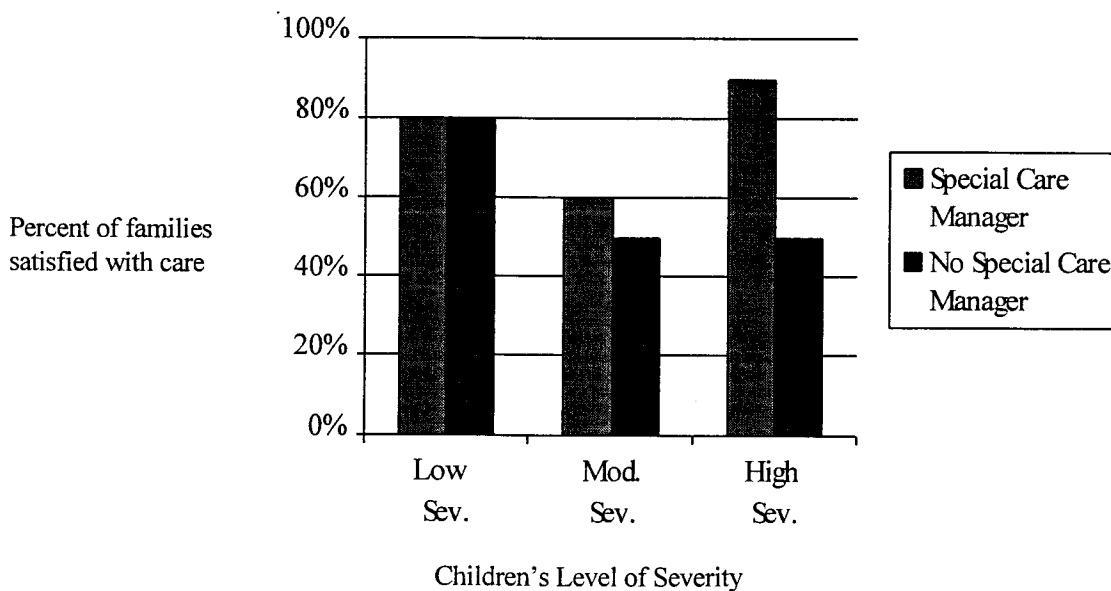


Figure 6a: Percent of Enrolled Families Satisfied with Care from Primary Care Physicians Over Time

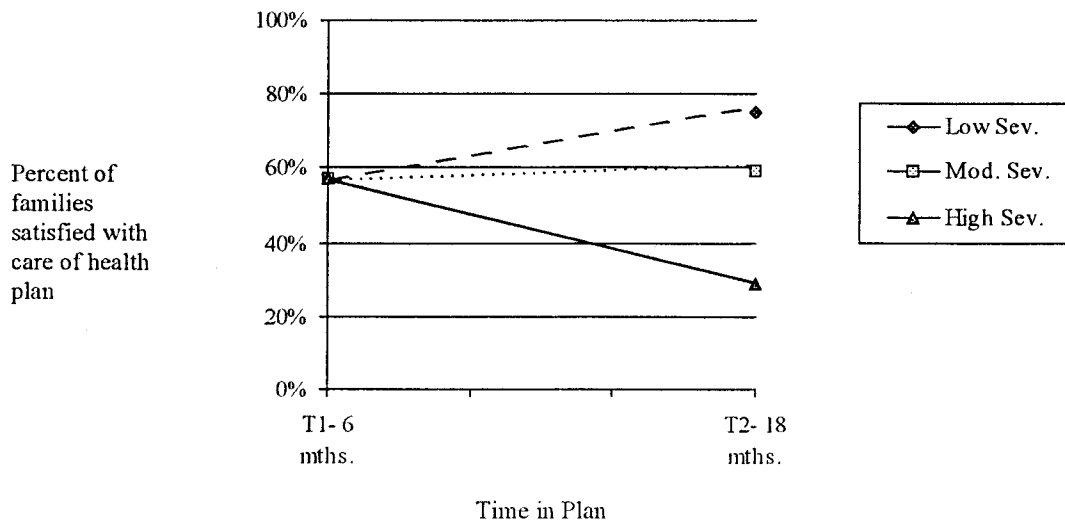
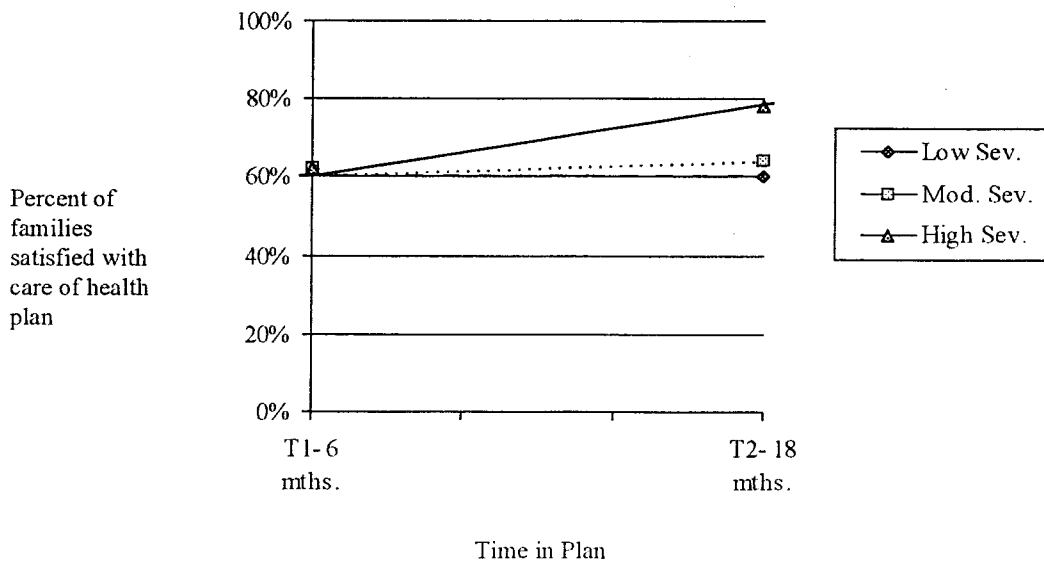


Figure 6b: Percent of Enrolled Families Satisfied with Care from Specialty Physicians Over Time



SECTION V

FUTURE APPLICATIONS

The potential uses of CDRs and the larger warehouses that house clinical, financial and utilization data are limited only by the imagination of those using them. With the increasing development and use of computerized patient records, more clinical and financial information will be available to enable investigators to examine the processes and outcomes of care. Some of the future applications of CDRs and warehouses may include:

Expanding the CDR and Warehouses to Contain Data from Other Agencies

Managed care organizations that are serving the aged, blind, and disabled populations are having to develop system interfaces with health, education, and welfare agencies in order to coordinate benefits for members which result in more cost-effective, community-based services rather than hospitalization or institutionalization. In addition to providing traditional covered benefits to members in their Medicare and Medicaid products, health plans are coordinating with housing agencies, volunteer community efforts, and social service agencies. This cost-driven coordination effort will result in greater integration of data systems that will facilitate the development of more comprehensive and accessible medical and plan of treatment information shared by providers and family caregivers.

Enabling Families to Monitor a Member's Care Over Distances

Once confidentiality issues are resolved, family members given the proper authorization may be able to follow the health status of an individual with complex health care needs in their family even though thousands of miles separate their residences. This may be done by allowing families to have access to a member's records and view them electronically. CDRs would be able to keep current data on clinical and community service activities for any member which, when appropriately accessed by authorized family members, would enable families to stay connected and aid them in their care management role. Communication with health service providers would be facilitated and coordinated. CDRs also could house basic health information which could be accessed conveniently for personal health management. Caregivers who daily assist in therapy or treatments could have an immediate source of instructions or guidelines and plan of treatment information.

Enabling Out of Town Providers to Have Access to an Individual's Medical Records

Individuals with complex health service needs could experience greater independence and mobility if they were assured that their current medical information would be available to them and their providers when they travel outside their traditional health services delivery area.

Creating Regional Data Repositories or Warehouses

In the future the myriad of managed care organizations and networks may merge into a few giant and regional systems integrators managing powerful and comprehensive data repositories or warehouses. Health service providers could subscribe or be members of these systems much like banks today are part of Cirrus, Plus, Most, or Honor bank card systems. Service providers could use these systems integrators to process their claims, pay them for their service to patients, and store medical records and comprehensive health service information. Individuals could look for the same logo that is on their health card when they enter the door of a physician or other health service provider.

Once inside the office of the health service provider or, if the provider comes to the home of the patient, medical records from a data repository could be viewed electronically with the use of the appropriate personal security code. Treatment would be given to the patient and the service would be entered into the medical record electronically directly to the data repository. The provider could be paid automatically by the service integrator and the medical service record updated. Individuals could have access to the same service anywhere in the country where their provider office displays the repository or warehouse logo code.

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APPENDIX A

PERFORMANCE MEASUREMENT SUMMARY

Project Title	Contact Person/Organization	Project Description
HEDIS 3.0	National Committee for Quality Assurance (NCQA)	-contains measures of health plans' performance on: effectiveness of care, access or availability of care, satisfaction with care, health plan stability, use of services, cost of care, informed health care choices, and health plan descriptive information-very few measures related to children with special health care needs (cshcn)
The Consumer Assessments of Health Plans Study (CAHPS)	Agency for Health Care Policy and Research (AHCPR)	-creating an integrated set of tested & standardized satisfaction surveys covering continuity, coordination of care, enrollment, access, communication and interaction with health care professionals; includes core set of items, some questions targeted to cshcn but no individual survey for them
Computerized Needs-Oriented Quality Measurement Evaluation System (CONQUEST)	Agency for Health Care Policy and Research (AHCPR)	-a system comprised of two databases, one of clinical performance measures and one of measures for specific conditions, AHCPR is developing and testing additional measures to add to this system (condition database has several measurement sets for chronic medical conditions but not mental retardation & developmental disabilities)
Measures for CSHCN	Foundation for Accountability (FACCT)	-develops quality measures focusing on consumer experiences with care and processes and outcomes of care for specific high-frequency conditions, life stages, and high population groups examining their health status or risk behaviors -currently developing measures of quality of care for cshcn based on a competency-oriented health care delivery framework to cover structure, process, and outcomes, satisfaction and experience of care
Two-year Study on Vulnerable Populations in Medicaid Man. Care	Health Care Financing Administration (HCFA)	-two year study mandated by Congress to report on vulnerable populations in man.care, including cshcn
Quality Improvement System for Managed Care (QISMC)	HCFA & National Academy for State Health Policy (NASHP)	-a system of standards and guidelines focusing on measuring a managed care plan's improvements in quality of care utilizing performance measurement; gives information on how purchasers of care, (HCFA & states) can use perf. measures to improve care and aims to create a quality oversight system for Medicaid & Medicare -little attention to children with special health needs
PROJECT SERVE	New England SERVE	-developing tools for monitoring and evaluating health care delivery patterns and outcomes for cshcn in managed care; most recently applied to MCHB for funding to work with Neighborhood Health Plan (NHP) to develop and demonstrate a model of quality assurance for cshcn that can be implemented by MCOs
Performance Measures for State Title V Programs	Maternal and Child Health Bureau (MCHB)	-states must set 5 year performance objective targets and report on these for each of 18 national performance measures and must develop at least 7, but no more than 10, additional performance measures with at least one measure for each of the types of services (direct, enabling, population-based, capacity/infrastructure) and each population group

Quality Community Managed Care: A Guide for Quality Assurance Measures for Children with Special Health Care Needs	MCHB funded project at the Division of Specialized Care for Children at the University of Illinois at Chicago	-outlines specific data needed for assessing quality of care for cshcn-the guide details the data needed for monitoring cshcn in managed care plans or for monitoring services funded by state cshcn programs using measures developed as part of this project (Quality Community Managed Care, QCMC) and a subset of Medicaid HEDIS measures
Linkages and Outcomes for Children (CHILD) Profile Care Coordination Project	MCHB funded project at the Office of CSHCN at the Dept. of Health, Washington State	-a personal interview tool assessing the impact of changes in the health care delivery system and managed health care on families with cshcn -also developing a module linked to a central database registry (CHILD Profile)-which allows specialized tracking & coordination of care for children with identified health or development problems, contains a functional assessment, family impact survey, demographic information and a services log
The ABCs of Managed Care Standards and Criteria for Children with Special Health Care Needs	Family Voices	-lays out a set of family-driven standards for managed care systems which treat children with special health care needs, includes general principals and how to apply them in the areas of access, benefits, capacity, decision-making, evaluation and data, and financing
Family Partners Project	Family Voices & Brandeis University	-joint project of FV & Brandeis Univ. to develop and distribute a survey to approximately 4,000 families of cshcn in 21 states to learn of their experiences with the health care system including managed care
Indicators to Monitor the Performance of Systems of Long Term Services & Supports for People with Lifelong Disabilities	Human Services Research Institute & United Cerebral Palsy, Inc.	-project funded by the Office of Special Education and Rehabilitation Services, Department of Education and the Office of the Assistant Secretary for Planning and Evaluation, DHHS -synthesizes performance indicators relevant to adults & children with disabilities, contains sets of indicators for: systems of acute health care for children with disabilities and early intervention services for children with developmental disabilities
Child Health Questionnaire (CHQ)	Medical Outcomes Trust	-creates a profile of 14 health concepts and summary measures of physical, psychosocial functioning, and well-being for children five or older, not specifically focused on cshcn
Indicator Measurement System (IMSsystem)	Joint Commission on Accreditation of Health Organizations (JCAHO)	-an indicator-based performance monitoring system originally for hospitals but now being expanded to include other health care organizations and a wider range of indicators of access, satisfaction and clinical quality of care -JCAHO also is working to integrate outcome and performance measures into the accreditation process through its project ORYX-The Next Evolution in Accreditation which in 1997 extended to hospitals, long-term care organizations, health care networks and in 1998 to all other accredited organizations
National Library of Healthcare Indicators	Joint Commission on Accreditation of Health Organizations (JCAHO)	-the first edition of this work has been developed and is a catalogue of performance indicators for clinical conditions, functional health status and satisfaction -no focus on children with mental retardation or developmental disabilities

