CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN): ISSUES AND OPTIONS IN SELECTING HEALTH INDICATORS

REVIEW OF LITERATURE AND QUALITY ASSURANCE TOOLS

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FAMILY HEALTH OUTCOMES PROJECT

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INTRODUCTION

Throughout the 1990s, there has been an acceleration in the transition of health insurance plans, both public and private into an array of managed care models. The massive move of children and families previously covered under fee-for-service Medicaid and private indemnity insurance systems into capitated managed care plans has resulted in considerable concerns as to whether the new systems will be able to meet the particular health care needs of children in general, and children with special health care needs (CSHCN) in particular. There is still no consensus on how to define the population of CSHCN. Therefore, measuring the impact of changes in health care delivery systems on this vulnerable population has posed a significant challenge to the public sector wanting to assure and maintain quality services, to managed care plans interested in containing costs and presenting a competitive market edge, and to providers, health care purchasers and advocacy groups who demand access and quality care for vulnerable populations.

In 1995, the Federal Maternal Child Bureau contracted with the Family Health Outcomes Project at the University of California, San Francisco School of Medicine to develop a set of indicators to be used by state Title V agencies for monitoring the impact of changes in the health care delivery system. One of the issues identified by the advisory group to the project was the need to identify resource materials for those state and local agencies grappling with defining and implementing CSHCN population-based indicators.

This purpose of this paper is to review the state of the art of indicators for CSHCN in order to provide guidance to those public/private agencies interested in measuring the impact of changes on this population. The paper is divided into two sections. The first section was developed in October, 1996 and updated in the fall of 1997. It reviews pertinent literature and government reports on approaches to monitoring the health status and outcomes of CSHCN. The section provides guidance to state and local health agencies in selecting indicators for CSHCN to better ensure that CSHCN receive care through health care systems which maximize their health, growth and development and overall ability to function within their families and communities. Since the time of the initial review, other excellent general reviews and guidance have been published regarding the issue of health care reform, CSHCN and quality assurance (Brook, et al, 1996; Newacheck, 1996). Work also continues throughout the country on development and application of various types of measures, but there is no consensus on a national standard for states or other agencies to use as a guide in monitoring the quality of managed care services for this population.

The second section provides a summary of currently available health status assessment tools and reference literature that can serve as resources for state and local health jurisdictions in developing quality assurance measures for CSHCN for public health surveillance and to monitor managed care services. The analysis includes identification of various measures currently in use, measures that have been defined and are being considered for application, and those measures which are still under

development. Contact information for further details about specific programs is also provided.

This paper may also be useful to state Title V performance measure efforts and to the workgroups created by Maternal Child Health Bureau (MCHB) Division of Services for CSHCN. These workgroups are composed of national experts and representatives from Maternal and Child Health regional offices who are making recommendations for: defining CSHCN, developing quality indicators, increasing provider participation and parent involvement and achieving cost-effective services and systems for CSHCN.

SECTION I: APPROACHES TO MONITORING THE HEALTH STATUS AND OUTCOMES OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN)

BACKGROUND

The prominence and attention focused on the "outcomes" of health and medical care is a fairly recent phenomenon in the United States. The health outcomes movement began during the 1980s and became a full-fledged movement in the 1990s. National concern for out-of-control health care costs has fueled an interest in assuring that these dollars are in fact being spent on care that assures good outcomes. This cost-consciousness has spurred a shift to new health care delivery systems, most notably managed care. Major purchasers of health care, in particular the government and corporations, have begun insisting on greater accountability along with cost-consciousness from health insurance carriers and service providers. This movement has resulted in a number of efforts to develop performance measures to be used to assess and assure quality of these mushrooming organizations. The National Committee for Quality Assurance (NCQA) in cooperation with purchasers, providers, insurers and public health administrators released the Health Plan Employer Data and Information Set *(HEDIS 3.0)* which incorporates Medicaid HEDIS measures for the Medicaid population. HEDIS contains some measures of quality for children, but very few which would be useful in assessing care for CSHCN.

At the same time that the above agencies began to develop performance measures, health care professionals and advocacy groups expressed concerns that the quality of care might be jeopardized by the trend towards transferring the care of Medicaid patients to large for-profit managed care organizations. Particular concern has arisen for the wellbeing of CSHCN since this population requires quantitatively more and more costly care, access to high quality subspecialty care and an array of special social and educational support services. Prior to the current shift towards managed care, low income CSHCN have received care through state Title V funded programs which certified subspecialty providers and reimbursed them on a fee-for-service basis. With the transition of the AFDC (TANF) population to Medicaid managed care, there is increasing legislative pressure to include CSHCN in the managed care contracts. Given the medical complexity and severity of medical problems experienced by CSHCN, they are one of the populations at highest risk for negative outcomes as a consequence of cost constraints which could limit access to routine and subspecialty care.

METHODOLOGY

In 1994, the federal Maternal and Child Health Bureau (MCHB) funded the Family Health Outcomes project (FHOP), at the University of California at San Francisco, to develop a set of indicators to be used by state Title V agencies for monitoring the impact of changes in the health care delivery system (with particular emphasis on the transition to Medicaid managed care). The project established an advisory committee consisting of representatives from the 8 states in public health regions IX and X, the regional directors, representatives from three managed care organizations, the American Academy of Pediatrics and the Centers for Disease Control Office of Managed Care. The group recognized that there were few readily available data to guide the selection of health outcome indicators for CSHCN. As a consequence, FHOP began a process to identify resource materials to inform the work of this committee as well as other state and local agencies grappling with CSHCN population-based indicators for monitoring public health changes in the health care delivery system. The MCHB Division of Services for CSHCN has focused on quality indicators related to managed care performance. In this paper, FHOP will also point out the relationship between public health monitoring and managed care performance measurement.

In early 1996. the federal Maternal Child Health Bureau (MCHB) Division of Services for CSHCN convened a number of work groups which included pediatricians parents, consumers groups, academic researchers and representatives from federal agencies, managed care organizations, county health departments and private enterprise. These workgroups reviewed the current status of literature and clinical practice in order to make recommendations to MCHB for definitions, standards and quality measures for state agency use in monitoring the performance of managed care organizations that have a contracted package which includes CSHCN. The areas of consumer satisfaction and involvement, quality assurance, cost and utilization (service requirements and service integration) and personnel preparation were considered.

Specific workgroup-related activities have included:

1. September, 1996 discussion of CSHCN experts from state MCH programs in Regions IX and X; including local California representatives of programs that use quality assurance measures for CSHCN within managed care settings.
2. November, 1996 tri-regional meeting of CSHCN representatives from states in federal Regions VIII, IX and X. This meeting included members of the Division of Services for Children with Special Health Needs (DSCSHN) pilot projects and work group leaders and focused on making recommendations to DSCSHN regarding operationalizing of definitions and quality indicators for CSHCN.
3. November, 1996 second tri-regional meeting of representatives from Regions VIII, IX, X and DSCSHN) to focus on issues related to involvement of health care professionals and parents within health care systems for CSHCN.

Input from these groups was sought in preparing this document.

A search was conducted in Medline using “children with special health care needs," “special health needs," "disabilities” and specific conditions or disease entities as key words. Information related to materials from the DSCSHN work group on quality assurance was also reviewed.

REVIEW OF THE LITERATURE

During the past few years, researchers and clinicians have begun to explore possible indicators for CSHCN. It should be noted that there is very little literature on using Indicators for CSHCN to monitor changes in the health care system from a population-based perspective. Published CSHCN-indicator articles focus on quality assurance, performance measurement or practice guideline development. A number of papers on the effect of managed care on CSHCN stress the need to ensure quality of care though indicator measurements. Brook, 1996 and McGlynn, Halfon and Liebowitz, 1995 describe general considerations in developing indicators in the currently changing health care environment. It is worthwhile to review this general work on developing indicators.

Brook discusses the development of managed care performance measures and attempts to provide new insights into the relationship between cost and quality, and the practice of medicine. In reviewing what has been learned about measuring quality of care and health status, he makes seven important observations:

1. Quality and health status can be measured
2. Quality of both processes and outcomes of care can be evaluated
3. Five methods used to evaluate quality differ in the aspect of care being assessed: the process, the outcome, or overall quality
4. To obtain meaningful measures of quality, administrative data and clinical data must be used (patient interviews, observation of provider-patient encounters or medical record abstracts)
5. Outcomes are multi-dimensional including: measurement of general, physiologic, mental, physical, and social health and patient satisfaction as well as disease-specific outcome data
6. Data obtained by interviewing patients are not sufficient to assess technical quality
7. Procedure-specific or disease-specific guidelines are valuable tools for deciding how to treat and refer patients

Brook suggests the following criteria for developing efficient, publicly accountable, quality-of-care performance measures. Measures should:

- Incorporate results consistent with economic incentives

- Rely on clinically valid process (vs. outcome) measures
- Be based on a model of medically preventable morbidity or mortality, with an emphasis on technical quality of care and on preventing under-use of necessary care
- Focus on cost-effective interventions
- Cover the scope of outcomes that are manageable and affordable
- Allow determination of whether a managed care organization (MCO) provides good quality across all diseases and patient subgroups, or is best in handling a specific disease or procedure

McGlynn et al reviewed existing quality measures of health outcome and status for children. They note that there are few readily available measures which reflects the lack of available tools owing to methodologic problems and funding priorities (emphasis has been on tools for common, high-cost adult diagnoses). They postulate that it is more difficult to gauge quality of care delivered to children because: children are quite healthy; growth and development and functioning are continually changing in childhood - what constitutes an “abnormal" outcome and how to measure deviation is a methodologic challenge; salient outcomes may not be observable until several years after the intervention; improved outcomes may not be routinely assessed by health care providers (teachers may be more appropriate for some indicators). There is a lack of scientific evidence to support many interventions commonly used in pediatric care. In addition, tracer conditions used in the development of adult indicators do not occur with enough frequency in children to be useful. To develop indicators for children, McGlynn recommends beginning with an epidemiological model that considers what is currently known about the prevention, diagnosis and treatment of a broad range of children's health problems.

The National Committee for Quality Assurance (NCQA) Health Employer Data and Information Set (HEDIS) has quickly become the minimum standard for performance measurement of managed care organizations. To be included in HEDIS 3.0, NCQA established the following criteria. Measures must:

- Be relevant: address issues that significantly affect health outcomes. be of interest to purchasers and/or consumers. be able to be influenced by a health plan, be used by purchasers and/or consumers in selecting a health plan
- Be feasible: precisely defined to produce easily measurable data, produced at a reasonable cost, ensure patient confidentiality
- Be scientifically sound: reproducible, valid, accurate, statistically significant, make logical sense

HEDIS quality measures are examples of disease-specific indicators and include some measures of quality for children, but few which would be useful in assessing the care for CSHCN. Examples of HEDIS quality measures relevant to CSHCN are childhood asthma and low birthweight.

The American Academy of Pediatrics (AAP) has long had a project to develop practice guidelines for specific conditions to assure that quality standards of care are provided for pediatric patients. These guidelines are now being considered as performance measures within managed care organizations. AAP methodology has been to first develop a set of treatment guidelines and then to monitor compliance with these guidelines as they relate to the functional outcomes in children with the designated conditions. Asthma and otitis media guidelines have been completed; juvenile rheumatoid arthritis and head injury guidelines are in process.

One approach being proposed for monitoring CSHCN in managed care is the use of functional status measures. A number of efforts are underway to collect data that is focused on the measurement of functional outcomes with particular relevance to the patient, such as quality of life and ability to function in family, peer and educational settings (Stein P, et al., Journal of Pediatrics, 1993 March). Several frameworks and scales based on the use of validated survey instruments have also been developed and proposed for measuring functional status and identifying its significant components. The National Health Interview Survey and the Survey of Income and Program Participation (SIPP) (MMWR, V. 44. No.33; August 25, 1995) are examples. The NHIS has also been used to estimate an epidemiologic profiles of the population of children with special health care needs (Newacheck, 1998).

Particular instruments for functional evaluation of children with special conditions are available (Section I, Appendix A). These questionnaires may be filled out by the older child/youth or by the parents/caretakers, and may cover general functioning levels or be adapted to consider the specific functional needs related to a particular medical condition. Efforts have also been made to customize functional outcome measures for specific disease states such as juvenile rheumatoid arthritis (JRA) (Cardiel M.H., Clinical and Experimental Rheumatoloy, 1993 March-April). This approach has the advantage of measuring the actual functional outcome of a child based on what a service provider does to meet the child's specific medical condition and related health needs for an array of chronic conditions.

The American Academy of Pediatrics also has a Functional Outcomes Project to look at children and the "quality of life and capacity to function in their social world" (Project Briefs, Child Health Care Update, Number 12, 1996). The AAP approach uses functional status measures, but they are applied to specific selected diagnoses rather than applying them to all children. This approach gives a more concrete character to the process that can be then used to target those children considered to be at high risk as well as to focus remediation where the outcomes are not optimal.

Several recent publications do an excellent job of presenting measures to assess the adequacy of the overall system in meeting the needs of CSHCN. A recent draft of the carefully considered document, Pediatric Excellence in Health, from the National Association of Children's Hospital and Related Institutions (NACHRI, 1996) focuses more on indicators of adequacy of health care service delivery. The goal of this project is to provide a framework for evaluating the performance of the system, not to measure the health or functional outcome of any given child. Of note is that the document "is intended as a guide for excellence rather than as a specific tool to evaluate performance."

The New England SERVE program describes in a detailed, but practical manner, what kinds of services in various categories should be available and utilized in the process of serving a CSHCN and his or her family.

Some efforts have also been made to establish reference sets for CSHCN, such as the resource book related to youth developed by an on-going project of the National Center for Youth with Disabilities (July, 1996). This publication is a collection of annotated bibliographies drawn from NCYD's National Resource Library. Topics in the bibliographic file include: chronic illness or disabling conditions; psycho-social issues; social issues; developmental processes; family; sexuality; education; employment and vocational rehabilitation; community and independent living; service approaches; professional issues; and policy, planning, legal right, issues and health issues.

DISCUSSION

Several important issues emerge from the literature review and as a result of input from experts.

- Issue I Controversy surrounding a standard definition for CSHCN
- Issue II The tension or overlap between condition-specific and functional outcome measures
- Issue III The difference between population-based monitoring versus measuring performance
- Issue IV The difference between process and outcomes monitoring
- Issue V Barriers to data availability, quality and consistency

ISSUE I: THE CONTROVERSY SURROUNDING A STANDARD DEFINITION FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Prior to the 1990s, few published papers addressed the area of population-based assessment of the health status and health outcomes of CSHCN. A main barrier to this discussion has been the lack of a clear, concise definition that specifies which children and which diagnoses to include in the target CSHCN population.

In defining the CSHCN population, a number of factors need to be considered including:

- Whether a child is currently impaired by a disease or condition
- Whether a child is likely to develop a condition due to having a particular risk factor
- Whether a child is likely to become disabled from a condition that is currently inactive
- The impact of a disease or condition on the child's well being (i.e., severity)
- When a condition should be considered “chronic”
- The need for specific treatment and follow-up

The current controversy is focused on whether the definition of CSHCN should be based on selection of specific (disease) conditions versus the determination of needs based on measurement of the functional status of the child. A number of papers have utilized specific conditions which are then related to practice guidelines that have been developed by various expert groups. A common example of a specific diagnosis is childhood asthma (American Academy of Pediatrics; National Heart, Lung and Blood Institute). An example of the functional approach is one recommended by Stein, Newacheck, Perrin and others, which includes or excludes children based on assessments of their function within their families, communities, schools and with peers. These authors stress the need to avoid a condition-specific or categorical approach and focus on a generic evaluation of a child's needs which transcends the variations of any particular condition.

The Federal MCHB Division of Services for CSHN currently defines CSHN as: “Children with special health care needs are those who have or are at increased risk of having chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally" (McPherson, 1998). This definition is broad in that it includes children at risk, recognizes the scope of child needs that may be affected (physical, developmental, behavioral and emotional) and addresses both direct "health" and associated “related services." The word "chronic" is included, but not defined in terms of length. The relevance of length of time in the definition of CSHCN has been discussed by other authors in reference to either three months, six months or one year periods, each of which has advantages and disadvantages regarding practical application in clinical and program situations.

It is likely that any national definition of CSHCN will need to be general and inclusive in order to allow state Title V agencies or other concerned organizations to modify the definition to suit its own needs. For example, in each state, CSHCN and developmental disability programs may need to implement variations in the definitions to meet state legislation and regulation requirements and fiscal limitations. On the other hand, some uniformity of definitions across same or similar types of programs and health care plans

will be necessary if meaningful comparison of data and outcomes across programs and states is to be achieved.

ISSUE II: CONDITION-SPECIFIC VERSUS FUNCTIONAL OUTCOMES INDICATORS

Chronic conditions have broad implications for the child, his or her family and the health and human services providers. Regardless of the specific disease, children with diverse chronic conditions have similarities in their life experiences and in the preventive and rehabilitative aspects of their conditions (Stein and Jessop, 1982). The commonalities that are shared by most children with special health needs make non-categorical or "generic" outcome indicators useful when assessing progress for individual children or when comparing, for example, the health status of groups of children between health plans, across geographic areas or when comparing specific race/ethnic populations. Selecting outcome indicators that capture the commonalties in life experiences of children with special health care needs in and outside the health care arena is difficult. To help resolve this problem, health services researchers have developed inclusion criteria based on functional status. There are many factors underlying recent trends in health outcomes research that account for the increased emphasis on generic functional indicators of child health. Some of these factors arise as a result of limitations in deriving condition-specific indicators, such as:

1. The number of individual chronic conditions to which children are subject are numerous. Even though the prevalence of all but a few conditions is low in children, rare conditions do cumulatively contribute significantly to the total number of children with chronic disorders (Stein et al., 1993). In response to this issue, Moclyon, Halfon and Liebowitz (1995) recommend developing functional indicators for an aggregate of common services for several conditions.
2. The process of making a diagnosis is subject to many errors and is often subjectively based on clinical judgment. There is considerable variability in the threshold of signs and symptoms used by different health care providers in ascribing a disease label. This variability in diagnosis occurs due to differences in experience or in institutional, cultural or geographic practice (Stein et al., 1993).
3. Children who have good access to health care are more likely to be formally diagnosed. Those not in the health care system are less likely to be counted, and perhaps even more likely to be functionally impaired. Children with readily recognized conditions are also more apt to be given a diagnosis. Others with diseases more difficult to diagnosis, (such as systemic lupus erythematosis or juvenile rheumatoid arthritis) may be under-represented since they may have a long period of symptoms and many medical visits before their condition is identified and labeled (Stein et al., 1993).
4. Disease manifestations may differ significantly in two individual children with the same condition; symptoms may differ in the same child over time; comparable consequences may be experienced with diverse conditions; and the combined effect of more than one chronic disorder may be more than simply additive (Stein et al., 1993).

5. A disease-specific perspective is falling out of vogue with federal legislation in determining eligibility for health and human service programs. For example, the 1990 U.S. Supreme Court ruling on Sullivan vs. Zebley noted that the Social Security Administration had inappropriately denied Supplemental Security Income benefits to children with serious disability who did not meet a threshold of severity within a single diagnostic category. This decision ignored the cumulative effect of several conditions that caused sufficient dysfunction to qualify had the dysfunction been caused by a single condition. The Court found that equity could best be achieved by determining the consequences of the chronic condition(s) on functioning. However, certain diagnoses remained automatically eligible for services, and potential changes due to the new welfare law may reverse some of the functional approaches to eligibility. In addition, the 1989 amendments to the Omnibus Budget Reconciliation Act directly affect state programs for CSHCN under Title V of the Social Security Act and broadened service requirements of the state CSHCN programs beyond diagnostic categories so that children are now considered for eligibility regardless of their specific condition (Stein et al., 1993; Perrin et al., 1993). Recent changes in SSI eligibility criteria focus more on specific conditions but maintain an emphasis on degree of functional impairment.
6. There is the potential that plans may behave differently with respect to care if they know they are being evaluated for a select group of children with a specific condition (Newacheck et al., 1996). The use of system indicators may be appropriate to monitor plan operations across conditions (e.g. timely referrals to pediatric sub-specialists).

Despite their appeal, generic functional measures of health status are not without limitations. For example. there is no consensus regarding the normal roles and functions of children at each age, both within and between social contexts. Children with special health care needs undergo considerable changes resulting from the interaction of environmental and biological factors. These factors affect the child's dependency and make it difficult to determine whether the failure of a child to achieve independent function in an area is part of the normal developmental process, a result of an environment that fosters dependency, or a loss of ability to function secondary to illness. The resulting complexity of these issues has led to questioning the appropriateness of measuring functional status of children under one and a half to two years of age (Stein and Jessop, 1982). There is also heightened concern regarding whether patterns derived from healthy children are applicable to children with significant handicapping conditions (Stein and Jessop, 1982; Stein et al., 1993).

Furthermore, condition-specific outcome indicators, or those designed to measure physical impairment and function related to a specific condition, have certain advantages. For example:

1. The population of children with special health care needs is very heterogeneous. Symptomatology, health care and related outcomes vary widely among children with differing conditions. Appropriate outcome measures for one illness (or subgroup of related illnesses) may be quite inappropriate for another illness or subgroup.
2. There are little existing data on functional outcomes for specific conditions with which to monitor and evaluate health plans, let alone the experience and wisdom to be able to draw meaningful conclusions across conditions and plans.

Monitoring and evaluating outcomes for specific conditions allows identification of deviation from treatment guidelines that might be unnoticed if outcomes are evaluated only on a generic functional basis.

ISSUE III: POPULATION-BASED MONITORING VERSUS MEASURING PERFORMANCE

Different concerns arise when selecting health indicators to be used for population-based assessment for CSHCN versus measures to be used to assess the quality or care for individual children or groups of children being served by particular service providers. Population-based measures provide data about the potential population in need of services as well as the health status of the entire population. These measures enable those responsible at state or local health agencies to plan for and assign appropriate resources for CSHCN. In addition, these measures provide a benchmark against which to measure outcomes in subpopulations receiving care in a variety of settings.

Performance measures reflect the quality of care received by CSHCN in a particular health care setting, such as managed care organizations (MCOs). These data can also be useful in evaluating the access of CSHCN to special public health programs such as PL 94-142, PH 102-119 (Part C-10EA), Head Start, Title V CCS, school health programs, etc.

In developing performance measures to be used across plans, a number of problematic issues arise. It is currently unclear whether the responsibility of Medicaid Managed Care providers (under different local, state, private and public health care systems) will include providing the full complement of services for CSHCN under a capitated agreement. Even if the MCO is responsible for the medical services that such children need, it remains to be determined whether a plan can be expected to provide for ancillary services (e.g., home health. parental support, etc.) and health education (health promotion and disease prevention) activities for both individual children/families and the enrolled population. Since many health outcomes are dependent on both parental knowledge of related medical care and the ancillary and support services available to the family, responsibility of the MCO should be to at least assure that parents are connected with supportive services as needed. Selected performance

measures need to correspond to the particular scope of services which are covered in the MCO contract.

Given the critical role some of these ancillary services have in determining the well-being of CSHCN, one could envision a scenario where the medical provider adheres to clinical practice guidelines, but the child has a poor outcome clue to lack of access to ancillary services. Furthermore, there may be some children who, either because they lack transportation or translation skills or for some other reason, do not access plan services that might be available. These children could be expected to have poor outcomes which would not be seen when using performance measures for enrollees. Therefore. in order to truly assess the impact of managed care on the CSHCN population, it will be critical to do broader public health, population-based evaluations.

ISSUE IV: PROCESS VERSUS OUTCOMES MONITORING

Because of the lack of research which validates the utility of particular outcome measures, quality assurance efforts for the CSHCN population have primarily focused on process of care (e.g., preventive care visits and immunization status) or patient/family satisfaction. Process outcomes are often directly related to whether appropriate services are being delivered to children and thus affect positive health outcomes. The ability to standardize approved processes and their direct connection with positive outcomes may make these indicators more sensitive measures of quality of care than the occasional mortality outcome (Brook, 1996). HEDIS specifically notes its intent to consider both outcome and process objectives. However, in many cases process of care is measured as a proxy for outcome. As noted above, most chronic diseases in children are infrequent, outcomes do not often result in death and any given managed care plan may have relatively few cases among their enrollees. Furthermore, condition variation, co-morbidities and social, educational and environmental factors may also influence outcomes, particularly in children.

ISSUE V: DATA AVAILABILITY, QUALITY AND CONSISTENCY

The most meaningful outcome indicators are of little value unless the relevant data can be identified, collected, reported and analyzed effectively. Numerator and denominator data for population-based health indicators may be difficult to obtain. In the absence of population-based data, health agencies frequently need to invest considerable resources in primary data collection on representative samples of the population.

Data necessary for the measurement of health provider performance requires encounter data or other client specific data collected by the service provider. Providers rarely have automated data collection systems other than for data used for billing purposes. These administrative data may be adequate for assessing the use of preventive services, but clinical data is necessary to evaluate acute and chronic care (Brook, 1996). Often there are no historical or baseline data. There are also issues of

consistency and comparability of data across providers, plans and geographic areas. All MCOs, and Medicaid plans in particular, are currently making program and fiscal decisions as to what are the necessary data to collect in order to efficiently monitor programs for both clinical and cost management reasons, and to balance governmental requirements for data with limited capitation revenue.

SUMMARY

The development and implementation of a strategy for monitoring the health status and outcomes for CSHCN and for assessing the quality of care they are receiving is critical during a time of rapid change in the health care delivery system. Indicators need to be developed and tested for use in both population-based monitoring and health plan performance measurement. Developing and testing these indicators is dependent on accomplishing a number of key tasks:

- Achieving consensus on a broad definition of CSHCN, and developing guidelines for application to subpopulations and service programs. National guidance (e.g., MCHB. HCFA, NCQA, AAP, NACHRI, etc.) is necessary to consider uniformity of definition implementation and application to particular situations
- Reaching consensus by key players as to the use of condition-specific versus functional indicators. It seems likely that the best approach would combine the use of some condition-specific measures with a functional evaluation of the child and family
- Continuing pilot projects that are testing the utility of various indicators for different settings with a central evaluation body to analyze the results and implications
- Involving health care providers, MCOs and public health administrators in the development of these measures in order to assure that they will be committed to collecting the data necessary to measure them
- Identifying or developing cost-effective data collection systems to assure availability of numerator and denominator data for constructing the indicators

ANNOTATED BIBLIOGRAPHY

This section provides a brief overview of available literature that may be helpful in developing health outcome indicators for children with special heath care needs. This bibliography is a point of departure, and other relevant published articles or reports may exist.

ACCESS-MCH: Center for Automation and Care Coordination Enhancing Service Systems in Maternal and Child Health (in progress). [contact: Lois Wainstock (617) 627-3626].

The goal is to provide families with the ability to provide input to state CSHCN programs and managed care planning and service delivery. Areas being addressed include training of parents, measuring outcomes of care coordination, a self-study system for care coordinators and tools to do periodic surveys of state CSHCN programs.

Allen LH. **Functional indicators and Outcomes of Undernutrition**. J Nutr, 1990 Aug, 120(8):924-32.

Abstract: The advantages and limitations of using functional methods are discussed in the context of identifying undernutrition and hunger in children in the United States. At this time, many of these methods have been used only in developing countries where undernutrition is more serious. However. there is great need to investigate whether, when and how undernutrition in the United States affects children's development. Functional measures can detect undernutrition and hunger in some situations where biochemical or clinical measures cannot.

Andersson Gare B; Fasth A; Wiklund I. **Measurement of Functional Status in Juvenile Chronic Arthritis: Evaluation of a Swedish Version of the Childhood Health Assessment Questionnaire.** Clin Exp Rheumatol, 1993 Sep-Oct, 11(5):569-76.

Abstract: Few well-validated self- and/or parent-administered instruments are available for measuring functional status in children with rheumatic diseases. Parts of the Stanford Health Assessment Questionnaire (HAQ) have been adapted for use in children in the so-called Child HAQ. The aim of this study was to investigate the validity of this instrument in a Swedish setting. The Child HAQ was administered to 186 patients and 211 patients participating in a population-based follow-up study of juvenile chronic arthritis (JRA) in southwestern Sweden. The EULAR criteria were used for inclusion. Children who were 9 years of age or older self-reported. Reliability, evaluated by test-retest, inter-observer correlations and internal reliability, was excellent. Convergent validity was demonstrated by strong correlations of the disability index, pain. and morning stiffness with disease activity and the Steiribrocker functional classes. Discriminant validity was evidenced by the capacity of the instrument to evaluate patients as being active or in remission. Thus, the Child HAQ showed

excellent measurement performance in a Swedish setting when using parents or children more than 9 years old as responders.

Arcia E; Keyes L; Gallagher JJ. **Indicators of Developmental and Functional Status of Mexican-American and Puerto Rican Children.** J Dev Behav Pediatr, 1994 Feb, 15(1):27-33.

Abstract: The overall purpose of this study was to describe the developmental and functional status of young Latino children. We analyzed data from the Hispanic Health and Nutrition Examination Survey and estimated the percentages of young Mexican-American and mainland Puerto Rican children with indicators of developmental need for special services, i.e., low birth weight, use of neonatal intensive care, congenital problems, chronic conditions of developmental concern, functional limitations, and physician diagnoses of medical conditions. Estimates suggest that Puerto Rican children had substantially poorer status than Mexican-American children who, in turn, have indicators that are comparable with those reported for the general population. The difference in status between the two Latino groups merits further investigation.

Bauman L. **Discussant Section.** Am J Respir Crit Care Med, 1994, 149: 540-S43.

Abstract: This article is a discussant piece in response to an article by Richards and Hemstreet on methodological issues important to consider in measuring functional status, quality of life and role performance. Ms. Bauman defines and describes quality of life, functional status and role performance in relation to developing an indicator for asthma.

Brave New Partnerships, Children with Disabilities, Families and Managed Care (1997). [contact: Peggy Mann Rinehart, Division of General Pediatrics and Adolescent Health, University of Minnesota (612) 626-2401].

This project has combined funding and is connected with an HMO (Health Partners) with the intent of using a parent centered approach to establish an integrated service system. The project will look at parent and physician needs and utilization and cost data with parent and community advisory groups.

Brook RH; Kamberg CJ; McGlynn EA. **Health System Reform and Quality.** J Am Med Assoc, 1996 Aug 14, 276(6):476-80.

Abstract: Brook presents eight critical questions that should be considered regarding the changing health care system in order to illustrate the importance of maintaining quality of care concerns on the policy agenda. There is further discussion regarding what happens to quality when the system is changed, and how quality can be measured and maintained on the policy agenda. Action suggestions are presented for

physicians to pursue to ensure that quality remains a central value of the health care crisis of the 1990s in the U.S.

Children and Youth with Disabilities in a Changing Health Care Environment. National Center for Youth and Disabilities. University of Minnesota, July 1996.

A reference source for bibliographic material and educational materials from the National Resource Library database which contains information about youth with chronic illnesses and disabilities, and up-to-date expertise, programs and literature of all relevant disciplines.

Cardiel MH; Abello-Banfi M; Ruiz-Mercado R; Alarcon-Segovia D. **How to Measure Health Status in Rheumatoid Arthritis in Non-English Speaking Patients: Validation of a Spanish Version of the Health Assessment Questionnaire Disability Index (Spanish HAQ-DI).** Clin Exp Rheumatol, 1993 Mar-Apr, 11(2):117-21.

Abstract: The HAQ-Disability Index (HAQ-DI) is a useful instrument to measure health status in rheumatoid arthritis (RA) patients. Translation into another language requires a validation process, however. We have translated the HAQ-DI to be used on Spanish-speaking populations. We administered the questionnaire to 97 RA patients during the course of routine medical care. Reliability, measured by a test-retest with a one-month interval, was high (Spearman's rho = 0.89). Convergent and construct validity was obtained for all comparisons (Pearson's r > 0.4). The instrument was sensitive in detecting clinical improvement. We conclude that the Spanish HAQ-DI retains the characteristics of the original index and can be used to assess outcome in Spanish-speaking patients with PA. The procedure described may be used to translate the instrument into other languages either directly from English or from the Spanish version presented here.

Czyzewski DI; Mariotto MJ; Bartholomew LK; LeCompte SH; Sockrider MM. **Measurement of Quality of Well Being in a Child and Adolescent Cystic Fibrosis Population.** Med Care, 1994 Sep, 32(9):965-72.

Abstract: The purpose of this study is to determine the Quality of Well-Being (QWB) Scale's utility in a clinical intervention involving children. The interespondent agreement between adolescent and parent reports on the QWB, the concurrent relationships between the QWB and physical and psychosocial measures in a child and adolescent sample, and the extent to which severity of illness moderates the relationship between QWB and a measure of pulmonary function were examined. Although there were several significant correlations between QWB scores and physical status scores from the NIH scale, the lack of agreement between respondents on the scale, the small correlations. and the absence of significant relationships with well-validated measures of psychosocial functioning calls into question the use of the QWB for clinical decisions and therapy outcome measure for the general pediatric cystic fibrosis population.

Donnelly S; Scott DL. **The Outcome of Arthritis: Measures of Function, X-rays Damage, Pain and Patients' Satisfaction.** Eur J Rheumatol Inflamm, 1992, 12(2):21-6.

Abstract: The outcome of arthritis has several dimensions. These include mortality, morbidity, radiological measures of joint destruction, pain, and patients' satisfaction with therapy. Functional disability measured by health status questionnaires, is directly associated with long-term outcome and mortality. Long term clinical trials should incorporate functional indices as outcome measures. Studies measuring the outcome of arthritis should define clear end-points involving the determination of functional classes and this will allow standardised and sensitive end points. An example would be the time taken to reach a given functional class or increase from baseline by one functional class. Patients' satisfaction with treatment is a different dimension of response. There are considerable advantages in using an index of patients' satisfaction when determining the therapeutic efficacy in short term clinical trials. It gives a different indication of the response to treatment than conventional clinical and laboratory measures of disease activity. Alleviating pain and preservation of function remain the major therapeutic goals, and both reflect the outcome of arthritis. Outcome measures have shifted from laboratory markers and radiographic techniques to measures of health status, pain, and patients' satisfaction. These should become a routine part of patient assessment.

Feldman AB; Haley SM; Coryell J. **Concurrent and Construct Validity of the Pediatric Evaluation of Disability Inventory.** Phys Ther, 1990 Oct, 70(1O):602-10.

Abstract: The purpose of this study was to determine the validity of the Development Edition (pilot version) of the Pediatric Evaluation of Disability Inventory (PEDI) in groups of disabled and nondisabled children. The PEDI is a new functional assessment instrument for the evaluation of disabled children aged 6 months to 7 years. The PEDI has been developed to identify functional status and change along three dimensions: 1) functional skill level, 2) caregiver assistance, and 3) modifications or adaptive equipment used. The PEDIs were administered as a parental-report questionnaire, and the results were compared with data obtained by the Battelle Developmental Inventory Screening Test (BDIST). The BDIST is a standardized assessment with developmental and adaptive content. Subjects were 20 children between the ages of 2 and 8 years with arthritic conditions and spina bifida and 20 nondisabled children matched for age and sex. All subjects' scores on the BDIST cognitive domain were no greater than 1.50 standard deviations below the mean for their age group. Concurrent validity was supported by moderately high Pearson product-moment correlations between BDIST and PEDI summary scores (r = .70-.80). Construct validity was supported by significant differences between the disabled and nondisabled groups PEDI scores and by discriminant analysis identifying the PEDI scores as better group discriminators than the BDIST scores. Results validate the Developmental Edition of the PEDI and support the further development and standardization of the final version. Use of the PEDI in clinical pediatric physical therapy practice is discussed.

Fox HB; McManus MA. **Medicaid Managed Care for Children with Chronic or Disabling Conditions - Improved Strategies for States and Plans**. Maternal and Child Health Policy Research Center, July 1996.

This paper is a thorough review of definitions, policies and state practices related to Medicaid managed care programs for CSHCN. Various structures for capitated plans are described and analyzed; and there is a detailed examination of essential elements for state managed care policies and plan practices. These include recommended elements of state contracting and oversight, and recommended elements of managed care practice. Pediatric quality of care measures constitutes a small but useful section.

Fries JF. **The Hierarchy of Quality-of-Life Assessment, the Health Assessment Questionnaire (HAQ), and Issues Mandating Development of a Toxicity Index.** Control Clin Trials, 1991 Aug, 12 (4 Suppl):106S-1175.

Abstract: Health, as defined by the World Health Organization, encompasses the more redundant and cumbersome phrase "health-related quality of life." Valuations by patients naturally separate this entity into the primary dimensions of absence of death, disability, discomfort, drug toxicity, and destitution. These dimensions separate naturally into subdimensions. and the subdimensions into components, thus providing a hierarchy under which assessment of particular aspects of health may be placed. In the clinical trial situation, it is essential that all dimensions always be assessed and reported, because otherwise, misleading conclusions may be drawn. On the other hand, it is much less important which assessment instrument is chosen, or how much detail is assessed for each dimension. The Health Assessment Questionnaire (HAQ) has been developed under a hierarchical conceptual model and widely used; its characteristics are described. A new index for measurement of drug toxicity has been developed for the HAQ, and its crucial role in comparing treatments in a clinical trial discussed. Issues in reliably describing comparative drug toxicity are developed, a toxicity index presented, and some preliminary results and conclusions outlined. With the ability to quantitatively describe drug toxicity, health assessment becomes conceptually more complete.

Gortmaker SL; Walker DK; Weitzman M; Sobol AM. **Chronic Conditions, Socioeconomic Risks and Behavioral Problems in Children and Adolescents.** Pediatrics, 1990 Mar, 85(3):267-76.

Abstract: Children with a chronic health condition have long been considered at excess risk for psychosocial morbidity. Despite an increasing prevalence of chronic childhood conditions and heightened concerns for the quality of life of the chronically ill, population-based studies of behavior problems among children with chronic physical conditions are rare. Findings on the epidemiology of behavior problems in a nationally representative sample of 11,699 children and adolescents aged 4 to 17 years in the United States are reported. Data included a 32-item parent-reported behavior problem index, measures of chronic childhood conditions, measures of school placement and performance, and sociodemographic variables. Analyses confirmed that chronic physical conditions were a significant risk factor for behavior problems, independent of

sociodemographic variables. Among children these differences were observed across all subscales: among adolescents the largest differences were found for the Depression/Anxiety and Peer Conflict/Social Withdrawal subscales. Rates of extreme behavior problem scores (those in the top 10th percentile) were 1.55 times higher among children with a chronic health condition compared with children without a chronic condition (195% confidence interval 1.29 to 1.86). These independent odds were lowered to 1.44 when covariates for confounding were introduced via a multivariate logistic regression. Other independent risks included the absence of either biologic parent (odds ratio 2.05), male gender (1.53), low vs high family income (1.30), low vs high maternal education (1.51), and young vs old maternal age at childbirth (2.57). Chronic health conditions were also a major risk factor for placement in special education classes and having to repeat grades. Despite evidence for effective interventions, health services for children with chronic conditions - particularly mental health services - remain fragmented, signaling the need for increased attention to behavioral problems and their treatment among all health professionals caring for children.

Haas DL. **Application of Orem's Self-Care Deficit Theory to the Pediatric Chronically Ill Population.** Issues Compr Ped Nurs, 1990 Oct-Dec, 13(4):253-64.

Abstract: The conditions under which children with long-term chronic health problems are cared for have changed dramatically in the past decade. These children are more often living longer and being cared for at home by their families and nursing supports. An effective tool allowing nurses to systematically assess, plan, implement, and evaluate the care needs of these children is a nursing theory. Orem's (1985) self- or dependent-care deficit theory is a useful basis from which the care of the chronically ill pediatric population can be planned. Attention is given to a caring relationship in which there is a dependent person in need of care and an individual who serves as that dependent person's agent of care. This article discusses several of the major concepts of the self- or dependent-care deficit theory and how it can be applied to guide clinical nursing practice aimed at meeting the care demands of the pediatric chronically ill population and their families.

Hariman LMF; Griffith ER; Hurtig AL; Keehn MT. **Functional Outcomes of Children with Sickle-Cell Disease Affected by Stroke.** Arch Phys Med Rehabil, 1991 Jun, 72(7):498-502.

Abstract: The nature and degree of functional recovery after stroke in children with sickle-cell disease (SCD) has not been extensively investigated. The purpose of this study was to evaluate retrospectively the functional status of 14 SCD children who had strokes and to compare them with age-matched and gender-matched SCD children who had not had strokes. By doing so, we would be able to quantify the eventual physical and cognitive functional outcomes of survivors of stroke secondary to SCD and assess the impact of stroke on these patients. These children (five boys and nine girls) with SCD and stroke(s) were 11.6 +/- 4.3 years of age (range five to 18 years). They experienced one to three strokes at a mean age of 6.1 +/- 5.2 years (range one to 17

years). A series of tests were administered to these subjects to evaluate physical and psychosocial functions. These tests were performed at least one year after the latest stroke. This study showed that all of the SCD-stroke children were physically independent. Only a few had impairments of hand functions and mild difficulties in self-care activities. However, most of these children demonstrated intellectual deficits ranging from borderline to moderate mental retardation, reduced language functions ranging from low normal to retarded range, and problems in adjustment. Intelligence quotient of the children with SCD-stroke(s) was significantly lower than those of age-matched and gender-matched nonstroke SCD children, suggesting that stroke caused an adverse effect on the cognitive functioning of these children. The results indicate that in the SCD-stroke children psychosocial deficits outweighed physical disabilities. ABSTRACT TRUNCATED AT 250 WORDS)

Healthy People 2000: National Health Promotion and Disease Prevention Objectives. Department of Health and Human Services; Office of Disease Prevention and Health Promotion, Washington, D.C. 1990. [Contact: (202) 472-5583}

HP 2000 serves as a key set of guidelines for monitoring and measuring the progress of health care within the United States. The two main measures that apply to disabilities relate to structural standards for hiring policies for people with disabilities and for establishment of state service systems for CSHCN or at risk for such - mainly based on early intervention laws.

Henderson J; Goldacre MJ; Fairweather J; Seagroatt V. **Time Spent in Hospital by Children as a Health Care Indicator: inter-District Comparisons.** J Public Health Med, 1992 Mar, 14(1):35-8.

Abstract: It has been widely recommended that children should be admitted to hospital only if treatment cannot be provided at home, and that duration of hospital stays should be minimized. We have used record linkage to calculate a statistic which is not yet commonly available, the total time spent in hospital by children per year, and have compared this between six districts in the Oxford Region. Hospitalization rates for children who stayed a total of two days or less per year in hospital increased over time; rates for children who stayed more than two days declined. Mean and median total days spent in hospital varied between districts but, in absolute terms, the differences were small at less than one day's difference between districts per year per child admitted. Inter-district variation decreased over time, although the variation in use of day case care which remained suggests that some districts could still do more work in this fashion.

Institute of Medicine, Board of Health Services. **Strategies for Assuring the Provision of Quality Services Through Managed Care Delivery Systems to Children with Special Health Care Needs**. Washington, DC: National Academy of Science, [contact: Jane S. Durch, M.A., (202) 334-2069].

Ireys HT; Werthamer-Larsson LA; Kolodner KB; Gross SS. **Mental Health of Young Adults with Chronic Illness: The Mediating Effect of Perceived Impact.** J Pediatr Psychol, 1994 Apr, 19 (2): 205-22.

Abstract: Examined psychological symptomatology in a community-based sample of 286 young adults with chronic health conditions randomly drawn from the rolls of two state programs for Children with Special Health Care Needs. The Psychiatric Symptom Index was used to assess mental health. We investigated how selected condition characteristics (e.g., indices of severity, symptom predictability, prognosis, age of onset, and visibility of condition) increased risk of psychological symptoms. Analyses indicate that (a) this population is at high risk for psychological symptoms, (b) selected risk factors (i.e., prognosis, restricted activity days, presence of hearing and speech problems, and perceived unpredictability of symptoms) have significant effects on mental health status when other variables are taken into account, and (c) respondents' perceptions of the impact of the condition mediates associations between selected risk factors and mental health. Results are discussed in relation to preventive interventions for this population of young adults.

Ireys HT; Gross SS; Werthamer-Larsson LA; Kolodner KB. **Self-Esteem of Young Adults with Chronic Health Conditions: Appraising the Effects of Perceived Impact.** J Dev Behav Pediatr, 1994 Dec, 15(6):409-15.

Abstract: The relationships between selected condition characteristics and self-esteem were investigated in a randomly drawn, community-based sample of 286 young adults with chronic illnesses and disabilities. Whether appraisals of the impact of the condition mediated relationships between condition characteristics and self-esteem, as measured by the Rosenberg Self-Esteem Scale, was also measured. As a group, the youth in this sample reported positive self-esteem. When sociodemographic and condition-related variables were considered simultaneously, maternal education, unpredictability of symptoms, prognosis, sensory impairment, and the presence of a co-occurring learning disability were found to have direct effects on esteem. Perceived impact mediated the relationship between condition characteristics and self-esteem. The results are discussed in relation to the role of impact appraisal in determining the emotional well-being of young adults with chronic illnesses.

Ireys HT; Grason HA; Guyer B. **Assuring Quality of Care for Children with Special Needs in Managed Care Organizations: Roles for Pediatricians.** Pediatrics, 1996 Aug, 98(2 Pt 1):178-85.

Abstract: Increasing numbers of children with special health care needs are enrolling in managed care programs. Although managed care may improve services coordination and use of primary care, it may also threaten health outcomes for these children by potentially decreasing access to the range of needed services, eroding progress in developing community-based service systems, and failing to ensure quality of care. To date, few frameworks have been proposed to assess quality of care for this population of children in managed care organizations. In this article, we adapt the Institute of Medicine's definition of quality and identify six key components: content of service delivery systems, the nature of desired health outcomes, risks associated with service delivery, constraints of care. interpersonal dimensions, and attention to developmental issues. These components can be assessed at three levels: the individual, the health plan, and the community. Pediatricians and other health professionals have critical roles to plan in assuring that policies and practices within managed care organizations promote a high quality of care for this vulnerable population of children.

Johnson A; Townshend P; Yudkin P; Bull D; Wilkinson AR. **Functional Abilities at Age 4 Years of Children Born Before 29 Weeks of Gestation [see comments].** Bmj (Clinical Research Ed.), 1993 Jun 26, 306(6894):1715-8.

Abstract: OBJECTIVES-To assess the rate of impairment and disability among babies born very preterm and to investigate the association between such impairment and gestational age at birth.
DESIGN-Cohort study of a geographically defined population of babies.
SETTING-Oxford Regional Health Authority.
SUBJECTS-All babies born alive before 29 weeks of gestation to mothers resident in the region during 1984-6.
MAIN OUTCOME MEASURES-Survival rates and rates of impairment and disability among survivors at the age of 4 years. RESULTS-Of the 342 babies, half (170) survived to be discharged home. Of the 164 survivors to age 4 years, 153 (93%) were assessed. A total of 35 (23%; 95% confidence interval 16% to 30%) were severely disabled and only 54 (35%; 28% to 43%) were unimpaired. The risk of impairment and disability increased with decreasing gestational age at birth ($p < 0.003$). CONCLUSIONS-With the increasing survival rate among babies born before 29 weeks of gestation. we need urgently to establish reliable ways of monitoring the proportion of survivors who have a disability.

Keith RA. **Conceptual Basis of Outcome Measures.** Am J Phys Med Rehabil, 1995 Jan-Feb, 74 (1): 73-80.

Abstract: Because of its treatment configuration and the assumption of long-term benefit. rehabilitation has had a continuing interest in the measurement of outcomes. The utility of outcome indicators rests on their conceptual foundations, the technical development of measures and validation research. Some measures, particularly of

functional status, have become increasingly sophisticated with the application of psychometric and statistical analysis techniques. Less effort has been devoted to an elaboration of their theoretical basis. A first step is an examination of the assumptions underlying outcome measures. the purpose of this article. Central to an understanding is clarification of definitions of key terms such as outcomes, independence, impairment, disability and handicap. All outcome measures must be seen as part of a social context of norms and expectations. However, most norms in rehabilitation are implied rather than explicit. The assumptions behind several common outcomes are examined with suggestions for ways to increase their utility. The ability of rehabilitation to compete in the current climate, stressing cost-effectiveness, will depend heavily on the robustness of outcome measures.

Korner-Bitensky N; Wood-Dauphinee S. **Barthel Index information Elicited Over the Telephone. Is it Reliable?** Am J Phys Med Rehabil, 1995 Jan-Feb, 74(1):9-18.

Abstract: This study examined the comparability of estimates of functional status elicited through a telephone interview and a face-to-face interview. The Barthel Index, a commonly used measure to assess activities of daily living, was administered over the telephone and then again in the home to 366 individuals, up to 5 years after their discharge from a rehabilitation hospital. One-half of the telephone interviews were performed by health professionals and the other half by trained lay interviewers; all of the home interviews were performed by health professionals. Proxy-respondents provided information for those unable to respond for themselves. The percent agreement between the scores on the telephone and on the home interview was always greater than 90%; the intraclass correlation coefficient for the telephone/home comparison was 0.89. Responses between the modes of interview were more consistent when provided by self-respondents than when provided by proxies. The telephone assessment worked well in identifying those who did not have functional disabilities; all individuals who scored 100 on the home interview, scored 95 or better on the telephone. When differences arose, they were always in those considered to have moderate to severe impairment and were most often (23 of 29 times) in the direction of higher scores, indicative of less disability, on the telephone. The results of this study suggest that, with the exception of a small subgroup of patients, functional status can be elicited reliably over the telephone by both lay persons and health professionals.

Kutner NG. **Assessing End-Stage Renal Disease Patients' Functioning and Well-Being: Measurement Approaches and Implications for Clinical Practice.** Am J Kidney Dis, 1994 Aug, 24(2):321-33.

Abstract: Along with survival and other types of clinical outcome, the functioning and well-being that characterize end-stage renal disease patients are important indicators of the effectiveness of the medical care that they receive. In addition maximizing functioning in chronically ill patients can be viewed as secondary prevention. Patient-reported functioning and well-being indicate how patients are doing in their daily lives and how they feel about their lives. Measurements used to assess patient functioning and well-being by health services researchers are applicable to health outcome assessment in the clinical setting. Disease- and treatment-specific outcome measurements are more sensitive to disease severity and treatment intervention

effects, while generic outcome measurements provide generalizability across diseases or conditions. Specific measurements can provide data about clinically meaningful changes, and generic measurements help to indicate the significance of these outcomes in patients' daily lives. Using both types of patient-reported measurements, as well as performance-based assessments, will provide outcome-based data on end-stage renal disease patients' functional limitation and disability, and help to define relevant rehabilitation protocols for end-stage renal disease patients.

Managed Care and Children with Special Health Care Needs. American Academy of Pediatrics (AAP), September, 1997.

This is a compendium of information which addresses key issues affecting CSHCN in managed care. Quality of Care is one of six issue briefs addressed. There is a summary of approaches for quality of care for children with special health care needs with a review of the major tools. There is a brief description of "implications for practicing pediatricians." The manual also includes AAP statements on issues related to managed care and CSHCN.

Marcenes WS; Sheiham A. **Composite Indicators of Dental Health: Functioning Teeth and the Number of Sound-Equivalent Teeth (T-Health).** Community Dent Oral Epidemiol, 1993 Dec, 21(6):374-8.

Abstract: This study investigated whether two new composite dental indicators - "the number of functioning teeth" and "the number of sound-equivalent teeth" are more efficient than the conventional DMFT index in revealing the social and behavioral factors which are significantly related to oral health status. The arbitrary set of weights given to the T-Health indicator was also evaluated. The number of functioning teeth was defined as the aggregate of filled (otherwise sound) and sound teeth. The T-Health was defined as a weighted average of sound teeth, filled (otherwise sound) teeth and teeth with some decay, the weights intended in principle to represent the relative amounts of sound tissue in these three categories of teeth. An arbitrary set of weights was used: 4, 2, and 1 for sound, filled, and decayed teeth, respectively. 164 families (father, mother and at least one 13-yr-old child) from Belo Horizonte, Brazil, were randomly selected from 13-yr-old children from private and state schools. The parents' ages ranged from 35 to 44 yr. Socio-economic status, area of residence, level of education, family income, sugar consumption, tooth brushing frequency and type of dental attendance were the social and behavioral oral health risk-factors considered in this study. The results indicated that the two new dental indicators are more sensitive to the influence of social and behavioral factors, such as those investigated here, than is the traditional DMFT index. A different set of weights (4, 1. and 1 for sound. filled, and decayed) was suggested for the construction of the T-Health.

Martinez-Climent J; Castel Sanchez V; Esquembre Menor C; Verdeguer Miralles A; Ferris Tortajada J. **Scale for Assessing Quality of Life of Children Survivors of Cranial Posterior Fossa Tumors.** J Neurooncol, 1994, 22 (1): 67-76.

Abstract: BACKGROUND. Evaluation of quality of life of survivors of brain tumors is an important aspect of outcome that most be included in clinical studies.
METHODS. We have developed a new scale for assessing quality of life (QL) of pediatric long-term survivors of posterior fossa tumors based on their physical, psycho intellectual, and endocrine/growth status. We have studied 39 patients, with a median follow-up of 9 years. Twenty-five had cerebellar astrocytoma (CA). 6 meciulloblastoma MDB), 5 brain-stem glioma (BSG) and 3 ependymoma of IV ventricle (EPD).
RESULTS. Sixty-six percent of children showed neurologic and/or visual sequelae. Little or no significant disability (Bloom's levels I-II) were present in 66%. Psycho intellectual dysfunction was present in 44%, with an IQ < 90 in 39%. Endocrine and growth disorders were found in 26%, mostly stature anomalies. According to our scale. QL scores were high in 19 patients (49%). intermediate in 8 (20%), and low in the remaining 12 (31%). Unfavorable outcomes were related to age of less than 4 years, tumors other than CA (MDB. BSG, EPD), incomplete tumoral resection, and employment of radiotherapy and chemotherapy.
CONCLUSION. Our results are comparable to others previously reported, and this supports the validity of our scale. We consider that this scale is applicable to evaluate QL of children survivors of cranial tumors.

McGlynn EA; Halfon N; Leibowitz A. **Assessing the Quality of Care for Children. Prospects Under Health Reform.** Arch Pediatr Adolesc Med, 1995 Apr, 149(4):359-68.

The authors discuss prospects for quality of care for children under managed care systems. There is a discussion of approaches to quality assessment under health reform, raising several system oriented questions. This is followed by discussion of quality assessments for these children with a table summarizing the proposed quality indicators and data sources under four proposed report card systems. There is an excellent summary of the unique health needs of children and the problems associated with developing appropriate quality measures. Recommendations are made for how to achieve these measures including consensus on priorities for research, development of alternate methods, development of tools to assess children's health outcomes and ensuring adequate funding. Cautions are noted regarding playing to the measures and "gaming."

McGlynn, EA. **Choosing Chronic Disease Measures for HEDIS: Conceptual Framework and Review of Seven Clinical Areas.** Managed Care Quarterly, 1996 Summer, 4(3):54-77.

Abstract: Few quality measures are available today that assess care for chronic conditions. Concern has been expressed by the developers of the Health Plan

Employer Data and Information Set (HEDIS) that the current system may not capture the critical dimensions of quality for chronic diseases. This article provides a conceptual framework for selecting chronic diseases for which measures of quality should be developed, reviews the literature on the effectiveness of interventions for the diseases that meet the criteria, and recommends possible areas for the development of quality measures. (Note: Childhood asthma is reviewed against the criteria for selection).

McPherson M; Arango P; Fox H; Lauver C; McManus M; Newacheck PW; Perrin JM; Shonkoff JP; Strickland B. **A new definition of children with special health care needs [comment].** Pediatrics, 1998 Jul, 102(1 Pt 1):137-40.

The Commentary reviews the need for and challenges related to development of a definition of CSHCN. The purpose of the definition is to assist states and programs in planning for services, advocacy and to meet other needs. The article describes the process of developing the new definition, analyzes the definition and its components, and discusses implications, including possible eligibility determination and concerns regarding relevance to managed care.

MsaII ME; Rogers BT; Buck GM; Mallen S; Catanzaro NL; Duffy LC (b). **Functional Status of Extremely Preterm Infants at Kindergarten Entry.** Dev Med Child Neurol, 1993 Apr, 35(4):312-20.

Abstract: Functional status was formally assessed in 149 of 153 surviving members of an extremely preterm (< or = 28 weeks) birth cohort born at one tertiary center between 1983 and 1986. The children were observed in the completion of motor. speech and self-care tasks. and administered either the Vineland Daily Living Skills Scale (VDLS) or the Functional Independence Measure for children (WeeFIM). 31 children had major neurodevelopmental impairment. Only 5 per cent were considered to have severe functional limitation. The prevalence of functional limitation varied by definition: 11 children were limited using the WeeFIM instrument and 35 using the VDLS instrument. These findings suggest that the majority of extremely preterm children are functional at kindergarten entry, but will require continuous monitoring of academic skills.

Msall ME; DiGaudio K: Rogers BT; LaForest S: Catanzaro NL; Campbell J; et al. (a). **The Functional Independence Measure for Children (WeeFIM). Conceptual Basis and Pilot Use in Children with Developmental Disabilities.** Clin Pediatr (Phila), 1994 Jul, 33(7):421-30.

Abstract: Few tools are available to pediatricians for tracking and monitoring disability status in children. We describe the conceptual basis and pilot use of the Functional Independence Measure for Children (WeeFIM). Our pilot use of this instrument in children with limb deficiency, Down's syndrome, spina bifida, cerebral palsy, and extreme prematurity demonstrates that the WeeFIM is a valid measure for tracking disability in preschool age and middle childhood. The WeeFIM measures the impact of developmental strengths and difficulties on independence at home, in school, and in the community. This allows the pediatrician to prioritize interventions for enhancing comprehensive functional outcomes and supporting families.

National Agenda for Children with Special Health Care Needs. Children with Special Health Care Needs in Managed Care Organizations: Summaries of Expert Work Group Meetings. Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau and Health Resources and Services Administration, December 1996. [contact: Merle McPherson, M.D., Health Resources and Services Administration Rockville, MD 20857].

The Division has conducted expert work groups to research and evaluate data and other information related to topics including defining and identifying children with special health needs, family participation in managed care, capitation and risk adjustment and quality of care. This report summarizes the findings of the groups at the time with specific reference to related tools and other resources.

Newacheck PW; McManus MA; Fox HB. **Prevalence and Impact of Chronic Illness Among Adolescents.** Am J Dis Child, 1991 December, 145: 1367-1373.

Abstract: A sample of 7465 persons aged to 17 years from the 1988 National Health Interview Survey on Child Health was used to assess the prevalence and impact of chronic conditions in adolescents. We defined a condition as chronic if it was first noted more than 3 months before the interview or a condition that ordinarily would be of lengthy duration, such as arthritis or heart disease. An estimated 31.5% of US adolescents were reported to have one or more chronic conditions. The most commonly reported chronic conditions included respiratory, allergies, asthma, and frequent or severe headaches. Chronic conditions had widely varying impact on adolescent activity levels. On average, adolescents with chronic conditions experienced 3.4 bed days and 4.4 school absence days related to their chronic conditions in the year before the interview. Adolescents with chronic conditions were also reported to experience 35% more behavioral problems than their counterparts without chronic conditions and had substantially more bed days. school absence days, and behavioral problems than adolescents with a single chronic condition. Implications of these findings are discussed.

Newacheck PW; Taylor WR. **Childhood Chronic Illness: Prevalence, Severity, and Impact.** Am J Public Health, 1992 Mar, 82 (3): 364-714.

Abstract: BACKGROUND. Using data from the 1988 National Health Interview Survey, this article presents national estimates of the prevalence and impact of childhood chronic conditions.
METHODS. Proxy responses to a checklist of child health conditions administered for 17,110 children under 18 years of age were used. Conditions were classified as chronic if they were first noticed more than 3 months prior to the interview or if they were the type that would ordinarily be of extended duration, such as arthritis.
RESULTS. An estimated 31% of children were affected by chronic conditions. Among these children, highly prevalent conditions included respiratory allergies 9.7 per 100. repeated ear infections 8.3 per 100 and asthma 4.3 per 100. These children can be divided into three groups; 66% with mild conditions that result in little or no bother or activity limitation; 29% with conditions of moderate severity that result in some bother or

limitation of activity, but not both; and 5% with severe conditions that cause frequent bother and limitation of activity. The 5% with severe conditions accounted for 19% of physician contacts and 33% of hospital days related to chronic illness.
CONCLUSIONS. Childhood chronic conditions have highly variable impacts on children's activities and use of health care.

Newacheck PW; Stoddard JJ; McManus M. **Ethnocultural Variations in the Prevalence and Impact of Childhood Chronic Conditions.** Pediatrics, 1993 May, 91(5 Pt 2):1031-9.

Newacheck PW; Stoddard JJ. **Prevalence and Impact of Multiple Childhood Chronic Illnesses.** J Pediatr, 1994 Jan, 124 (1): 40-8.

Abstract: OBJECTIVE: To determine the prevalence and impact of multiple chronic conditions on children's health status and utilization of health services.
DESIGN: Analysis of the 1988 National Health Interview Survey on Child Health.
SETTING: rationally representative sample of the U.S. civilian, non-institutionalized population.
PARTICIPANTS: A total of 17,710 children less than 18 years of age selected in a stratified cluster sampling of U.S. households.
INTERVENTION: None.
RESULTS: We estimated that fewer than 5% of children have multiple (two or more) chronic conditions and that less than 1% of children had three or more such conditions. However, despite this low overall prevalence, some notable features of multiple chronic conditions stand out. Many of the most prevalent condition-pairs were allergy related, and the rates of co-occurrence of these disorders were generally higher than would be predicted on the basis of prevalence rates for the individual conditions. Children with multiple chronic conditions had more mental and physical health problems and used substantially more health services than other children. For example, the prevalence of developmental delay, earning disabilities, and emotional and behavioral problems increased sharply with the number of chronic conditions reported. Notable deterioration in such health status measures as days in bed, school absences. and activity limitation was also observed with increasing numbers of chronic conditions. Similarly, utilization of hospital and physician services increased in tandem with increasing numbers of chronic conditions.
CONCLUSIONS: Children who have multiple conditions of a chronic nature, even if few in number, have increased morbidity across a variety of measures.

Newacheck PW; Stein RE; Walker DK; Gortmaker SL; Kuhlthau K; Perrin JM. **Monitoring and Evaluating Managed Care for Children with Chronic Illnesses and Disabilities.** Pediatrics, 1996 Nov, 98(5):952-8.

Abstract: OBJECTIVE: Children with chronic illnesses and disabilities are increasingly enrolling in managed care arrangements. Yet, the rapid expansion of managed care has unknown consequences for children with chronic conditions and disabilities. As managed care is likely to become the predominant mode of medical practice for children with chronic health problems, information gained from a thorough assessment of existing managed care models could be helpful in indicating adjustments and modifications that could result in improved outcomes for this population. The purpose of this article is to outline a new strategy for collecting needed information on the effects of managed care on children with chronic health problems.
METHODS: We reviewed the literature on the effects of managed care on children with chronic conditions and disabilities. We identified key domains relevant to monitoring and evaluating managed care for this population.
RESULTS: Two research approaches can provide helpful information for assessing the effects of managed care on children with chronic conditions. First, a monitoring strategy could be pursued in which enrollment trends in managed care, enrollee perceptions of access and satisfaction with care, and other general indicators of outcomes would be tracked over time using inexpensive and rapid turnaround data sources. Second, an evaluative strategy could be pursued using experimental or quasiexperimental designs, in which outcomes across a variety of domains for children with chronic conditions in managed care are compared with: (a) outcomes for the same children before enrollment in managed care; or (b) outcomes for similar children remaining in traditional fee-for-service settings. Evaluation and monitoring strategies should focus on outcomes in a number of domains including: (1) access to care; (2) utilization of services; (3) quality of care; (4) satisfaction with care; (5) expenditures for care; (6) health outcomes; and (7) family impact.
CONCLUSION: Assessing outcomes that result from enrollment in managed care for children with chronic health problems presents a formidable challenge. The research strategy outlined in this article presents one approach to meeting that challenge. The monitoring and evaluation strategies described here would require commitment of additional resources on the part of government, private foundations, and/or health plans. Given the paucity of existing information and the stakes for children with chronic conditions and their families, investment of added resources in a comprehensive monitoring and evaluation strategy is essential.

Newacheck PW; Strickland B; Shonkoff JP; Perrin JM; McPherson M; McManus M; Lauver C; Fox H; Arango P. **An epidemiologic profile of children with special health care needs [see comments].** Pediatrics, 1998 Jul, 102(1 Pt 1):117-23.

Abstract: OBJECTIVE: To present an epidemiologic profile of children with special health care needs using a new definition of the population developed by the federal Maternal and Child Health Bureau.
METHODS: We operationalized the new definition using the recently released 1994 National Health Interview Survey on Disability. Estimates are based on 30 032 completed interviews for children <18 years old. The overall response rate was 87%.

RESULTS: Eighteen percent of US children <18 years old in 1994, or 12.6 million children nationally, had a chronic physical, developmental, behavioral, or emotional condition and required health and related services of a type or amount beyond that required by children generally. This estimate includes children with existing special health care needs but excludes the at-risk population. Prevalence was higher for older children, boys, African-Americans, and children from low-income and single-parent households. Children with existing special health care needs had three times as many bed days and school absence days as other children. An estimated 11% of children with existing special health care needs were uninsured, 6% were without a usual source of health care, 18% were reported as dissatisfied with one or more aspects of care received at their usual source of care, and 13% had one or more unmet health needs in the past year.
CONCLUSIONS: A substantial minority of US children were identified as having an existing special health care need using national survey data. Children with existing special health care needs are disproportionately poor and socially disadvantaged. Moreover, many of these children face significant barriers to health care.

Papola P; Alvarez M; Cohen HJ. **Developmental and Service Needs of School-Age Children with Human Immunodeficiency Virus Infection: A Descriptive Study.** Pediatrics, 1994 Dec, 94 (6 Pt 1): 914-8.

Abstract: OBJECTIVE. To describe the developmental functioning and service needs of a group of school-age children with human immunodeficiency virus (HIV) infection. DESIGN. Retrospective data were collected through chart reviews and follow-up telephone calls to primary care givers.
SETTING. A multidisciplinary team provided care at a developmental diagnostic and treatment center.
PATIENTS. Cases were 90 school-age children (ages 5 to 14 years with presumed perinatally acquired HIV infection. RESULTS. Forty-four percent of the 86 children on whom there were diagnoses were functioning in the low average to average range of intelligence. whereas 56% were functioning in the borderline range or lower. Fifty percent of the children demonstrated significant language impairments, with 28% also demonstrating an articulation disorder. Thirty-six of the children (42%) were formally diagnosed as having emotional/behavioral disorders. Eighty-six of the children were in school-based programs and of that group. 74% were in special education classes and receiving related services.
CONCLUSIONS. Most of the children in this study demonstrated deficits in the cognitive and learning areas. although they are clearly functioning better than earlier studies of children with HIV infection would have predicted Their service needs include alternative living arrangements. remedial education. and psychotherapeutic interventions. The children's increasing longevity will place strains on the respective service systems.

Perrin EC; Newacheck P; Pless lB; Drotar D; Gortmaker SL; Leventhal J; et al. **Issues Involved in the Definition and Classification of Chronic Health Conditions.** Pediatrics, 1993 Apr, 91 (4): 787-93.

Abstract: The need for a widely applicable definition of chronic conditions for research, policy, and program development has led to an extensive review of the development of such definitions, the considerations involved in their use, and some recommendations for a new approach. This paper examines some of the methodologic and conceptual issues related to defining and classifying chronic conditions and describes some consequences resulting from decisions made about these issues. While most examples are taken from child health applications, the basic concepts apply to all age groups. The dominant method for identifying and classifying children as having a chronic condition has relied on the presence of an individual health condition of lengthy duration. This condition-specific or "categorical" approach has increasingly seemed neither pragmatically nor conceptually sound. Thus, the development of a "generic" approach, which focuses on elements that are shared by many conditions, children, and families, is recommended. Such a definition might reflect the child's functional status or ongoing use of medical services over a specified time period. In addition, it is suggested that conditions be classified based on the experience of individual children, thus emphasizing the tremendous variability in expression of seemingly similar conditions.

Plaut TF; Howell T; Walsh S; Pastor M; Jones T. **A Systems Approach to Asthma Care.** Managed Care Quarterly, 1996 Summer, 4(3):6-18.

Abstract: This two year asthma intervention focuses on provider education emphasizing early diagnosis of asthma. early use of oral steroids, proper use of inhalation devices, objective monitoring of patient status, and use of daily preventive treatment. Patient education is an integral part of treatment. This approach supports the primary care physician as the provider and coordinator of care by supplying monitoring and treatment devices, books. diaries, home care services, and allergy consultation. It also manifests a systems approach to asthma care in its reliance on a nurse case manager who oversees patient and family support networks.

Protecting and Improving Quality of Care for Children Under Health Care Reform: Workshop Highlights. Committee on Maternal and Child Health Under Health Care Reform. Institute of Medicine, National Research Council, July 1994. [contact: Jane S. Durch, M.A., (202) 334-2069].

This summary from the workshop is not focused on CSHCN, but the discussion of the difficulties involved in monitoring quality services for children under new health systems of care is still very applicable. There is analysis of special needs of children, conceptual and methodological considerations, the levels of assessing quality and developing and enhancing resources for assessing children's care.

Raddish M; Goldmann DA; Kaplan LC; Perrin JM. **The Immunization Status of Children with Spina Bifida.** Am J Dis Child, 1993 Aug, 147(8):849-53.

Abstract: OBJECTIVE-To estimate immunization levels among children with spina bifida and describe factors that may influence immunization completeness.
RESEARCH DESIGN-Cross-sectional survey.
SETTING-Tertiary care referral center.
PATIENTS-One hundred twenty children, from 4 months to 18 years of age, seen in the myelodysplasia clinic of Children's Hospital, Boston, Mass, from February through August 1990. RESULTS-Fifty-eight percent of the children 2 years of age or older and 55% of the children 7 years of age or older had completed the immunization series recommended by the American Academy of Pediatrics. All but one child had an identified primary care provider. Lower immunization levels at 24 months of age occurred in older and in poorer children. Most children (80%) received the first diphtheria and tetanus toxoid and pertussis and oral poliovirus vaccines on time. Immunization delay increased from 20% to 50% through the 18-month diphtheria and tetanus toxoid and pertussis and oral poliovirus vaccines and declined to 24% at school entry.
CONCLUSIONS-Many children with spina bifida are under immunized despite having an identified source of primary care.

Richards JM Jr; Hemstreet MP. **Measures of Life Quality, Role Performance and Functional Status in Asthma Research.** Am J Respir Crit Care Med, 1994 Feb, 149(2 Pt 2):S31-9; discussion S40-3.

Abstract: Recently a consensus has emerged that health care research should address outcomes important to patients, especially quality of life, role performance, and functional status. The assessment of such outcomes is beset by conceptual and methodological difficulties that may be especially problematic for asthma. Nevertheless. several broad conclusions may be drawn about the use of measures of these outcomes in asthma research. Asthma usually is reasonably well controlled if patients are moderately adherent to their recommended regimens. Consequently, the beneficial impacts of interventions are likely to be small, and large samples are required to detect them. Outcome assessment should combine asthma-specific measures with generic measures applicable to a variety of conditions. Generic measures aimed at severely debilitating disease are less appropriate than measures designed for use in the general population. Asthma-specific measures should emphasize the incidence and impact of such symptoms as coughing, wheezing, sputum production, and shortness of breath. Current procedures for computing utility scores and cost-benefit ratios based on them have serious measurement limitations, and use of such scores should be postponed until those limitations are overcome. These assessment issues should be addressed separately for adults and children.

Rosier MJ; Bishop J; Nolan T; Robertson CF; Carlin JB; Phelan PD. **Measurement of Functional Severity of Asthma in Children.** Am J Respir Crit Care Med, 1994 Jun, 149(6):1434-41.

Abstract: The usefulness of surveys for measuring the severity of asthma in school-age children depends on the availability of reliable and valid questionnaires. The aim of this study was to develop a measure of functional seventy of asthma over the previous 12 months for use in population studies and in investigating treatment regimens. Of 10,198 children surveyed, 9,192 (90%) in school years 2, 7, and 10 (mean ages 8, 13, and 16 year) in Melbourne were screened for wheeze. The parents of the 1.267 children with wheeze were interviewed. Symptoms and restriction of activity due to asthma were analyzed using factor analysis and the partial credit version of the item response theory measurement model. The result was a continuous severity scale that was highly consistent with the data and with goodness of fit statistics indicating the severity of 97% of children was well described by the scale. The scale correlated significantly with school absence due to wheeze (r = 0.35), functional impairment during the 2 wk before interview (Functional Status ll-R [FSII-RI, r 0.30), visits to medical care for wheeze (r = 0.22), and amount of medication (r = 0.36). For descriptive purposes, a simple index with four bands of severity was developed from the continuous severity scale: low severity (47% of children with wheeze), moderate (30%), mild (18%), and high (5%). The scale and index facilitate standardized description of the impact of asthma on daily life on the basis of responses to six survey questions.

Saigal S; Szatmari P; Rosenbaum P; Campbell D; King S. **Intellectual and Functional Status at School Entry of Children Who Weighed 1000 Grams or Less at Birth: A Regional Perspective of Births in the 1980s.** J Pediatr, 1990 Mar, 116(3):409-16.

Abstract: The intellectual and functional status of a regional cohort of children who weighed 501 to 1000 gm when born between 1980 and 1982 was evaluated at a mean age of 5 1/2 years by standard psychometric tests. Of 90 long-term survivors (survival rate 49%), 73 children (87%) had the full test battery, 5 children (6%) had other tests (4 were blind), and one child was untestable. Most of the mean scores were within 1 SD of the test norms; the lowest scores were in the McCarthy Motor scale and in the Beery Test of Visual-Motor Integration. Children without neurologic impairments and those with an IQ greater than or equal to 68 (n = 60) had higher overall scores but still performed poorly on the Motor subscale and the Beery test. Children who weighed less than 800 gm at birth (n = 28) were similar to those who weighed greater than 800 gm (n = 50), except in the Memory and Motor subscales, in which they performed significantly less well. At a functional level, determined by the Vineland Adaptive Behavior Scales, two thirds of the children were performing in the adequate range and the remainder in the moderately low to low range. Of the 43 children with no neurosensory impairments and an IQ greater than or equal to 84, 49% were identified (by the Florida Kindergarten Screening Battery) to be at mild to high risk for future learning disabilities. The data from this unselected population provide an unbiased estimate of the prevalence of intellectual and functional problems in children who weighed less than or equal to 1000 gm at birth.

Saigal S; Rosenbaum P; Stoskopf B; Hoult L; Furlong W; Feeny D; et al. **Comprehensive Assessment of the Health Status of Extremely Low Birth Weight Children at Eight Years of Age: Comparison with a Reference Group.** J Pediatr, 1994 Sep, 125 3): 411-7.

Abstract: OBJECTIVE: To apply a multiattribute health status (MAHS) classification system to data available on two cohorts of school-aged children to describe several dimensions of health simultaneously. The MAHS system describes both the type and severity of functional limitations according to seven attributes: sensation, mobility, emotion, cognition, self-care. pain, and fertility (fertility not applicable in this study), with four or five levels of function within each attribute.
DESIGN: The MAHS system was applied retrospectively to clinical and psychometric data collected prospectively at age 8 years. MAHS application was by selection of items from the database and development of computer-assisted algorithms to assign functional levels within each attribute.
SETTING: Geographically defined region in central-west Ontario, Canada. PARTICIPANTS: One hundred fifty-six extremely low birth weight (ELBW) survivors born between 1977 and 1982 (follow-up rate 90%) and 145 reference children matched for age, sex, and socioeconomic status. RESULTS: 14% of ELBW subjects had no functional limitations, 58% had reduced function for one or two attributes, and 28% had at least three affected. The corresponding figures for the reference group were 50%, 48%, and 2% (p 0.0001). The limitations were more severe and complex in the ELBW group. and were notably in cognition (58%), sensation (48%), mobility (21%), and self-care (17%), compared with 28%, 11%, 1%. and 0% for reference children (all p < 0.0001).
CONCLUSIONS: These data indicate that fewer ELBW than reference children were free of functional limitations and a significantly higher proportion had multiple attributes affected. The MAHS classification approach is a useful instrument to compare the health status of different groups and populations, and to monitor changes with time.

Schwalberg, Renee et al and Perrin, JM. **Managed Care and Children with Special Health Care Needs: Strategies for Monitoring the Quality of Care.** Health Systems Research, Inc. March 1997. [contact: Health Systems Research, Inc. (202) 728-9469].

Based on HRSA funded consultation to North Carolina, discusses aspects of strategies for monitoring and assuring provision of high quality services to CSHCN in managed care delivery systems. The approaches offered for use include *prospective* establishment of structural standards, and *retrospective* monitoring of compliance of structural standards and measurement of the *process* and *outcome* of care. Newacheck's seven domains of interest are utilized under *Process*; while the dimensions of health and functional status are covered under *Outcomes*. Examples of efforts to develop monitoring systems are noted. Sample measures are provided for each area. There is also a section dedicated to definition of CSHCN as it relates to population identification and comments on the pros and cons of each approach.

Slade GD; Spencer AJ. **Development and Evaluation of the Oral Health Impact Profile.** Community Dent Health, 1994 Mar, 11(1):3-11.

Abstract: The capacity of dental clinicians and researchers to assess oral health and to advocate for dental care has been hampered by limitations in measurements of the levels of dysfunction, discomfort and disability associated with oral disorders. The purpose of this research was to develop and test the Oral Health Impact Profile (OHIP), a scaled index of the social impact of oral disorders which draws on a theoretical hierarchy of oral health outcomes. Forty nine unique statements describing the consequences of oral disorders were initially derived from 535 statements obtained in interviews with 64 dental patients. The relative importance of statements within each of seven conceptual subscales was assessed by 328 persons using Thurstone's method of paired comparisons The consistency of their judgments was confirmed (Kendall's mu. $P < 0.05$). The reliability of the instrument was evaluated in a cohort of 122 persons aged 60 years and over. Internal reliability of six subscales was high (Cronbach's alpha, 0.70-0.83) and test-retest reliability (intraclass correlation coefficient. 0.42-0.77) demonstrated stability. Validity was examined using longitudinal data from the 60 years and over cohort where the OHIP's capacity to detect previously observed associations with perceived need for a dental visit (ANOVA, $p < 0.05$ in five subscales) provided evidence of its construct validity. The Oral Health Impact Profile offers a reliable and valid instrument for detailed measurement of the social impact of oral disorders and has potential benefits for clinical decision-making and research.

Starfield B; Bergner M; Ensminger M; Riley A; Ryan S; Green B; et al. **Adolescent Health Status Measurement: Development of the Child Health and Illness Profile.** Pediatrics, 1993 Feb, 91 (2): 430-5.

Abstract: This report describes the early stages in the development and testing of an instrument, known as the CHIP (Child Health and Illness Profile), for assessing the health of individuals aged 11 through 17. The purpose of the instrument is to assess health in epidemiological surveys, to determine the existence of systematic differences in health in subpopulations (including the socioeconomically disadvantaged), and to provide a basis for assessing the impact of changes in health services or health policies. An instrument consisting of six domains with 25 subdomains was developed based on the literature, the involvement of focus groups and expert panels, and pretesting in four groups of teenagers known to differ in their health. The results of work with panels of experts suggest that the instrument has content validity. Most domains and subdomains had acceptable reliability as measured by alpha coefficients. Differences in the scores of individuals in the four groups were in the predicted directions, suggesting that the instrument also has construct validity. Additional research is under way to establish other aspects of validity as well as reliability in school populations of adolescents as well as specific clinical settings.

Stein RE; Bauman LJ; Westbrook LE; Coupey SM; Ireys HT. **Framework for identifying Children Who have Chronic Conditions: The Case for a New Definition.** J Pediatr, 1993 Mar, 122(3):342-7.

Abstract: Efforts to identify children with ongoing health conditions generally rely on lists of diagnoses. However, there has been a growing trend to use a non-categorical, or generic, approach in which such children are identified by the consequences of their condition. Recent legislation and the Supreme Court decision in Sullivan vs. Zebley adopt this broader concept and mandate that a noncategorical approach be used in determining eligibility for services and benefits. Traditional condition lists are less desirable because (1) every disorder to which children are subject cannot be included, (2) diagnoses may be applied inconsistently by clinicians and across settings, (3) condition labels alone do not convey the extent of morbidity for individuals, (4) there is a bias toward identifying only those children who have access to the medical care system, and (5) there is often a gap between emergence of symptoms or consequences and diagnosis. We developed a noncategorical framework for identifying children with ongoing health conditions that responds to the federal mandate and uses consequences of disorders, rather than diagnostic labels. It can be applied to meet the objectives of services, research, policy, reimbursement, or program eligibility; is consistent across diagnoses; is descriptive of the impact of morbidity: is adaptable to meet specific purposes; and can be modified by imposing different severity levels. Our screening tool will soon be available for practical use.

Stein RE; Jessop DJ. **A Noncategorical Approach to Chronic Childhood Illness.** Public Health Rep, 1982 July-August, 97 (4): 354-362.

Stein RE; Jessop DJ. **Functional Status II(R). A Measure of Child Health Status** [published erratum appears in Med Care 1991 May;29(5):following 489]. Med Care, 1990 Nov, 28(11):1041-55.

Abstract: Few measures are available to assess the health status of the growing numbers of children who now survive long-term with chronic physical disorders. A Functional Status Measure. FS I, that had considerable promise for measuring individual child health status and characterizing populations was developed in 1978. This paper describes a revised version of that measure. Data were collected using a new sample of 732 children (aged 0 to 16 years) with and without chronic physical conditions in order to assess the psychometric properties of the new instrument. The FS 11(R) has both a long (43-item) and a short (14-item) version. The long version has a total score derived from a one factor solution and a two factor solution consisting of general health and stage specific factors for each age group. The 14-item version of FS 11(R) uses a common core of items across the entire age span. Internal consistency estimates (alphas) for the factor-based and 14-item versions are all greater than 0.80. At each age, long and short versions behave similarly in a wide range of tests of discriminant, construct, and content validity-strong support that they constitute a common measure. The FS II (R) has excellent psychometric properties and provides concise measures of health status of children spanning the entire childhood age range from 0 to 16 years. It has particular strengths for the measurement of health status of children with chronic physical conditions who are not disabled.

Verbrugge LM; Reoma JM; Gruber-Baldini AL. **Short-term Dynamics of Disability and Well-Being.** J Health Soc Behav, 1994 Jun, 35 (2): 97-117.

Abstract: For persons with serious chronic morbidity, disability is a very dynamic process as morbidity advances or retreats, and as interventions succeed or fail. This article studies trajectories or function (cognitive, emotional, social, physical, and global well-being) over a year for 165 persons whose chronic morbidity prompted a hospital stay. Changes in functioning from hospital admission to one year post-discharges are analyzed; functional status was measured nine times in that period. Both intra-individual and inter-individual changes are studied by means of a combination of visual and statistical techniques. (1) Individuals: After the hospital stay, functions typically improve in the first month, stabilize for several months, then begin to fluctuate and worsen. Individual trajectories are very changeful over a year, yet there is short-run continuity (from one measurement point to the next). (2) Groups: Persons with fracture of hip show the most striking and protracted improvements over the year, compared to persons with other conditions. Chances of functional recovery are the highest for persons with just one chronic condition; those chances decline as comorbidity increases. Having many social contacts is associated with initial high function. The analyses point to the scientific value of short re-measurement intervals for persons with severe or multiple morbidity.

Vivier PM; Bernier JA; Starfield B. **Current Approaches to Measuring Health Outcomes in Pediatric Research.** Curr Opin Pediatr, 1994 Oct, 6 (5): 530-7.

Abstract: Because improving health is the ultimate goal of a health care system, the measurement of health outcomes in research is a logical and important goal for the evaluation of the impact of health services. Although health can be defined in various ways, here we employ a conceptualization that has several domains including longevity, disease, comfort, perceived well being, activity, achievement, and resilience. Given that health is such a broad concept, the difficult task for outcomes research is to provide the means of measuring it. As this brief summary of current work indicates, a number of approaches has been used in recent pediatric studies. Most focus on a small subset of health concerns. However, some studies have attempted to broaden the assessment of health outcomes either by using multiple health measures or developing multidimensional instruments for measuring health. Care must be taken in evaluating the usefulness of any of the instruments until sufficient data are obtained as to their reliability and validity. Further work in this area is needed, particularly with regards to multidimensional approaches, which are beginning to provide a more sensitive and comprehensive means of assessing the impact of health services.

Walker DK; Stein RE; Perrin EC; Jessop DJ. **Assessing Psychosocial Adjustment of Children with Chronic Illnesses: A Review of the Technical Properties of PARS III.** J Dev Behav Pediatr, 1990 Jun, 11 (3): 116-21

Abstract: Four groups of investigators in the Research Consortium on Chronic Illness in Childhood have used the Personal Adjustment and Role Skills Scale (PARS) Ill to assess the psychosocial adjustment of children with chronic physical illnesses and no mental impairment. The PARS Ill consists of 28 items that measure psychosocial

functioning in six areas: peer relations, dependency, hostility, productivity anxiety-depression, and withdrawal. Analyses of the measures reliability and validity, using a total combined sample of 450 school-age children (ages 5-18 years) with a variety of chronic illnesses and three comparison samples of healthy children, provide evidence that the PARS Ill can be used successfully to assess psychosocial adjustment of children with chronic illnesses and no cognitive impairments.

Walker LS; Greene JW. **The Functional Disability inventory: Measuring a Neglected Dimension of Child Health Status.** J Pediatr Psychol, 1991 Feb, 16(1):39-58.

Abstract: Described the development and validation of the Functional Disability Inventory (FDI) for school-age children and adolescents. Results provide support for construct, concurrent, and predictive validity. FDI scores also demonstrated stability over a 3-month period in patients with a chronic condition, and the instrument was sensitive to changes in patient status subsequent to medical treatment. There was some evidence that gender played a role in disability, particularly in adolescence. The instrument may be used (a) in studying individual differences in pediatric disability, (b) in examining the relation of disability to psychosocial functioning in the child and other family members, or c) as an outcome measure in assessing the impact of interventions on patient functioning.

Wise PH; Lowe JA. **Noise or Fugue: Seeking the Logic of Child Health Indicators.** Ment Retard, 1992 Dec, 30(6):323-9.

Abstract: Despite improvements in many child health indicators, several important ones, including the racial disparity in infant mortality, have not improved in recent years. A focus on dramatic but rare risk factors has distracted attention away from the primary determinants of these indicators. An analytic model to assess these indicators identifies three interacting determinates: (a) social well-being, (b) our technical capacity to reduce the risk that low social status conveys, and c) our performance in providing access to this technical capacity. These three determinants can move independently and can, therefore, mask important trends in social status and the impact of programs and policies.

Wright FV; Law M; Crombie V; Goldsmith CH; Dent P. **Development of a Self-Report Functional Status Index for Juvenile Rheumatoid Arthritis.** J Rheumatol, 1994 Mar, 21(3):536-44.

Abstract: OBJECTIVE. There are few functional indices available for juvenile rheumatoid arthritis (JRA). Our goal was to develop a reliable, valid and responsive self-report physical functional status index for individuals with JRA, ages 8-18 years. METHODS. Activity (item) generation by interview of children, parents, teachers, clinicians yielded 280 items. Categories of self-care, domestic, mobility, school, and extracurricular were chosen by clinicians. Twelve clinicians sorted the items into categories. Item reduction was by these clinicians who rated items for common problems in JRA, importance of performance, and potential for change.

RESULTS. Ninety-nine items were retained. A separate section was designed for respondents to identify their priority activities. Content validity of the questionnaire, the Juvenile Arthritis Self-Report Index (JASI), was evaluated by 17 different clinicians. One item was added and none eliminated; all rated the index as a credible functional measure for JRA.
CONCLUSION. The JASI has been rigorously developed, and has demonstrated content validity. Index validation is being completed.

Ziebland S; Fitzpatrick R; Jenkinson C. **Tacit Models of Disability Underlying Health Status Instruments.** Soc Sci Med, 1993 Jul, 37 (1): 69-75.

Abstract: In recent years much attention has been paid to the development of measures of subjective health status yet, although statistical criteria of reliability and validity have been quite rigorously tested, there has been little consideration of the different theories of disability which underlie the design. The sociology of disability may illuminate such Tacit theories. It is suggested that the development of health status questionnaires has not been one of simple rational accumulation in response to methodological advances. Through an examination of the content of health assessment questionnaires, four distinct models of disability are identified. These are shown to influence not only the focus of the content and phrasing of the questions but also, crucially, the way that they perform and how responsive they are to change. The models (the functional. subjective distress, comparative and dependence) are illustrated and discussed in terms related to research design.

Zucconi SL; Carson CA. **CDC's Consensus Set of Health Status Indicators: Monitoring and Prioritization by State Health Departments.** Am J Public Health, 1994 Oct, 84(10):1644-6.

Abstract: A survey assessed the extent to which state health departments monitor and prioritize the Centers for Disease Control and Prevention's consensus set of health status indicators. A response rate of 100% was obtained. Although mortality indicators are often monitored, only 75.5% of the states monitor work-related injury deaths. Most states monitor the incidence of acquired immunodeficiency syndrome, measles, tuberculosis, and syphilis. Low birthweight, births to adolescents, and lack of prenatal care are monitored in nearly all states and are considered high-priority problems. Only 46.9% of states are monitoring poor air quality, and only 58.8% are monitoring childhood poverty. Survey results suggest a need for standardized assessment of indicators for policy development and program planning.

OTHER

These resources include references for maternal and child health and CSHCN data and related articles.

1. National Center for Education in Maternal and Child Health, Georgetown University. Specific areas of interest can be researched, and there is a comprehensive NMCHC Publications Catalog which includes material related to CSHCN. [contact: Pamela W. Coughlan (703) 524-7802].

2. Division of Services for Children with Special Health Care Needs, Maternal and Child Health Bureau; Public Health Service, Health Resources and Services Administration, Rockville, MD 20857 (Merle McPherson, M.D., Director). Resources include August 3, 1995 letter to Title V CSHCN State Directors regarding federal definition for CSHCN.

3. **Children and Youth with Disabilities in a Changing Health Care Environment.** National Center for Youth and Disabilities. University of Minnesota, Division of General Pediatrics and Adolescent Health. July 1996. [contact: Elizabeth Latts, M.S.W., (612) 626-2401].

   This annotated bibliography addresses a variety of topics, with a separate section on Disability and Health Care Reform.

4. Wehr, E. **Medicaid Contracting for Managed Care Services for Children with Special Health Care Needs.** Center for Health Policy Research, The George Washington University Medical Center: 1-7.

   This and other related articles address the importance of including appropriate language within state Medicaid contracts to ensure services to CSHCN are delivered as part of a measurable quality system.

5. State Title V Programs

   Many of the state Title V staffs have made significant efforts to look at both definitions of CSHCN and quality outcome and monitoring tools. Some of the tools and data sources referenced in this report are utilized. The proposed state systems are designed specifically for applicability within the particular state, but many of the general approaches and examples of specific structural and process indicators may be useful to other states and counties. The CSHCN plans in progress related to Title V block grant applications can be especially instructive. Plans from Arizona and Washington as well as other states may be useful. Similar quality of care

issues are being addressed by the Boston-based Research Consortium on Chronic Illness in Childhood.

WEB SITES

The Internet is becoming a major way of accessing all kinds of information, including materials relevant to quality assurance for CSHCN. Many of the available web sites include information and materials related to some of the above areas and combinations of those areas. Also, many of the web sites from individual agencies noted above (e.g., NCQA, CDC, AHCPR, etc.) have a variety of information which includes quality assurance for CSHCN. Some of the sites noted below are either new or lesser known resources for this type of information. All sites are accessed via **http://www** unless otherwise noted.

1. ichp.ufl.edu/MCH-NetLink/listings.html

This site is organized and managed by the Institute for Child Health Policy (ICHP) in Florida. It is the major resource for research and application information on managed care and CSHCN. Topics are organized according to the MCHB, Division of Children with Special Health Care Needs work groups on defining and identifying CSHCN, pediatric capacity development, pediatric provider and service requirements, family collaboration and participation, community based service integration, cost and utilization issues and quality assurance and improvement. There is also a gopher connection (gopher://mchnet.ichp.ufl.edu) that covers many related areas such as Family Voices, Genetic Services and SSI).

2. os.dhhs.gov/hrsa/mchb/

Maternal and Child Health Bureau web site. One can access ICHP as well as other CSHCN related areas.

3. CSHCN-L@LISTS.UFL.EDU

This is a list serve run by ICHP and contains both scientifically based information and consumer discourse regarding a variety of CSHCN issues. Contact Deanna Dearholt at DRD@ICHP.EDU.

4. irsc.org/

Internet Resources for Special Children (IRSC) provides a wide variety of information regarding CSHCN, including issues related to managed health care systems and the quality of special needs services. Hyperlinks to related areas are especially useful.

5. igc.apc.org/NADDC/qi.txt

The National Association of Developmental Disabilities Councils (NADDC) and the Human Services Research Institute (HSRI) have developed quality indicators aimed at work and operation of the Councils. "Twelve areas of principle" are included with each containing 4-14 specific quality indicators. The focus is on Council development and performance, but can be considered in the context of quality health assurance in the community. [contact: (202) 347-1234]

6. med.stanford.edu/touchstone/index.html

This site is based on a "volunteer organization that provides emotional and practical support services for children with chronic or life-threatening illnesses." Although this site is mostly focused on parent support, situations related to health care system quality services are likely to become more pertinent. There are detailed hyperlinks to both pediatric e-mail discussion groups and pediatric health resource organizations. This includes contacts to major university medical centers and detailed references listed alphabetically.

7. *(no www.)* hiru.hirunet.mcmaster.ca/ebm/userguid/10_map.htm

This site is based on work from the Evidence-Based Health Informatics Project at McMaster University. It provides an "outcome analysis map" as a guide for development of a health outcomes evaluation system. In addition to a schematic of the process, there is detailed analysis of the issue of outcome measures. Patient scenarios are utilized to provide examples of the clinical significance and implication of using measures of health status. Cautions are also given regarding use and interpretation of the potential options. Most of the attention is on adult medicine, but the discussion can be revised and applied to children and CSHCN.

8. *(no www.)* utsph.sph.uth.tmc.edu/www/utsph/CS/framepor.htm

This site is prepared by Carl H. Slater, M.D. from the Health Services Organization, University of Texas School of Public Health. It provides a visual framework for outcomes research with columns of analysis levels consisting of *community, system, institution and patient*. These levels are divided into rows of *approach, example, data*

sources, outcome measures, risk adjustment and study designs. At the end, there are listed “typical outcomes research questions by level of analysis. References are given for approach and examples. This is a general approach and not specific for either children or CSHCN; but it is a helpful way to look at all the components of the outcomes issue.

SECTION II: SUMMARY OF CURRENTLY AVAILABLE HEALTH STATUS ASSESSMENT TOOLS AND REFERENCE LITERATURE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN)

This section will provide a summary of currently available health status assessment tools and reference literature that can serve as resources for state and local health jurisdictions in developing quality assurance (QA) measures for Children with Special Health Care Needs (CSHCN) in managed care settings. It is directed to an audience which includes health care providers, state child special health care directors, families and community agencies.

BACKGROUND

The first section of this report was completed in 1996 and since that time there have been additional general reviews and guidance regarding the issue of health care reform, CSHCN and quality assurance (Brook, et al, 1996; Newacheck, 1996.) Most suggested measures for CSHCN relate to program structure, process or health outcome (Schwalberg, 1997). These measures either assess the quality of care for children with specific conditions (condition-specific approach) (NACHRI, 1996) or the impact of care on the functional status of CSHCN and their families (the functional assessment approach) (NE SERVE, in process). Condition/diagnosis-specific or functional measures have been developed which can be used to assess the status of groups such as enrollees of managed care organizations. Other tools are more appropriately used to clinically evaluate individual children or groups of CSHCN in the community. An updated review of the literature in this area reveals the following concerns regarding the definition of CSHCN and quality assurance:

DEFINITIONS

There is no standard definition of who is included in the population of children with special health care needs. This lack of consensus must be addressed to determine which children with special needs will be considered in the distribution of coverage and service benefits as well as the population to be monitored for quality of care. Three alternative approaches that have been raised as part of a national dialogue on the development of a definition for CHSCN are:

1. Condition-Specific vs. Functional

   The condition-specific approach has been traditionally used in both public health and clinical settings to define this population. The functional approach may be a more accurate reflection of the severity of the disability, the service needs and related costs for an individual. There are pros and cons to each approach and various authors have attempted to develop criteria for selection and make recommendations on methodology (Newacheck, 1997; Miller, 9/96; Stein, 1993).

2. Federal vs. State vs. Program Use

   There are major discrepancies among the definitions used at the federal, state and local levels. The current federal definition is very broad due to political pressures to assure access to public dollars to cover services for as many children with special needs as possible. States with limited resources generally have chosen to adopt considerably narrower and more condition-specific definitions. In many states, meeting the needs of CSHCN of different types (e.g. physical disabilities, cognitive, learning, emotional, etc.) is the responsibility of different state and/or local programs depending on the specific condition (e.g. physical/medical, developmental, education related, mental health, etc.). Each of these agencies uses a different definition to define eligibility. Public agencies generally use condition-specific definitions. Consideration of each child's functional status is usually addressed only secondarily within the context of a specific condition.

3. Public Health Surveillance vs. Health Care System Monitoring

   It is part of the obligation of public health agencies (national, state, and local) to evaluate the population for which they are responsible in order to assess the health service needs of the population, to assure adequate provision of high quality services, and to assure the coordination of those services. Public health agencies therefore have a need to take a broad and more inclusive view which is not program specific. It is also in the public interest to ensure that health care services provided within both the general and specific health care systems are of quality and based on appropriate standards (e.g., family-centered, adequate benefits, access to care, etc.). There is also an increasing interest to facilitate public comparison of health care delivery systems in order to monitor quality of care delivered and to promote public access to information to facilitate choices among plans.

Before implementing a uniform set of health status quality assessment measures, it will be necessary to resolve the above issues. Decisions must be made as to which definition for CSHCN will be used by each of the constituencies mentioned above. Ideally, there should be consistency across levels of government organizations for both definitions and quality assurance (QA) activities.

SELECTION OF QUALITY ASSURANCE MEASURES

In reviewing current suggestions for quality assurance measures, it is important to consider the following issues:

- Whether the measures need to be applicable across all models and sectors
- Many experts believe that the indicators used for public health surveillance should be consistent with the performance measures used by health plans for their enrollees. This will allow comparisons of the relative health status of those served by the plan with the general population of CSHCN within the given community.
- Whether to include a measure that addresses the proportion of CSHCN served by a particular plan in identified geographical locations to guarantee that there is an equitable distribution of these children across plans and to allow better inter-plan comparison.
- Whether these measures should be based on specific clinical conditions or on the child's functional level
- Whether a measure meets the minimal criteria of being valid and reliable, is subject to health plan intervention and can be measured with available data
- Whether the set of measures includes an assessment of the following three domains:

    1. STRUCTURAL: the measure is based on a standard of care or service expected to be part of ("built into") the public or managed care delivery system. For example, a plan may require that all primary care health care providers for children under 14 years of age be board certified pediatricians. It is assumed, based on clinical experience and/or research, that fulfillment of a given structural indicator is necessary or at least directly related to a positive health outcome for the individual(s).

    2. PROCESS: the measure is based on a process that is required to be followed as part of caring for CSHCN. For example, health care providers will provide AAP-TIPP injury prevention counseling and brochures appropriate for age at each well and sick child examination. Again, it is assumed, based on clinical experience and/or research, that fulfillment of a given process indicator is necessary or at least directly related to a positive health outcome for the individual(s).

    3. HEALTH STATUS OR OUTCOME: the measure is based on program service actions directed at specific morbidity or mortality concerns to produce improved outcomes. For example, a decrease in infant mortality may be indicative of the effectiveness of the managed care plan's program. Analysis should be conducted to clarify cause and effect. The decrease may be related to a Back-to-Sleep program which decreased SIDS deaths, a home

neonatal follow up program which decreased deaths related to child abuse, an intensive immunization program which successfully prevented deaths from acute infectious diseases, or some other cause(s) of death which may or may not be related to managed care activities.

The Federal Title V Block Grant application for 1997-8 contains specific guidance for States to classify services and activities under the categories of Infrastructure, Population Based, Enabling, or Direct Service and then to report on performance measures. Five of the eighteen required performance measures address issues specific to CSHCN. Additional performance measures can also be selected. A quality assessment measure of structure will most likely apply to a service or activity in the Infrastructure category. Process measures may apply to all levels, and health status or outcome measures may be developed for Population Based, Enabling or Direct Services.

Newacheck (1996) has proposed an approach to development of quality measures which includes seven key domains (access to care, utilization of services, quality of care, satisfaction with care, expenditures for care, health outcomes and family impact). Agencies may want to consider this approach as well.

PRESENTATION OF ARTICLES AND TOOLS

Most reference articles and quality assessment tools focus on a selected domain of interest, or present a framework for consideration of the issue of CSHCN in general, or specifically for CSHCN/quality assurance. In many of the approaches, there is attention to more than one of many different domains and there is considerable overlap in coverage of measures within the domains.

Quality assessment tool resources with annotations are presented and are partially based on comments from the recent Health Systems Research, Inc. report (Schwalberg, 1997) and the compendium on *Managed Care and Children with Special Health Care Needs* from the American Academy of Pediatrics (September, 1997). Table I lists the quality assessment tools either in current use or proposed for use. Tools have been categorized into content areas although most of the quality assessment systems in the table have overlapping purposes.

ANNOTATED QUALITY ASSURANCE TOOL RESOURCE LIST

1. **Practice Parameters of the American Academy of Pediatrics: A compilation of Evidence-Based Guidelines for Pediatric Practice.** American Academy of Pediatrics, 1997.

   Practice parameters are being developed by a variety of groups in order to help ensure quality ("evidence-based") services to CSHCN. The American Academy of Pediatrics (AAP) follows a thorough process aimed at providing scientific-based decision-making tools for managing common pediatric problems including asthma, febrile seizures, and otitis media with effusion. The practice parameters "are not intended as an exclusive course of treatment or as standards of care."

2. **Ambulatory Care Quality Improvement Plan (ACQIP).** American Academy of Pediatrics, 1996. (contact: AAP 800/433-9016; Division of Quality Care)

   In order to compare their office practices to their colleagues, physicians may utilize national scores and AAP recommended practices in areas of practice management, clinical management and patient satisfaction measures. Areas of focus for CSHCN include asthma management, ear infections and vision and hearing screening.

3. **Consumer Assessments of Health Plans Study (CAHPS).** Agency for Health Care Policy and Research. August 1996. [contact: Christine Crofton (301) 594-1349].

   As stated in the background of the draft survey, the "overall goal of CAHPS is to provide an integrated set of carefully tested and standardized survey questionnaires and accompanying report formats that can be used to collect and report meaningful and reliable information from health plan enrollees about their experiences." Areas covered include enrollment/payment, perceived quality of health care (access, preventive care, communication/interaction, continuity and coordination, global evaluation), perceived quality of health plan, utilization, health status, and demographics. The individual functional evaluations section is minimal and there is no focus on CSHCN.

4. Radkiff, LS. **The CES-D Scale: A Self-report Depression Scale for Research in the General Population.** Applied Psychological Measurement 1 (1977); 385-401.

   This tool uses a self-report format to assess the impact of parental mental health on the growth, development and health status of their children. Parents answer 20 items related to specific types and frequency of depressive symptoms. This tool is more specific to parental mental health needs than the SF-36.

5. Landgraff JM; Abetz L; Ware JE. **Child Health Questionnaire (CHQ): A User's Manual.** Boston: The Health Institute, New England Medical Center, in press.

   The CHQ is based on the long standing Medical Outcome Study SF-36 Health Survey and measures health concepts such as general health perceptions, mental health, self esteem and effects of the child's condition on the household. There are versions of 50 and 28 items with different forms geared to older children (10+) or filled out by parents for children 5-10 years. A similar form for children 2 months - 5 years is being developed. Samples may be obtained directly from the Institute.

6. **Quality Compass.** National Committee for Quality Assurance (1996). [contact: Anne Kail (202) 955-5196].

   Public reports, printed and CD-ROM, based on accredited national and regional information and data from HEDIS; establishes "benchmarks" for comparison of quality in HMOs to standards and among plans. NCQA is establishing an electronic submission and validation tool to minimize errors in submitted data. Reports will also contain descriptive information about each participating plan and guidelines for interpreting the information. Selected benchmarks will be made available on the Internet at NCQA (http://www.ncqa.org). Quality measures for CSHCN will still be scarce, but the system establishes a methodology for reporting indicator results. Comparisons among programs should be done with appropriate caution.

7. **Computerized Needs-oriented Quality Measurement Evaluation System (CONQUEST) An Overview**. Center for Quality of Care Research and Education, Harvard University School of Public Health. February 1996 [contact: AHCPR Clearinghouse (800/358-9295) - Publication No. 96-N009].

   This tool was developed with AHCPR funding as a scheme for collecting and evaluating clinical performance measures. There are two interlocking databases (measure database and condition database) that are linked through codes for clinical conditions and their associated services, co-morbidities, complications and

risk factors. Operationalizing through Microsoft Access allows comparison and evaluation of clinical performance measures. Related papers have been published by AHCPR addressing using clinical practice guidelines to evaluate quality of care and choosing clinical performance measures for quality improvements via the CONQUEST typology.

8. Epstein SG; Taylor AB; Halberg AS; Gardner JD; Walker DK; Crocker A. **Enhancing Quality: Standards and Indicators of Quality Care for Children with Special Health Care Needs.** Boston: New England SERVE, 1989. [contact: Susan G. Epstein, M.S.W., (617) 574-9493].

   The aim is mainly to measure and monitor quality care in any type of health care system based on structural standards. The focus is on the process of delivering family-centered care. A broad functional definition is used across the five domains of individualized services, health care professional and team characteristics, health care agency or facility responsibilities, state health department responsibilities and guidelines for community and societal supports. The indicators are not operationalized and data sources are not identified.

9. **Ensuring Quality: Monitoring the Impact of Managed Care and Health Care Reform on Children with Special Health Care Needs and Their Families**. New England SERVE, 1997 (in process). [contact: Susan G. Epstein, M.S.W. (617) 974- 9593].

   The goal is “to integrate a specialized set of quality measures for CSHCN into existing program and statewide data collection and quality measurement efforts in both public and private sectors” (New England SERVE, October 1996). The process is based on interviews of families, providers, managed care organizations and Title V program staff. The process includes utilization of a task force comprised of appropriate representatives from these sectors. Pilot testing will continue in late 1997, including evaluation of the QuICCC functional assessment tool for individual children and families. Other areas to be addressed include primary care, care coordination, pediatric specialty care, mental health services, emergency and inpatient care, related therapies and services, medical supplies and equipment and plan management and administration.

10. Family Health Outcomes Project (FHOP). [Contact Nicole Cosand: (415) 476-5283].

    Software packages related to data collection, reporting and analysis have been developed by FHOP and are available via public domain. The software allows usage of vital statistics (Epi BC) and hospital discharge data (Epi HOSP) that can be utilized for local needs assessment and program planning.

11. Functional Outcomes Project. American Academy of Pediatrics. Summer 1997. [contact: Lynn Olson, Ph.D., 847-981-7631].

    The AAP began this project in 1992 to develop valid and reliable measurement tools to assess the impact of disease and medical treatment in children and families. The focus is on condition-specific health status measures, and covers areas such as activity, physical (pain and symptoms), emotional and social functioning. Impact on both the child and family are assessed. Health care utilization is also identified. Current efforts are directed at asthma, head injury, otitis media and juvenile rheumatoid arthritis.

12. Oliva G; Milder T; Greene JD; Cosand NL. **Selecting Indicators for Performance Monitoring and Needs Assessment for Health Plans and Health Care Providers.** Family Health Outcomes Project, University of California, San Francisco. November 1997. [contact: Nicole Cosand (415) 476-5283].

    Health outcome and process indicators related to the maternal and child health population are categorized by infants, children, adolescents and women of childbearing age. Definitions, numerators, denominators and data resources are provided in detail and compared with HEDIS 3.0 and Healthy People 2000. Data templates have also been developed to assist counties and states to operationalize the indicators utilizing specific data applied to Excel formats. There are no indicators specific to CSHCN but some of the generic child health measures may be applied.

13. Walker LS; Greene JW. **The Functional Disability Inventory: Measuring a Neglected Dimension of Child Health Status.** Journal of Pediatric Psychology, 16/1, (1991), p.39-58.

    This instrument is aimed at school-age children and adolescents and has been validated. Authors suggest use for studying individual differences in pediatric disability, examining the relation of disability to psychosocial functioning in the child and other family members, and as an outcome measure in assessing the impact of interventions on patient functioning.

14. Stein REK; Jessop DJ. **Functional Status II®: A Measure of Child Health Status.** Medical Care 28/11, 1990. P. 1041-55.

    This tool focuses mainly on a child's level of dysfunction, regardless of the relationship to acute or chronic illnesses. For CSHCN, FS II helps identify the impact of illness on the usual daily activities of the child. Problems are first identified according to their severity and then related to degree of relationship to a health problem. There are long and short versions, each of which can be applied to children of all ages. There is question about it's usefulness for measuring health plan performance indicators; but it is a valid and useful instrument to assess individual children's level of function. As noted by Stein (1997), it does not differentiate children who need compensatory assistance from those with normal function due to compensatory mechanisms.

15. Schuster M. **Measuring and Monitoring Quality of Care for Children with Special Health Care Needs Under Managed Care Arrangements; The Global Quality Assessment Tool**. Paper presented to AHCPR conference on CSHCN; September 1997. [contact: Mark Schuster, MD, Ph.D., UCLA].

    This scientifically based tool is in development and will address a wide variety of pediatric clinical conditions, some of which relate to CSHCN. Responses will allow composite scoring for chronic conditions, a review of preventive, acute and chronic needs, a comparison of pediatric versus adult subspecialists and additional related indicators. Literature review, expert panels, pilot testing in managed care organizations and laptop computer software development and revision will result in final submission of the tool to HCFA.

16. National Committee for Quality Assurance. **HEDIS 3.0 Draft.** Washington, DC: National committee on Quality Assurance; July 1996.

    The focus is on self reporting by health care plans based on an agreed upon set of indicators, but few measures are provided for children, and even fewer for CSHCN. However, some of the existing indicators may be utilized and applied to the subpopulation of CSHCN. It has been recommended to apply some primary care measures (e.g., immunization) separately to CSHCN. Others (Monahan, et al., 1996) have explored using HEDIS as a base for developing more specific measures for CSHCN. NCQA is also investigating the use of standardized performance measures with a Report Card Pilot Project; but asthma is the only chronic disease of childhood which is being tested. Another potentially useful approach being developed by NCQA is an electronic data base on health plan quality (see COMPASS below). Indicators of quality of care, accreditation status and consumer satisfaction information will be available to a wide audience. Measures of chronic diseases are also being explored, but asthma is again the only childhood illness being considered.

17. **Pediatric Excellence in Health Delivery Systems.** National Association of Children's Hospital and Related Institutions (NACHRI). July 1996. [contact: Laura Gerel, (703) 684-1355].

    This tool presents mostly structural and process standards for CSHCN across the areas of primary care, acute care and chronic care. It covers components related to screening, child/family education, prevention, access, comprehensiveness, coordination and continuity and accountability and responsibility. An additional system-wide standard includes components of education and training, quality assurance, community interface and health information linkage. Data resources are not identified and the measures are not operationalized; but the purpose of the document is mainly to establish a standard of operation of a pediatric network of services. A summary chart is helpful.

18. United States Department of Health and Human Services. **1994 National Health Interview Survey on Disability, Phase 1. CD-ROM Series 10, No.8.** Centers for Disease Control, National Center for Health Statistics, Hyattsville, MD: 1996.

    This tool has been used extensively by Newacheck and others to estimate the numbers and types of children with disabilities in the United States and individual states and to gauge the extent of limitations in function. The questionnaire is quite detailed, but the numbers surveyed in some areas are small. There is a plan to increase the focus on CSHCN in future surveys.

19. Haley HM; Coster WJ; Ludlow LH. **Pediatric Evaluation of Disability Inventory (PEDI). Development, Standardization, and Administration Manual.** Boston: PEDI Research Group, New England Medical Center Hospitals, 1992.

    This tool includes both disability and function scales for children age 6 mo.-7.5 years (or equivalent functional age). Assessment covers areas of child ability, caregiving required, equipment needed, and function related to mobility, self-care and social skills. It takes longer to administer than the WeeFIM.

20. **Quality Assurance Reform Initiative (QARI): Experience in Medicaid Managed Care. National Academy for State Health Policy.** December 1994. [contact: Greg Scott (410) 966-0763].

    This collaborative effort began in 1991 among HCFA, states, the National Academy for State Health Policy, the managed care industry, beneficiary advocates and others. The purposes of QARI are to improve the consistency of oversight of Medicaid managed care quality across states and to assist states in updating and strengthening their quality assurance systems. The guidelines and guide are directed to Medicaid state agencies and focus on clinical measures of performance. Measures related to access and consumer satisfaction will also be developed. HEDIS responses will be coordinated with Medicare, accreditation and other standards. Pilot testing has been conducted in three states and a new revision is in process.

21. Monahan C; Harders-Hanahan R; Maloney M; Song J. **Quality Community Managed Care: A Guide for Quality Assurance Measures for Children with Special Health Care Needs, Includes Pertinent Measures from Medicaid HEDIS.** Chicago: University of Illinois at Chicago, January 1997. [contact: Colleen Monahan: (312) 996-6380].

    Measures based on Medicaid HEDIS and measures developed by QCMC are identified under topic areas of membership, utilization, quality, access, health plan management, clinical management systems and finance. Numerators, denominators and data resources are identified.

22. Stein REK; Westbrook LE; Bauman LJ. **The Questionnaire for Identifying Children with Chronic Health Conditions (QuICCC).** Pediatrics, 99/4 (1997) 513-521.

    The focus of this tool is to identify children with chronic conditions based on a short questionnaire related to functional limitations, reliance on compensatory modalities and need for services beyond routine care. This functional approach is independent of diagnosis and has been reported to demonstrate validity and reliability. The tool is directed toward epidemiological usage but may be pilot tested to determine its usefulness in evaluating children within managed care programs as a potential performance measure.

23. Ware JE; Kosinski M. **SF-36 Physical and Mental Health Summary Scales: A User's Manual.** Boston: The Health Institute. New England Medical Center, 1993.

This is the adult version of the child health questionnaire (CHQ) noted above. It describes both physical and mental health problems in eight areas: physical limitations, social activity limitations due to physical or emotional problems, bodily pain, mental health (psychological distress and well-being), role limitations due to emotional problems, vitality (energy and fatigue) and general health perceptions. It has been in use since 1988 and is a good measure of the coping skills and stresses associated with caring for a child with special health care needs.

24. **Disabilities Among Children Aged </= 17 Years - United States, 1991-1992**. Morbidity and Mortality Weekly Report; V. 44. No. 33. August 25, 1995.

The Survey of Income and Program Participation (SIPP) provides measures of categorical disabilities per the International Classification of Impairments, Disabilities and Handicaps (ICIDH) and includes related functional limitations associated with the personal and social consequences of the diseases. There are limitations in exclusion of key groups (e.g. children in institutions and foster care children) and definitions that are age dependent. Also, the current focus is on epidemiology and not managed care performance monitoring; but such application could be considered. In 1999, the ICIDH will be revised to emphasize measures of disability and handicap among children and assist in standardization of data collection.

25. Department of Health and Human Services: **A Health Care Quality Improvement System for Medicaid Managed Care: A Guide for States.** Washington, DC. July 1993.

26. Schwalberg R; et al. and Perrin JM. **Managed Care and Children with Special Health Care Needs: Strategies for Monitoring the Quality of Care**. Health Systems Research, Inc.; March 1997. [contact: Health Systems Research, Inc. (202) 728-9469].

An excellent review of an approach to state monitoring of managed care systems for CSHCN. The focus is on development of recommendations for use by a particular state, but principals and examples may be used by other agencies and states.

27. **Report on the Development of Indicators to Monitor The Performance of Systems of Acute Health Care for Children with Disabilities.** United Cerebral Palsy, Inc. May 15, 1997.

A series of performance indicators are directed toward measuring "effective service design and delivery" by managed care organizations for CSHCN. The indicators are grouped into nine domains: 1. prenatal care, childhood immunizations, infant screening and follow up; 2. well child care; 3. access to and availability of care; 4. health care services provided; 5. cost and financing of health care; 6. provider and health plan competency; 7. care coordination/family involvement; 8. health plan quality assurance; and 9. quality of life. Within each domain, indicators are categorized according to related areas of service within that particular domain.

28. Msall ME; DiGaudio K; Rogers BT; LaForest S; Catanzaro NL; Campbell J; et al. **The Functional Independence Measure for Children (WeeFIM). Conceptual basis and pilot use in children with developmental disabilities**. Clinical Pediatrics, 1994 Jul, 33(7):421-30.

    The focus is to assess physical functioning and level of dependence of CSHCN according to an 18 item, 7 level instrument. Areas covered are self care, sphincter control, transfers, locomotion, communication and social cognition. The measure can be used on both preschool and school age children and for a variety of conditions; and is reported to be both valid and well-tested.

Psychological functioning of CSHCN may also be addressed by two other tools that are described in Schwalberg, 1997. These include:

- Child Behavioral Checklist (CBCL)
- PARS III

TABLE I Quality Assurance Tools for Children with Special Health Care Needs

Resource #	Quality Assurance Tools	Condition -Specific	Functional -Child	Functional -Caretaker	Structural Quality Measure	Process Quality Measure	Health Status Outcome	Population -Based Measure	Individual -Based Measure	Provider Quality Assurance
1	AAP-Practice Parameters	X								X
2	ACQIP	X							X	
3	CAHPS	X				X		X		X
4	CES-D Scale			X						
5	CHQ		X	X					X	
6	COMPASS	X			X	X	X	X		
7	CONQUEST	X				X	X	X		
8	Enhancing Quality			X	X	X		X	X	X
9	Ensuring Quality	*In Development; Expansion of Enhancing Quality*								
10	Epi Hosp/Epi BC	X						X		
11	Functional Outcomes Project	X	X	X		X	X		X	
12	FHOP - HOI	X				X	X	X		
13	Fn. Disability Inventory		X						X	
14	Functional Status II		X						X	
15	Global QA Tool	X	*In Development*							
16	HEDIS 3.0	X			X	X	X	X		
17	NACHRI-Ped. Exc.	X	X		X	X		X		X
18	NHIS - Disability	X	X	X				X		
19	PEDI		X	X					X	
20	QARI	*Revision of Key HEDIS Indicators for Use by States for QA*								
21	Qual. Comm. MC	X			X	X	X	X		
22	QuICC		X					X		
23	SF - 36			X					X	
24	SIPP	X	X					X		
25	Medicaid Managed Care State Guide	*Guidelines for State Quality Improvement*								
26	*Schwalberg Review of QA Approaches and Tools for Monitoring Quality Care*									
27	UCP-Perform. Indicators		X	X	X	X	X	X		X
28	WeeFIM		X	X					X	

Readers should refer to the narrative description of QA tools for more information. Some tools focus more on children in general than on CSHCN.