# The Health of Children

*Peter G. Szilagyi and Edward L. Schor*

---

**Objective.** To summarize the concept of child health and the measurement of child health status in order to help guide the evaluation of the effectiveness of medical, social, and policy programs.

**Conclusions.** Opportunities for research on children's health status and quality of care abound. Comprehensive and functional definitions create problems of measurement, but investigators are making progress in measuring children's health status both generically and for specific chronic health conditions.

**Recommendations.** Measures of child health need to be developed, improved, tested, and made user-friendly for clinical and policy research. The relationship between health status and a variety of social programs for children and families needs study. The impact of changes in healthcare organization and financing must be investigated, especially for children from vulnerable subgroups. Determining the value and effectiveness of preventive services is a pressing issue. It is crucial to understand better the link among quality of care; other factors biological, family, and social; and children's health status.

**Key Words.** Child health, child health status measures, childhood development, preventive healthcare, healthcare utilization

---

The health of children and adolescents has received relatively little attention from health services researchers. This shortcoming has been recognized, and interest and support for research on children's health status and healthcare utilization is increasing. The development of conceptually sound and reliable measures of child health status is an important goal for health services researchers and clinicians. Child health measures can be used to assess the effects of disease or injury on health; to identify vulnerable children in clinical practices and vulnerable population subgroups in health plans or geographic regions; to measure the effect of medical care, policy, and social programs; and to set targets to improve healthcare.

Childhood is a period of dependency and development: (1) Children's health and well-being is greatly dependent on the care they receive from their families and communities, and to a lesser extent on the healthcare they receive; (2) assessing children's health often depends on reports by adult caretakers whose reliability varies; (3) continual physical, cognitive, emotional, and social development sets childhood apart from later life; and (4) the manifestations of health problems also change with age. Consequently, cross-sectional data resemble snapshots of moving objects, blurry, inexact, and unstable. Preventive healthcare has special significance during these formative years of rapid development, but the outcomes of preventive care are distant.

Children's health should not be defined narrowly, but comprehensive and functional definitions create problems of measurement. Although conventional clinical measures, satisfaction measures, and cost-related measures from administrative or claims data are often used to assess child health, the most promising methods involve functional measures obtained by interviewing parents and children. Investigators are making progress in measuring children's health status both generically and for specific chronic health conditions such as asthma.

Mortality is unusual in childhood, but morbidity is common and frequently involves physical, developmental, psychological, emotional, or behavioral problems or clusters of conditions. In addition to these chronic conditions and family factors, important risk factors for ill health among children and adolescents include culture, race, and poverty. Child health and quality of care should be measured separately for these population subgroups, and for children of different age categories.

## USES OF CHILD HEALTH STATUS MEASURES

Improving the health and well-being of children is a primary goal of healthcare systems. To assess the achievement of this goal, the development and application of conceptually sound and reliable measures of child health status are important for health services researchers and clinicians. In addition, child health indicators have been shown to be excellent proxies for measuring the

---

Address correspondence to Peter G. Szilagyi, M.D., M.P.H., Associate Professor of Pediatrics, Director of Ambulatory Pediatrics, University of Rochester, Strong Memorial Hospital, 601 Elmwood Avenue, Box 632, Rochester, NY 14642. Edward L. Schor, M.D. is Medical Director, Division of Family and Community Health, Iowa Department of Public Health. This article, submitted to *Health Services Research* on July 8, 1997, was revised and accepted for publication on March 5, 1998.

health of communities, states, and nations, further underscoring the importance of improving measures of child health status.

The purpose of this article is to summarize the concept of child health and the measurement of child health status, in order to help guide the evaluation of the effectiveness of medical, social, and policy programs. We first summarize the potential uses of child health status measures. We then present a conceptual framework for assessing the health of children, including determinants of health and different perspectives on child health. The third section summarizes a large body of literature about key threats to child health that result in mortality and morbidity, and risk factors that lead to poor health. While child health status measures are increasingly needed, the measurement of child health is challenging from both a conceptual and a methodological standpoint. These challenges are discussed in the fourth section. The fifth section summarizes different means to assess child health and discusses both generic and disease-specific methods. Finally, we present recommendations for future research.

## POTENTIAL USES OF CHILD HEALTH AND FUNCTIONAL STATUS MEASURES

It is essential that anyone developing or interpreting child health status measures consider their specific objectives and uses. Different uses may require different population subgroups (e.g., age groups, children with chronic conditions); specific characteristics of the assessment tool (e.g., length, mode of application, frequency of application); and particular methods of presenting results (Deyo and Carter 1992). A measurement tool designed for screening for clinical problems in a busy practitioner's office may not be appropriate for evaluating the effect of medical financing on vulnerable children. There are four broad categories of uses of child health status measures.

### *Assessing the Impact of Disease or Injury on Health*

Studies have assessed the general health of child populations, the impact of chronic diseases or injuries on children, the clustering of conditions in childhood, and the relationship between childhood conditions and adult diseases. Public health leaders and child health researchers are particularly interested in using child health status measures for these purposes.

### *Identifying Vulnerable Patients and Populations*

Children's health could be substantially improved if vulnerable children were readily identified (Greenfield and Nelson 1992). Child health status measures could be used in physicians' offices to identify children with unrecognized conditions, social or emotional problems, or poor functioning. At a population level, these measures can identify vulnerable (and costly) groups of children within health plans or geographic regions allowing for risk adjustment for case mix. It is especially important to monitor the health of these vulnerable populations (such as children who have chronic conditions or are poor) in light of the pressures to limit healthcare costs.

### *Measuring Effectiveness of Medical Care, Policy, and Social Programs*

Child health status measures can inform the process of care by providing more and better information on the link between structural factors, process factors, and health outcomes (Starfield 1973). For example, care could be improved by evaluating variations in the process and outcomes of care and measuring the effectiveness and efficacy of care (Starfield 1991a). In particular, since prevention is so central to child healthcare, it is important to study the short- and long-term effectiveness of preventive services. Two landmark studies that investigated the effect of structural changes in healthcare delivery on health outcomes were the RAND Health Insurance Experiment, which investigated the relationship between different types of healthcare financing arrangements on health status (Valdez et al. 1985; Valdez et al. 1989), and the Medical Outcomes Study, which investigated the relationship between clinicians' specialties, technical and interpersonal styles, and features of the healthcare system on the health status of adults (Tarlov et al. 1989). Managed care organizations, as well as clinicians and families, are extremely interested in assessing the effectiveness of healthcare. Policy experts and political leaders need information about the relationship between social programs and health status.

### *Setting Targets to Improve Medical Care, Policy, and Social Programs*

Since the ultimate goal of medical and social programs is to improve health and functioning, it is important to establish measures of success. This requires some consensus on what is meant by health and functioning. The Year 2000 goals are national health targets, based on current mortality, morbidity, and risks to children, youth, and adults (U.S. Department of Health and Human Services [DHHS] 1990). Identifying targets for child health allows medical and human services to be more appropriately evaluated and improved.

# CONCEPTUAL FRAMEWORK FOR ASSESSING THE HEALTH OF CHILDREN

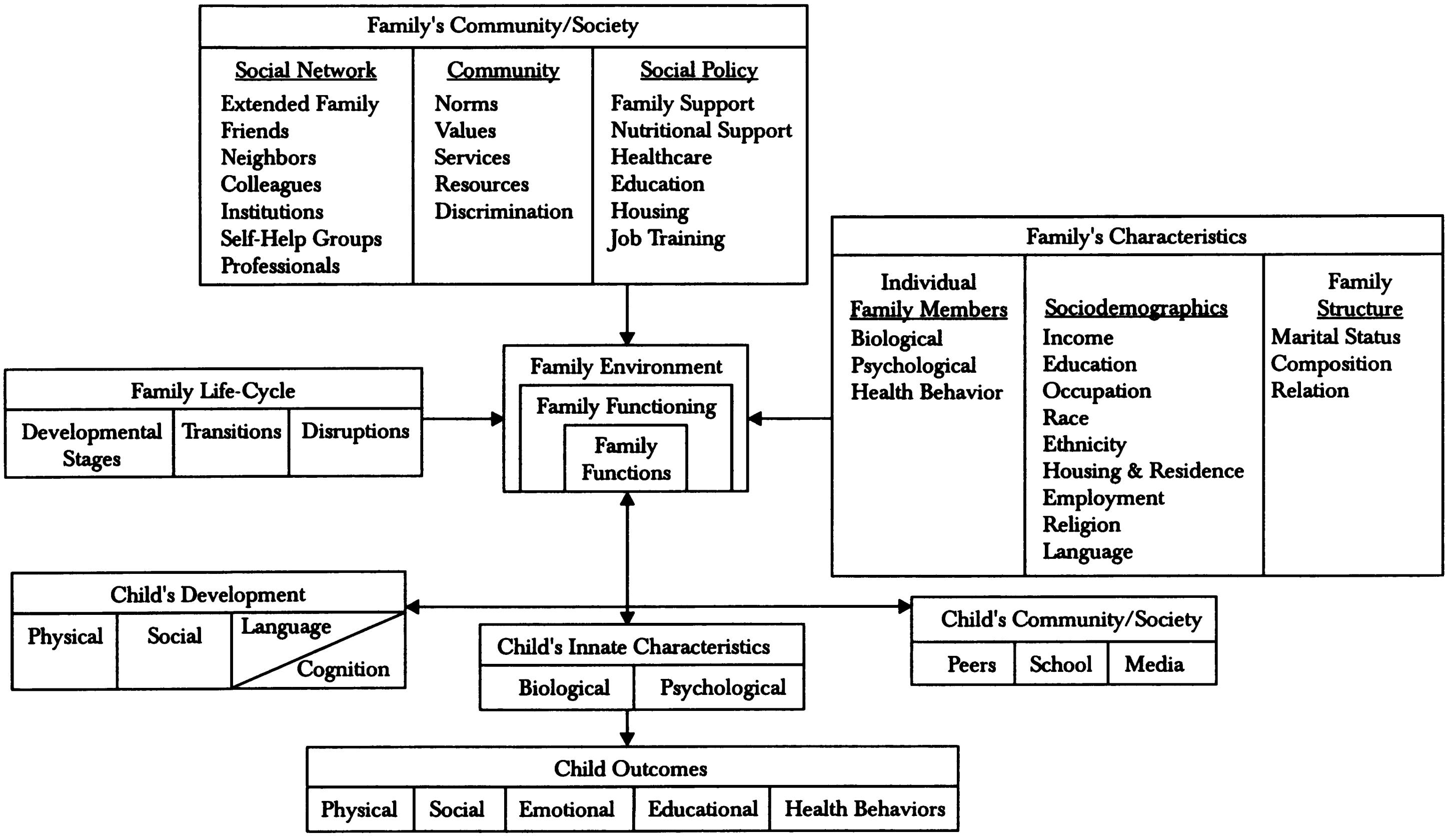
## CONCEPTUALIZATION OF CHILD HEALTH

There is not, nor is there likely to be, a single definition of child health that will serve all purposes or be adopted universally. The purpose(s) for which definition is sought—and these may range from guiding the assessment of a discreet clinical intervention to guiding international health policy and the distribution of resources—drive and delimit the defining process (Schor 1997a). Different concepts have different purposes and different potential applications (Evans and Stoddart 1994). Selecting one set of concepts, that is, one definition over another, leads to disregarding or devaluing some health outcomes. Even efforts to test definitions empirically are tautological and rest on theoretical assumptions that may not encompass the universe of possible health concepts.

Nevertheless, the development of most of the better measures of child health has rested on some definition of health and on a related conceptual model (Eisen, Ware, and Donald 1979; Starfield et al. 1995; Schor 1995b; Wilson and Cleary 1995; Langraf, Abetz, and Ware 1996; Boyle et al. 1987). Although the definition is usually broad—for example, "a state of complete physical, mental and social well-being and not merely the absence of disease or injury" (World Health Organization 1948)—and the model is nearly all-encompassing, side-by-side comparison of these instruments reveals important differences in their health concepts (Landgraf and Abetz 1996). These differences reflect the professional orientations and reasons for measurement that instrument developers bring to their task (Lerner and Levine 1994). When a theoretical model was not used as the principal basis for instrument development, the values and concerns of patients (Stein and Jessop 1990) or providers (Baribeau et al. 1991) guided the process.

Child health is clearly a multidimensional state, conceptualized best as a continuum (as in Figure 1). Although it is impossible to measure precisely the abstract concept of "health," researchers have made significant strides in understanding the determinants of health status and the indicators of health. A number of researchers have proposed four categories of health status indicators: (1) biological and physiological factors that are typically measured in clinical practice; (2) symptoms status, which refers to specific symptoms noted by patients and which often affects healthcare-seeking behavior; (3) functional

Figure 1: Social Context of Child Health



status, which refers to the ability of patients to function within their environment; and (4) perceived well-being, which involves overall health perceptions and some individualized integration of the other health status indicators. The latter three indicators are often noted to have several components, including physical, emotional, or psychological components; role components; and social components. Children, as well as adults, have an additional dimension of health status—namely, development. All persons develop and change, and therefore health status is an evolving state.

## WHO DECIDES ON THE DEFINITION OF CHILD HEALTH?

A key issue in measuring the health of children is the perspective from which health is being assessed. The different perspectives include those of the child, the parent, the physician, third-party payers, and society. People with different perspectives may include different dimensions in their definitions of health.

Patients tend to adopt a broad definition of health and thus to have extensive expectations of the healthcare system (and of their insurance coverage). Pediatricians and child advocates have promoted this holistic definition of child health. The definition has found some policy support in the SSI (Supplemental Security Income) program (prior to welfare reform) and in special education legislation. Legislators, purchasers, and managed care organizations who are trying to control costs have a vested interest in defining health narrowly, that is, biomedically, and thus have much more limited expectations of what the healthcare system should provide. This conflict between patients' expectations and what the healthcare financing system is prepared to offer (or authorize) is apparent in disagreements on the definition of "medical necessity." One might argue that the unique nature of childhood (i.e., developmental vulnerability) calls for a definition of medical necessity different from the definition applied to adults. Measures of child health status can be critical to resolving this conflict because it is likely that what is measured is what will be paid for. Thus the adoption of broad, comprehensive measures of child health will support the argument for more extensive covered benefits for children.

The inclusion of domains that may extend beyond the influence of clinical pediatric care raises the question of whether a broad view of health is useful to clinicians. Perhaps different methods of assessing child health, each of which depends on the purpose of the investigation, should be used rather than searching for and applying a single approach to child health status measurement. For assessing medical interventions, health status measures might appropriately be narrow, excluding some key areas that children, parents, and child advocates undoubtedly view as critical factors. For other purposes, such as screening in pediatric practices, measuring the health of vulnerable populations, or evaluating the effect of managed care, health status assessments might need to be broad. A case can be made for identifying and including certain "core" measures of child health in all instruments to allow for comparisons.

## DETERMINANTS OF CHILD HEALTH

The conceptualization of health that guides most measurement is ordinarily derived from beliefs about what the factors are that affect or determine health. One approach to dealing with this inherent bias, that is, selecting an outcome based on what is thought to have caused it, is to employ a multidimensional, multilevel measure of health as a matter of routine, thus covering all the bases. Ware suggests (Bungay and Ware 1993) that biological normalcy or functioning is at the core of other concepts of health. Therefore, biologic measures are the purest measures of health, and other measures, such as physical functioning, are more or less proximal to that biologic core. Since the source of conventional biomedical information (e.g., symptoms, signs, and laboratory data) often is not available from the parent or the patient while information is available from them on functioning and well-being, measures of child health status that rely on one source of information will be incomplete. Thus, generic measures of health status are often supplemented with disease-specific, clinical information.

A reductionist, biomedical view of health leaves out the less specific dimensions of health that many parents judge to be important (Evans and Stoddart 1994). In addition, current therapies are not uniformly able to modify the body's physiology directly. Children's behaviors and circumstances are intermediary between interventions to improve health and the desired biologic responses. Therefore, if one chooses to measure physical functioning as one aspect of health, that choice rests on the assumption that factors that affect physical functioning are important determinants of health. The circularity of this formulation highlights the duality of selected concepts and definitions of health, the determinants of those definitions, and the importance of distinguishing between them.

Much as the health concepts that are chosen to be measured are linked to the purpose for which measurement is undertaken, so is the purpose for measurement reflective of beliefs about what factors determine children's health. For example, for the purpose of evaluating a new antibiotic, an investigator may want to define health only as the absence of a microorganism from the body. Choosing such a narrow, biomedical definition reflects the belief that the presence or absence of such an organism is the primary determinant of the child's health. Alternatively, for the purpose of justifying psychological treatment, a school counselor may define health as having a positive sense of self and believe that succeeding at school can promote such self-esteem. In the first example, the presumed determinant of health is biological and the outcome is biologic; in the second example, the determinant and outcome are social. These formulations are incomplete. Research demonstrating the influence of emotional state on immune response highlights the important but often overlooked relationship between social and biological variables.

The role of behavior and social circumstances as intermediaries between interventions to improve health and the resulting health status or outcomes is particularly acute for children. Recent research suggests that early life experiences can structure a sustained pattern of neurochemical and immune responses to later events and circumstances. Early experiences occur within the context of genetic predispositions and physical and social environments. The determinants of children's health therefore include heritable states, physical and social experiences, and the developmental time frame within which those experience occur.

## THE INFLUENCE OF THE FAMILY ON CHILD HEALTH

Children are uniquely dependent on their families to control their social and physical environments and therefore the characteristics and timing of their experiences. This dependence is so pronounced at young ages that much intervention—medical, educational and social—is directed not at the child but rather toward influencing the parents' attitudes and behaviors (Schor 1997b). Society expects parents to carry out a number of functions on behalf of their children. These include the material and instrumental functions of providing food, clothing, shelter, supervision, and access to healthcare and education, and adherence to treatment. They also include cognitive and affective functions such as providing social support, teaching coping skills, and socializing the child for a secure life in the world (Schor 1995b). How and when in a child's life parents carry out these functions—in interaction with the child's innate characteristics—may be the principal determinant of most children's health status (see Figure 1). The physical, social, emotional, and educational outcomes for children as well as their health behaviors rest heavily on experiences within their family or on the substitution of other adults who can perform these parenting functions.

The centrality of their families in determining children's health provides a strong argument for assessing family functioning and well-being as an essential component of child health. Aspects of family health that have been included in some child health measures include maternal depression, family cohesion, caregiver burden, and family health risk behaviors. Since to a considerable extent the child's family is the patient, an argument can be made that a more extensive assessment of families, including their social, economic, educational, and developmental circumstances, should be used to quantify the determinants of children's health.

### SOCIAL DETERMINANTS OF HEALTH

Healthcare is important to individuals; it can relieve suffering and in some cases extend life. But it does not explain differences in health status among populations. These differences fail to conform to the expected segregation of populations into haves and have-nots based on their access to healthcare. They demonstrate a social gradient instead, in which rates of morbidity and mortality decrease with each step up the social hierarchy.

To account for this gradient, social scientists point out that social class is powerful, complex, and pervasive, and that it affects nearly every facet of life from lifestyle choices and nutrition to self-esteem, empowerment, entitlement, and feelings of control. As class influences the quality of the social environment, so too does the ability to control or cope with the stresses of the social environment affect health outcomes. In general, a poor ability to manage stresses, both physical and social—including the inability to muster social support for oneself—can adversely affect body physiology and immune responses, and can diminish health. Children who are physically and emotionally resilient, and thus healthier, have the innate capacity or the learned ability to adapt to challenging or threatening circumstances (Garmezy 1991). Both macro-social (e.g., inequality in the distribution of wealth), and micro-social (e.g., family, circumstance) factors modify children's development and health status by altering biologic pathways and responses.

## THREATS TO CHILD HEALTH: CAUSES OF DEATH, DISABILITY, AND FUNCTIONAL LIMITATION

This section summarizes some of the major causes of mortality and morbidity in children and adolescents and discusses risk factors that threaten health status. The purpose is not to provide an exhaustive review, but rather to highlight some examples of threats to child health (with selected references) in order to help guide future research. One measure of quality of care is the degree to which healthcare systems or clinicians address these problems. It is critical to point out, however, that the factors contributing to mortality and morbidity are well beyond the scope of the current medical system; there are limits to the ability of healthcare to affect these outcomes. A major issue during the next decade is the extent to which healthcare can or should be accountable for improvements in these health outcomes.

## MORTALITY

While mortality is unusual (Guyer et al. 1996; Singh, Kochanek, and MacDorman 1996), several important trends over time are noted.

### *Infant Mortality*

Infant mortality rates have declined in the United States by 42 percent since 1979 (from 13.1 to 7.5 infant deaths per 1,000 live births). There are disparities in infant mortality between minority and white populations, with African American infants having twice the mortality rates of white infants. In addition, the United States does not rate well against other nations with respect to infant mortality rates. A primary threat to infant health is low birth weight (under 2,500 grams), which occurs in 7 percent of live births (U.S. Department of Health and Human Services [DHHS] 1990), and which has not declined significantly in recent years. Many potentially amenable risk factors have been associated with low birth weight, including low socioeconomic status, cigarette smoking, maternal drug use, maternal age, maternal nutrition, and environmental hazards (DHHS 1990).

Infant mortality is less an indicator of the quality of the healthcare system than it is a measure of social well-being and inequalities among families of childbearing age. The variations in infant mortality across time and across populations demonstrate that it is sensitive to medical, social, and environmental factors (Starfield and Budetti 1985). A major area of research on quality of care involves evaluating methods linking the healthcare system to other social programs to reduce infant mortality.

### *Childhood Mortality*

While overall mortality rates have declined, most leading causes of childhood death are preventable. The primary cause is unintentional injuries, and further improvements are needed. A rise in deaths from homicide reflects the health problem of family violence and child abuse, and highlights an important area for research on the role of healthcare in preventing social problems.

### *Adolescent and Young Adult Mortality*

Unintentional injuries are also the major cause of death in adolescents. Adolescent and young adult males are the only age groups with rising death rates. Deaths from homicide and suicide are increasing dramatically and accounted for one-third of all adolescent and young adult deaths in 1994; many of these deaths were associated with alcohol or drug use.

## MORBIDITY

Child death represents merely the "tip of the iceberg" with respect to child health status, often masking the bulk of the problem (morbidity). An understanding of the causes of childhood morbidity will help guide research in assessing and improving the quality of care for children and will assist in allocating resources for the delivery of services. There is no standard report card of child health. However, many studies are available that use national databases or representative populations in highlighting diseases, disabilities, and functional limitations.

### *Morbidity in Infants*

Surprisingly scant information has been published about the health status of infants. But clearly, many of the conditions affecting infants are related to prenatal problems, maternal or family factors, and congenital anomalies. The lack of data is due both to the difficulty of measuring health status in infants and to the small sample sizes for the infant age group in population-based studies. In one study of one-year-olds (Shapiro, McCormick, and Starfield 1983), about 20 percent of the infants had at least one major health problem during the first year of life; 9 percent were hospitalized at least once; one percent had severe impairment from a congenital anomaly or from severe developmental delay; and 7 percent had moderate impairment. A major clinical issue is the identification and management of the developmental problems that emerge during infancy.

Recent research on brain development among infants and young children demonstrates that sensory and social experiences have a decisive effect on the architecture of their brains, and on the nature and extent of their adult capacities. Environmental factors have dramatic and specific effects on the brains of young children, with implications for their growth, development, and ability to cope with social and biologic stress. Thus, experiences early in life make substantial contributions to children's subsequent morbidity whether that morbidity takes the form of illness, injury, risk behaviors, or social/behavioral deviancy.

### *Morbidity in Childhood*

Studies have used national survey data to describe health problems of children (Starfield and Budetti 1985; Newacheck and Taylor 1992; Newacheck and Stoddard 1994; Jessop and Stein 1995). Many studies have focused on chronic physical problems; however, psychological and mental problems are even more prevalent and are at least as disabling. Different analyses use different age cut-offs and a variety of definitions of chronic disease; this accounts for estimates of chronic diseases ranging from 3 percent to 30 percent. Overall, it appears that about 30 percent of children do have at least one chronic condition; however, most of these conditions are mild, causing little or no functional limitation. About 3–5 percent of school-age children have significant functional limitations. Not surprisingly, children with chronic conditions, because they are perceived by their parents to be in poorer overall health, use more ambulatory and hospital services (Newacheck and Starfield 1988).

Critically important areas for preschool and school-aged children involve psychological and emotional development. Perhaps due to improved methods of detection, or perhaps resulting from environmental factors, the emotional, psychological, and behavioral problems of children are on the rise; examples include attention deficit disorder, depression, and behavioral disturbances (DHHS 1990; Brent 1993; McCormick, Workman-Daniels, and Brooks-Gunn 1996). Some functional outcome measures are available since educational and psychological testing provide useful criteria for assessing developmental status, but these are not applied uniformly.

Lifestyle, an important dimension of health in children, affects morbidity, mortality, and health status later on, in adulthood. This domain is an important and legitimate component in researching the overall health status of children. Studies have found that many unhealthy behaviors often start before adolescence—use of tobacco, alcohol, and drugs; use of violence to resolve conflicts; lack of exercise; and poor dietary habits (DHHS 1990). Preventing or modifying risk behaviors is an important aspect of child health care, and for this reason child health status measures should include these lifestyle measures.

### *Morbidity in Adolescents*

The spectrum and the prevalence of chronic physical diseases are similar among adolescents and school-aged children. Apart from these impairments, the health problems of adolescents lie in four categories. The first involves physical and emotional morbidity from violence (Lewit, Schuurmann, and Baker 1996), which is clearly related to social, economic, and family problems. The second category involves school and developmental problems, which are common and manifest in school drop-outs, poor performance, and behavior disturbances (American Medical Association [AMA] 1992). The third category involves mental disorders, affecting 10–20 percent of adolescents. The fourth and perhaps the largest morbidity category involves the development of unhealthy lifestyles among adolescents, including the use of tobacco and smokeless tobacco, alcohol, and other drugs; poor nutrition (excessive dieting or excessive eating); inadequate cardio-respiratory fitness; and unsafe sexual activity with all of its consequences. Unhealthy lifestyles in children and adolescents result in substantial short-term and long-term morbidity and healthcare costs. Future research should evaluate methods by which healthcare systems can change unhealthy lifestyles of children and adolescents, and should measure the degree to which they are addressing these areas.

## RISK FACTORS FOR ILL HEALTH AMONG CHILDREN AND ADOLESCENTS

A large body of literature is available on the social and demographic risk factors for poor health in childhood. Starfield and Budetti (1985) have pointed out that poor health in children is often associated with multiple risk factors, and that there is a vicious cycle of child health problems increasing the risk of either similar or other health problems (Starfield 1991b). There are several key risk categories.

### *Age*

Since illnesses and their manifestations are age-specific, it will often be useful to perform separate assessments for infants and very young children, for school-age children, and for adolescents.

### *Culture and Race*

Children from ethnic and racial minority populations have been noted to have poorer access to healthcare and poorer health outcomes in some areas

(Rosenbaum, Layton, and Liu, 1991; Schor and Menaghan 1995). One of the dimensions by which health systems should be assessed is the health status of minority populations. Furthermore, improved understanding of health and its determinants for other minority populations (such as Latino, Asian, Native American, and other cultures) is needed.

### *Socioeconomic Status*

Poverty is one of the best predictors of mortality, activity limitations, and the use of healthcare (Egbuona and Starfield 1982; McCormick 1983; Wise et al. 1985; National Center for Health Statistics 1986; Newacheck 1994). Childhood poverty has such a strong association with poor child health that the health status of poor children should be systematically measured over time and across healthcare systems. This is particularly important given the evidence that medical care can attenuate some of the adverse effects of poverty and other risk factors (Starfield 1985).

However, only a portion of the burden of illness and injury among children—poor or rich—can be ameliorated by healthcare. The extent to which healthcare can affect the health of children is determined in part by how broadly one defines both healthcare and the health of children. For example, violence is a major contributor to poor health in children and adolescents. Is this fundamentally a health problem? How much can medical care ameliorate this problem? There is scant information about specific quality of care measures by which to judge whether a clinician or a healthcare system is effectively addressing the problem of violence. A major area of research in the coming years is to develop these quality of care measures, and perhaps to reach consensus about the limits to the responsibilities of healthcare.

### *Family and Environment*

Both the overall health of children and the burden of health problems are much affected by family and environmental factors. In general, the family's influence on children's health is less dependent on family structure (i.e., single-parent divorced, two-parent married) than it is on how well children's physical, social, and emotional needs are met. Families greatly influence children's use of health services, health risk behaviors, health-promoting behaviors, emotional health, and social functioning (Schor 1995). Family characteristics that are risk factors for poor outcomes in children include divorce, violence in the family, paternal unemployment, parental alcohol or substance abuse, low parent literacy, parental retardation, single parenthood, and teenage parenthood (Schor 1995; Schor and Menaghan 1995). Many of these family characteristics are associated with poverty. A family's ability to function effectively is strongly influenced by the interaction between the family's personal resources and its social environment.

In addition, children are influenced by and vulnerable to environmental and social factors beyond their immediate families. Peers and the school have a major influence on older children and affect many dimensions of health status, including cognitive development, emotional status, and healthy lifestyles or risky behaviors. The burden of ill health in children with chronic conditions is influenced by the quality of their social support. Although health status measures for children and adults have focused on the individual patient, many of the major causes of childhood mortality and morbidity have social or family origins and require solutions broader than traditional patient-specific medical treatments. Future research should develop better measures of family health status and family functioning.

### *Chronic Conditions*

Perhaps the greatest risk factor for suboptimal functioning and general health status in childhood is the presence of one or more chronic conditions (Newacheck and Taylor 1992; Newacheck and Stoddard 1994) and the severity of each chronic condition (Perrin et al. 1993). As the number of health conditions grows, health status progressively worsens. There is a tremendous variability in the impact of chronic conditions on health status; however, the effects of healthcare may be greater for these particularly vulnerable children than for the general child population. Thus it is critical in evaluating care, whether at the level of an individual provider, a health plan, or a nation, that the quality of care and the health status of children with chronic conditions be assessed.

## KEY ISSUES IN MEASURING THE HEALTH OF CHILDREN

Measuring the health of children requires instruments that have excellent psychometric properties, are easy to administer, and are useful for clinical or policy purposes. Many psychometric and application issues are relevant for both children and adults, and others are particularly important for children.

## PSYCHOMETRIC PROPERTIES OF CHILD HEALTH STATUS MEASUREMENTS

There are excellent reviews on the psychometric properties of health status measurements (Streiner and Norman, 1989; Bungay and Ware 1993; Langraff and Abetz, 1994). Measurement issues are the same for child and adult health status instruments. Key psychometric properties include the validity of the instruments and their reliability over time. Developers of health status indexes have spent considerable effort to assess their content, construct, and criterion validity (Bungay and Ware 1993). Issues of reliability are particularly challenging for child health status because of the developmental changes of childhood.

Since a major use of health status measures is to determine the impact of care, the sensitivity of these measures to a change in health or in social care is critical. In addition, although many children (and adults) are healthy, an important subset with chronic conditions have extremely poor health; thus, measurement issues related both to ceiling effects (from many healthy children) and to floor effects (from extremely ill children) are important. While this issue is not unique to children, it supports the need for increased attention toward vulnerable population subgroups, who tend to have poorer health status.

## CHALLENGES IN MEASURING CHILD HEALTH

Pediatricians are fond of saying that children are not just smaller versions of adults—that they have challenges unique to childhood. The same can be said with respect to assessing the health and functional status of children. Most of the attention in health status measurement has focused on adults, particularly the elderly. There may be a variety of reasons for this: a greater national commitment to the health of the elderly, the larger share of healthcare costs borne by adults, and perhaps a generalized perception that children are usually healthy (Starfield 1987). Another reason is that the measurement of child health status is especially challenging both conceptually and methodologically.

One conceptual challenge is the difficulty of defining child health and its determinants (Bunker 1995). Part of the dilemma is that a very broad definition makes it difficult for clinicians to address the various components; yet a very narrow definition (e.g., physical health) excludes major health concepts that are important for children. Increasingly, measures of child health status are multidimensional so that different aspects of health can be assessed simultaneously.

A related and second challenge is the concept of "disability" as it applies to children. There are negative aspects to labeling a child "disabled" (e.g., social stigma), and since children are so resilient and adaptable, a disability may not be permanent. However, labeling a child with a disability also has positive consequences, such as improving the child's access to needed social services, financial assistance, and special education. Again, one solution is to define disabilities on multiple dimensions.

Part of the difficulty in defining both health and disability is that children are developing and changing rapidly, and normative values are "moving targets." There is a world of difference between the concept of health and normative functioning for a 10-year-old versus a 14-year-old, or a one-year-old versus a 5-year-old, due simply to developmental progression. These differences dwarf the changes that occur with aging in adults. Further, the attainment or achievement of certain health states/status are additive and depend on what has been accomplished previously. In addition, the way each health concept is measured varies with age. Child psychologists consider "developmental equivalence" with respect to some continuity within certain domains regardless of age. Is riding a tricycle at age 3 in some way equivalent to riding a bicycle at age 6 or driving a car at age 16?

This moving target poses two specific challenges: addressing the stability of health status for a particular child over time, and measuring health across the age spectrum. Clinicians want measures that can help them manage specific patients; this assumes that measures today have some meaning tomorrow. Second, different health status measures are needed for different age groups. Health status measures for adolescents cannot be easily applied to school-age children or to infants, but ideally they should be conceptually related to one another.

Illness and disability are "developing" within certain children, just as the children themselves are developing. While illness and disability in adults often have been present for some time, children's are emerging and showing greater variability. For example, it may be more difficult to identify developing mental illness in children than to identify established mental illness in adults.

The domains of health and development (e.g., physiological, psychological, social) are more interconnected and overlapping in children than they are for adults. Children need certain physical skills to develop socially (e.g., language). Disability in one domain may manifest as disability in another domain.

Many child health problems are social in nature and etiology. They are more prevalent in certain social circumstances, such as poverty, and they have different long-term consequences than do physical problems. Examples include attachment and attention deficit disorders that in the future may manifest as violence or substance abuse. Adults also have ill health resulting from social problems, and many adult health status measures do not deal adequately or explicitly with these disabilities.

In addition to the conceptual challenges, measuring the health of children is subject to a number of methodological challenges. The first challenge lies in the probability that young children cannot provide the needed information about their health, and that child health status frequently is obtained from parent proxies and thus reflects the parents' views. For optimal child status measures, as much information as possible should be obtained directly from children, or from both parents and children. Recent studies have shown that specific domains of health can be elicited even from very young children (Adesman and Walco 1993). Nevertheless, the cognitive capability of children to understand questions poses a major technical challenge. The issue of proxy responding is also an important challenge to studies of adults with impairments and of the elderly.

A second methodological challenge is to develop valid measures that account for the two moving components described earlier: the developmental changes of children as they age, and the development of disease or disability as they progress. These changes make it difficult to evaluate changes in child health status over time, or to distinguish the effects of interventions from simple developmental changes. Similarly, the wide range of normality in childhood functioning makes it difficult to differentiate behavioral or developmental abnormalities from normal behaviors or development. Measurement techniques may be inaccurate due to the lack of specificity between age and the developmental or behavioral achievements expected.

Health problems, whether traditional biomedical diseases, the new social morbidities, or risk behaviors, tend to cluster together and to have an additive or even multiplicative effect on individual children. Optimal health status measures should identify children with clusters of health problems, because interventions that target these children should be multifaceted rather than "categorical" (Starfield 1991b). Since child healthcare emphasizes prevention, it is especially important to identify children with clusters of health risks in order to target interventions, and to measure the effectiveness with which healthcare systems address these health risks and related, preventable health problems.

A methodological problem that is particularly important in efforts to measure child health status is the fact that diverse disabilities have similar manifestations. For example, the functional "final pathway" for depression, attention deficit disorder, learning disabilities, or normal adolescence may involve similar overt behaviors. Each of these problems has different etiologies, morbidities, and clinical management.

### CHARACTERISTICS OF POPULATION SUBGROUPS

It is important to identify key population subgroups that differ from the overall population in their health status and in their vulnerability to changes in access to healthcare and its provision, and who may require different methods of health status assessment. The earlier section on morbidity risk factors identified several population subgroups by age, culture and race, socioeconomic status, family, social environment, and chronic disease. Child health status measures should be tested empirically with these subgroups. Studies of the effectiveness of healthcare or social programs should also consider these vulnerable groups.

## MEASURING CHILD HEALTH

There are four general measurement categories of medical care outcomes for children: (a) conventional clinical measures obtained by history, physical examination, and diagnostic tests; (b) functional measures obtained by interviewing patients and parents; (c) measures of satisfaction regarding the process of care and the consequences of care, also obtained by interviewing patients or parents; and (d) cost-related measures obtained from administrative data and claims or from encounter data for specific clinical activities, including office visits, specialty visits, procedures, and hospital use. For children, several other categories, including health behaviors, resilience, and family functioning, have been proposed.

### CONVENTIONAL CLINICAL MEASURES

These are the primary means by which clinicians identify the health of their patients, and these measures generally follow the traditional biomedical model (Mishler 1981). A standard part of routine clinical evaluations is screening for diseases. In this model, "health" is the absence of disease or pathophysiology, and "illness" represents deviations from accepted biological norms. With the exception of standard screening procedures, conventional clinical data are not ordinarily collected in a uniform fashion, thus contributing to variations in level of care and quality of care.

On a population level, these conventional "clinical" measures are useful indicators of the health of children. Examples include data on mortality, prevalence of diseases, and disability from diseases or injuries. These health measures are useful in comparing populations and in evaluating trends over time.

## FUNCTIONAL MEASURES OBTAINED BY INTERVIEWING PARENTS AND CHILDREN

The two types of functional measures are generic measures of child health status, and disease-specific measures. Each type is important and has specific advantages. Generic measures are very useful clinically as screening tools, in assessing and comparing the health of different groups of children, in evaluating the effect of the process of care on the overall child population, and in setting appropriate targets for child health. However, generic measures often do not provide sufficient detail about specific chronic conditions to be useful in changing disease-specific processes of medical care.

Clinicians regularly assess the health status of children and the functioning of families using information available in the office setting. In fact, during preventive visits, a substantial part of the history-taking involves determining how well the child is developing and functioning. An increasing number of clinicians during preventive care visits are using standardized forms that include questions about functional health status and risk behaviors. There is little information about the concordance between clinicians' "gestalt" impressions of functional health status obtained from conventional clinical measures and overall health status obtained from more rigorously tested functional health status instruments.

Disease-specific measures are not relevant for the overall child population. However, they provide more specific information about the outcomes of care as the care relates to a particular condition. In addition, disease-specific measures can include established standards of care for particular diagnostic criteria and therapeutic interventions. They also may assess specific activity levels, disease severities, and functional outcomes. Disease-specific health status measures should also incorporate other family, social, and developmental factors that affect child health.

Both generic and disease-specific child health status measures are needed. Next we summarize generic measures and disease-specific health status measures for one chronic disease: childhood asthma.

### *Generic Child Health Status Measurement Instruments*

Landgraf and Abetz (1992) reviewed the medical and psychological literature to identify generic instruments for measuring child health status. These instruments were designed for a broad array of children irrespective of the presence of a chronic condition, and at a minimum all of them measure both physical and psychological health status. Results of psychometric testing have been published for most of these instruments. Tables 1 and 2 (adapted from Landgraf and Abetz 1992) summarize the content of each instrument and their purpose, target age range, respondent, mode of administration, number of items, number of minutes required for completion, and special features.

A great deal of progress has been achieved by researchers who have developed and tested these generic instruments. However, limitations and gaps in our knowledge remain. Many of these limitations stem from the fundamental difficulties of conceptualizing and measuring child health status. First, although many of the instruments have been applied to different populations (e.g., both urban and rural), there has been no consistency in the cultures, socioeconomic groups, settings, or health conditions evaluated. This makes it difficult to compare the instruments, and little direct comparison across instruments has been done (Lewis, Pantell, and Keickhefer 1989). Second, most of these instruments are lengthy and not easily used in clinical settings, so most of them have not been used widely. Several researchers currently are developing short forms or briefer versions to facilitate their clinical use. Third, the content of the instruments varies greatly. It would be useful to achieve consensus about core content areas. Paired administration of these measures would provide useful information about their potential applications. In the future, when enough published experience has accrued, it may be useful to reach some consensus regarding the standardization of these measures and putting them into operation. The fourth problem is a dearth of measures for very young children, due in large part to the difficulties of defining health and quality of life. And fifth, since most instruments use parent reports, there is a need to compare parent and child perspectives; this has been done for only a few instruments (Starfield et al. 1995).

### *Health Status Measures for Children with Asthma*

Asthma is the most common chronic physical condition of childhood (Newacheck and Taylor 1992), affecting about 5 percent of children. A number of researchers have developed tools to measure the health of children with

Table 1: Content Areas of Generic Child Health Status Assessment Instruments [adapted from Langraff]

| | | | | *THI/CHAP* | | | *HIE* | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | *Over 5 yrs* | | *0–5yrs* | | | | | |
| *Content* | *CHIP* | *COOP* | *FSII-R* | *Parent* | *Self* | *Parent* | *5+* | *0–4* | *NHIS* | *OCHS* | *QWB* |
| *Conditions/Symptoms* | | | | | | | | | | | |
| Conditions | ✓ | | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | |
| Symptoms | ✓ | | | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ | ✓ |
| Illness-specific symptoms | | | ✓ | | | | | | ✓ | ✓ | |
| *Functioning* | | | | | | | | | | | |
| Cognitive (school) | ✓ | ✓ | | | | | | | | ✓ | |
| Family | ✓ | ✓ | | ✓ | ✓ | ✓ | | | | ✓ | |
| General | | | ✓ | ✓ | ✓ | ✓ | | | ✓ | | |
| Number of sick days | ✓ | | | | | | | | | | |
| Physical/Mobility | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Role | ✓ | | | ✓ | ✓ | | ✓ | ✓ | | ✓ | |
| Social | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ | | | ✓ | ✓ |
| *Mental Health* | | | | | | | | | | | |
| Behavior | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ | ✓ | |
| Energy | | ✓ | | | | | | | | | |
| Mental health | ✓ | ✓ | | ✓ | ✓ | | | | | ✓ | |
| Self-esteem | ✓ | ✓ | | ✓ | ✓ | | | | | | |
| Temperament | | | | | | ✓ | | | | | |
| *Parent* | | | | | | | | | | | |
| General health | | | | ✓ | | ✓ | ✓ | ✓ | | ✓ | |
| Impact on parent | | | | ✓ | | ✓ | ✓ | ✓ | | | |
| Mental health | | | | ✓ | | ✓ | ✓ | ✓ | | | |

*continued*

Table 1: (Continued)

| | | | | *THI/CHAP* | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | *Over 5 yrs* | | *0–5yrs* | *HIE* | | | | |
| *Content* | *CHIP* | *COOP* | *FSII-R* | *Parent* | *Self* | *Parent* | *5+* | *0=4* | *NHIS* | *OCHS* | *QWB* |
| *General Perceptions* | | | | | | | | | | | |
| General health | ✓ | ✓ | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | |
| Growth/Development | | | | | | ✓ | | ✓ | | | |
| Pain | ✓ | ✓ | | ✓ | ✓ | ✓ | | | | | |
| Coping | ✓ | | | | | | | | | | |
| *Risk Behaviors* | ✓ | ✓ | | | | | | | | ✓ | |
| *Social Support* | | ✓ | | | | | | | | ✓ | |

*Note:* CHIP (The Adolescent Child Health and Illness Profile (Starfield, Benger, and Ensminger 1993; Starfield et al. 1993).

COOP (The Dartmouth COOP Charts for Children and Adolescents (Baribeau et al. 1990).

FSII-R (The Functional Status II(R); Stein and Jessop 1990).

THI/CHAP (The Health Institute/Child Health Assessment Project; The Health Insititue's Child Health Assessment Project (Langraff and Abetz 1994).

HIE (The RAND Health Insurance Experiment child health status measure (Eisen et al. 1988; Eisen, Ware, and Donald 1979).

NHIS (National Health Interview Survey 1988).

OCHS (The Ontario Child Health Study (Boyle, Offord, and Hoffman 1989).

QWB (The Quality of Well-Being Scale (Mulhern et al. 1989).

Table 2: Key Aspects of Generic Child Health Status Assessment Instruments [adapted from Langraff*]

| *Instrument* | *Purpose* | *Age Range (yrs)* | *Respondent* | *Mode of Administration* | *No. of Items* |
|---|---|---|---|---|---|
| The Adolescent Child Health and Illness Profile (CHIP) | Assess physical and mental health | 11–17 | Youth | Self-administered survey | 153 |
| Dartmouth COOP Project (COOP) | Assess functioning and health-related quality of life | 8–12<br>13–18 | Child<br>Youth | Self-administered picture and word charts | 9<br>14 |
| Functional II(R) (FSII-R) | Assess general and specific health factors | 0–16 | Parent | Structured interview | Long: 43†<br>Short: 14 |
| The Health Institute Child Health Assessment Project (THI/CHAP) | Assess physical and psychosocial functioning | 0–5<br>5–15<br>10–15 | Parent<br>Parent<br>Youth | Self-administered questionnaire | 135‡<br>107‡<br>106‡ |
| The RAND Health Insurance Experiment (HIE) | Assess physical and mental functional disability | 0–4<br>5–13 | Parent | Self-administered questionnaire | 157<br>122 |
| The National Health Interview Survey (NHIS) | Epidemiologic | 0–18 | Parent | Structured telephone interview | 65 |
| Ontario Child Health Study (OCHS) | Assess prevalence of emotional and behavioral disorders | 4–16<br>12–16 | Parent<br>Youth | Interview and self-administered questionnaire | 304<br>169 |
| Quality of Well-Being Scale (QWB) | Assess applicability to pediatric oncology patients | 4–18 | Parent | Structured face-to-face interview | Not reported |

*Psychometric properties (reliability and validity) are summarized in Langraff and Abetz (1996) and in references below.

†Number of items is age dependent.

‡Psychometric evaluations of short forms are currently under way; number of items in short forms range from 25 to 50.

*Note:* The Adolescent Child Health and Illness Profile (Starfield et al. 1993).
The Dartmouth COOP Charts for Children and Adolescents (Baribeau et al. 1990).
The Functional Status II(R) (Stein and Jessop 1990).
The Health Institute's Child Health Assessment Project (Langraff and Abetz 1994).
The RAND HIE child health status measure (Eisen et al. 1988; Eisen, Ware, and Donald 1979).
The National Health Interview Survey (NHIS 1988).
The Ontario Child Health Study (Boyle, Offord, and Hoffman 1989).
The Quality of Well-Being Scale (Mulhern et al. 1989).

asthma. The conceptual and methodological challenges that exist in measuring the health status of children generically also exist for measuring the health status of children with asthma. There are several methods for measuring the health status of children with asthma: (1) physiologic measures, (2) physical findings, (3) asthma clinical symptom instruments, and (4) asthma health status instruments.

*Physiologic Measures.* Physiologic measures, such as the results of pulmonary function tests (Enright, Lebowitz, and Cockroft 1994) correlate relatively well with each other and with symptom scores at a particular point in time. However, they are often impractical (particularly for young children), and they correlate poorly with functional health status measures.

*Physical Findings.* The sensitivity, specificity, and repeatability of physical findings relative to pulmonary function tests have been measured, and the relatively poor performance of physical findings limits their usefulness for evaluating quality of care (O'Connor and Weiss 1994).

*Asthma Clinical Symptom Measures.* Several clinical symptom measures have been developed for asthma in children (Gibson et al. 1969; Mitchell and Miles, 1983; Salome et al. 1987; Usherwood, Scrimgeour, and Barber 1990; Wilson et al. 1997); they focus on the intensity, duration, and frequency of asthma symptoms.

*Asthma Health Status Instruments.* Over the past two decades asthma health status measurement has increasingly included assessment of quality of life, role performance, and functional status (Richards and Hemstreet 1994). Content areas generally include the severity and frequency of symptom episodes; the degree of specific respiratory symptoms, such as cough or wheeze; the extent of physical activity limitation, such as exercise intolerance; and the degree of limitation of functional activities, such as school attendance. There are a number of published examples of asthma-specific health functional status measures for children (American Institutes for Research 1984; Wilson 1991; Creer et al. 1988, 1992; Creer, Marion, and Crer 1983; Columbia University Department of Pediatrics 1984; Hindi-Alexander and Cropp 1981; Ellis 1983; Kiechkhefer 1987; French, Christie, and Sowden 1994; Juniper et al. 1996a,b), and others are in development.

### *Measuring Health for Children with Chronic Diseases*

The variations of asthma outcome measures illustrate the complexity of measuring health status in children with chronic diseases and highlight some difficulties in relating quality of healthcare to the health outcomes of children with chronic diseases. The first issue is that the terms biological disease severity and morbidity are different but are often used interchangeably. Disease severity connotes the extent and intensity of physiological disease, while morbidity has a broader meaning that includes suffering from the disease. Ideally, one would wish to distinguish among biological severity, morbidity from the disease, and the impact of health care on morbidity from the disease. But unfortunately, the biological severity of disease is an illusive construct to measure (Stein et al. 1987). However, researchers should describe the degree to which morbidity has been attenuated by healthcare; thus it may not matter that "biological severity" is unmeasurable.

A second issue is that morbidity from disease has both generic and disease-specific characteristics (Bauman 1994). For example, the generic characteristics of asthma include interference with sleep, play, and school. Disease-specific characteristics include exercise intolerance, cold intolerance, and degree of cough or wheeze. Both the generic and disease-specific characteristics should be measured by functional health status instruments. Thus, generic health status instruments may be useful for certain purposes, even for children with chronic diseases. For example, a recent study (Forrest et al. 1997) found that a generic health status instrument, the CHIP-AE, was useful in describing patterns of health in adolescents with asthma. Disease-specific instruments are helpful if more detailed information about a specific disease is desired, or if generic instruments are insensitive to health status variations among patients with specific diseases.

A third consideration is measuring the burden of illness on the family or on society (Stein et al. 1987). The impact of disease on family life, finances, employment, and emotional well-being can vary tremendously and can be affected by the quality of healthcare. This dimension is particularly important for children because their health outcomes are so often articulated by parents, whose perceptions are profoundly influenced by the burden of illness. Some functional status measures for asthma incorporate this dimension (Juniper et al. 1996b). The burden on society involves both current costs and future costs (e.g., loss of productivity). An important area for future research is better elucidation of this dimension in assessing both disease-specific and generic outcomes.

A fourth issue is that family, environment, and other child factors may affect the morbidity or consequences of diseases and the relationship of this effect to quality of care. For example, family stress, the impact of siblings, poverty, and comorbidities may all affect functional asthma outcomes such as the degree of wheezing or days missed from school due to asthma symptoms. Just as the burden on families from illness needs to be measured, so too the impact on morbidity from these other factors needs to be considered, whether outcomes are assessed on an individual patient level or on a population level.

Fifth, different types of health status measures may not correlate well with each other, particularly with disease-specific measures. For example, relatively poor correlations have been reported between physiologic asthma measures and functional asthma measures in adults with chronic lung disease (Alonso et al. 1992), and in children with asthma (Enright, Lebowitz, and Cockroft 1994). Disease-specific functional health status measures may be measuring different dimensions of health status than generic functional measures.

## SATISFACTION MEASURES REGARDING THE PROCESS OF CARE AND THE CONSEQUENCES OF CARE

Satisfaction has to do with meeting patients' values and expectations about the care they receive. Satisfaction varies with some patient characteristics. Poorer satisfaction with care is reported by men, the affluent, and those who are younger, more ill, and more educated. In general, most patients express high levels of satisfaction with their care, but careful measurement can identify aspects of care that are viewed less favorably.

There is no agreed-on list of domains of satisfaction, and such a list would reflect the intended use of the information to be collected. Two of the more prominent efforts to conceptualize and measure patient satisfaction are those by Davies and Ware (1991) in the Group Health Association of America's Consumer Satisfaction Survey, and by Meterko, Nelson, and Rubin (1990) in the Patient Judgments of Hospital Quality Questionnaire.

Patients usually seek care because they are distressed by symptoms related to a diminution in their functional health status or their sense of well-being. It seems logical that some aspects of their satisfaction with care would reflect the degree to which they feel that the problem that led them to seek care has been addressed and, one hopes, resolved. In addition, satisfaction with care has been shown to predict other outcomes such as compliance with treatment recommendations. A number of measures of satisfaction have been developed specifically for use with children and/or their parents (Lewis et al. 1986; Rifkin et al. 1988; Simonian et al. 1993). The key issue in using satisfaction measures as indicators of health status is the ability to distinguish satisfaction with care from satisfaction with quality of life. Here again the issue of proxy respondents is relevant because parent satisfaction might be different from child satisfaction.

### COST-RELATED MEASURES OBTAINED FROM ADMINISTRATIVE, CLAIMS, OR ENCOUNTER DATA

Cost-related measures obtained from claims files, or from administrative or encounter data, have been used to assess the health status of populations. These data are relatively available and do not require additional primary data collection. In addition, since healthcare costs and the distribution of resources are two major forces currently shaping health policy in the United States, analyses of cost-related measures become relevant.

Cost-related measures have some usefulness as measures of quality of care when they are used in assessing the utilization of specific types of services at a population level. For example, there is a major policy thrust to enhance the delivery of preventive care and primary care (DHHS 1990), and to reduce subspecialty, emergency department, and hospital care. Cost-related data can assess the use of different levels of care and describe the types of health problems noted on claims. In addition, there is great potential to use these cost-related data for risk adjustment for patients with chronic conditions.

On the other hand, many experts believe that cost-related measures are actually process measures, and that we expend resources to achieve outcomes rather than seeing resource use as an outcome in itself. The large variations in access to care make cost-related data difficult to interpret: lack of costs may reflect lack of access as well as lack of morbidity.

## USE OF HEALTH STATUS MEASURES IN ASSESSING THE QUALITY OF CHILD HEALTHCARE

How can generic or disease-specific instruments for child health measurement be used to assess the quality of healthcare for children? Child health status is an outcome of a complex array of biologic and social factors that includes healthcare. The quality of child healthcare, then, can be assessed, in part, by the health status that is achieved or maintained, although the unique contribution of healthcare, especially of medical care, is difficult to determine and often can only be inferred.

One view of quality of care is that it rests on (1) the competence of the healthcare provider (i.e., skills and knowledge); (2) the effectiveness of the treatment that is selected; and (3) the appropriateness of the treatment to the individual patient's circumstances, values, and preferences. Child health status measures, especially those that assess functional outcomes and well-being from the perspective of the child or parent, reflect but do not directly assess all three of these elements of quality. It is particularly difficult to determine which of these three components is contributing to the outcome when generic measures of child health are being used, because generic measures so largely reflect the effects of factors other than the quality of medical care. Consequently, generic measures are likely to find their greatest use in the assessment of the health of populations in relation to social circumstances or to the organization or financing of systems of care. Unlike conventional clinical outcome measures, their use in quality assessment does assure that some aspects of the child's perspective are represented. In the clinical setting, the use of generic measures can improve quality by providing a timely, standardized assessment of health status.

Disease-specific measures that include the assessment of both diagnostic and therapeutic processes, as well as measures of functioning and well-being, are more comprehensive and better measures of the quality of care for children with chronic conditions. Quality of care assessment that contributes to improved quality promotes an understanding of the relationships between the structure, process, and outcome of care. Well-designed disease-specific measures of child health status allow this to happen. However, both their development and their application are time-consuming, so their use is likely to be restricted to significant chronic health problems of relatively high prevalence or expense, or both.

## RESEARCH AGENDA IN CHILD HEALTH STATUS

### DEFINING CHILD HEALTH AND HEALTHCARE

Too often overlooked is the need to agree on what is meant by child health. There are various definitions of child health and incomplete consensus on the domains that should be included. These differences of opinion arise, in part, from the different reasons why health can be measured. Defining health is far from an academic undertaking, because the way child health is defined, that is, what is chosen to be valued, is what will be measured and acted on. It may not be feasible or wise to attempt to derive an empirical definition of health, and so the process must be consensual and conceptual. While awaiting consensus on the precise definition and boundaries of child health, it would be very useful to reach some consensus regarding the core dimensions of child health status, including functional health status and well-being. Dimensions that probably should be included are physical, emotional, and social health; health behaviors; development/education; and some aspects of family health and functioning.

A second critical and fundamental question to be addressed concerns identifying the boundaries of medical care system responsibility for the health of children. Health insurance plans base coverage on their determination of medically necessary services. What is medically necessary care? And what is the impact of medical care, including traditional and new technological interventions, on health status? Much more study is needed to evaluate the effects of various non-conventional services and service providers on children's health, particularly on the health of poor children and that of children with chronic health problems.

## MEASURING CHILD HEALTH

A second broad category of inquiry relates to the measures and measurement of child health. Child health research depends on having valid and reliable measures of child health that allow the comparison of outcomes of various interventions and determinants of health. More research is needed in areas unique and particularly problematic to measuring child health status. These include (1) devising developmentally equivalent measures for different ages; (2) adjusting assessments and analyses to take into account broad ranges of normalcy; (3) determining the value and trade-offs of proxy respondents; (4) identifying assessment formats (i.e., approaches to data collection) that work with children; (5) adapting measures to benefit from what is known about sensitive or critical periods of child development during which some aspects of health are more important than they are at other times; and (6) developing measures sufficiently sensitive to detect changes in health status over time. Special attention to the development of health status measures for infants and young children is needed.

Several psychometrically sound generic and disease-specific health status and functional outcome measures are already in use for children. However, they are not widely used in clinical practice or in health services or policy research. Some need to be modified to be applicable to other groups of children (i.e., defined by socio-demographics or health condition) and easier to use. All need to become better known and more readily available. It remains to be seen whether the use of these measures in clinical practice will improve the quality of care.

The existing health status and functional outcome measures should be applied to large populations of children, with oversampling of vulnerable populations, including children of different ages, cultures, socioeconomic backgrounds, family characteristics, environmental characteristics, and chronic conditions. Information about the prevalence of functional limitations among groups of children and about the natural history of many chronic conditions is scant. The impact of access to healthcare and of new methods of care delivery or financing should be evaluated, especially on high-risk subgroups.

## FACTORS THAT INFLUENCE CHILD HEALTH

The third, and largest category of research includes the more familiar questions addressed by health services researchers.

### *Social Determinants*

Many factors that affect child health status are derived from social, environmental, or family characteristics. Since the boundaries between medical care and social or human services are so fuzzy, and since an increasing number of interventions combine social services with more traditional medical care, further study is needed to assess the relative impact and interaction of these types of interventions on child health. Studies of outreach, care coordination, family-focused and family-directed care, and public health–private sector collaboration are all examples of important investigations in this area. The relationship between family functioning and child health outcomes, particularly functional outcomes, is in need of more study.

### *Clinical Interventions*

Much of pediatric care is based on personal and peer experience rather than on structured research. It is important to evaluate new and existing therapies more formally with regard to their effects on child health status. Many ethical dilemmas related to children's participation in clinical research are being resolved, and there will be more occasion to apply health status assessment to children in the context of research. The ultimate yardstick by which medical interventions, including technologies, should be measured is their effect on health status and functioning. Among the opportunities to apply health status assessment is the pressing need to study the links between preventive care, risk behaviors, and functional status and well-being. The field of child health care needs much more evidence that current services are effective if they are to continue to be supported. In addition, new, alternative, or unconventional treatments are frequently being proposed for children, especially those with chronic diseases. Their effectiveness should be measured, ideally using disease-specific health status measures. Finally, new measures of child health status should be applied to research testing the impact of continuity, comprehensiveness, and other aspects of care on child health.

### *Healthcare Financing*

Cost-containment strategies potentially threaten children's access to effective and appropriate healthcare. Populations of poor children and of children with chronic health problems may be particularly vulnerable to marketplace behaviors that fail to respond to special healthcare needs. Further study is needed on the effects (both positive and negative) of different types of managed care on health status, in particular for children at high risk because of biological or social factors. Most states are moving their Medicaid programs from fee-for-service to managed care. Some research suggests that poor people may fare worse in prepaid healthcare systems, and these state-level changes merit careful study. In addition, the children's health insurance legislation signed by President Clinton in August 1997 (Children's Health Insurance Program 1997), represents a potentially major shift in the financing of healthcare for poor children. The impact of changes in healthcare access and delivery resulting from this legislation, as well as from other recent changes such as Welfare reform, should be evaluated with an emphasis on child health status.

### *Organizational Change*

In addition to the transition to managed care, the healthcare system is experiencing unprecedented changes in the organization of services. Some examples include a shift from hospital care to outpatient care, and shifts from the public sector as a care giver to the private sector. Current trends are leading to a reevaluation of what personnel are needed to provide child health services. For example, what is the role of the pediatrician or the pediatric subspecialist? Assigning new or different responsibilities to healthcare practitioners has implications not only for the patterns of service delivery and reimbursement, but also for professional education. New professions may evolve and existing professions may require different skills and orientations. The effects of these organizational changes should be evaluated.

### *Quality Improvement*

Within the avalanche of initiatives to assess, manage, and improve the quality of healthcare, children's health care largely has been neglected. It is crucial to understand more fully the link between quality of care and child health status. In many situations it is and will remain easier to measure the process and content of medical care than to measure health status directly. Therefore, it is essential to achieve a better understanding of the relationships between the structure, process, and outcomes of child health care.

## SPECIAL PRIORITY: CHILDREN AT RISK

Child health indicators have long received special attention, in part because the health of children has been viewed as a sensitive barometer for the health of society. Within the larger population of children, those with special health-care needs because of higher biologic and social risk are especially likely to be affected by changes in the healthcare system. Subgroups of children with chronic health problems or disabilities; racial and ethnic minorities; children in families burdened by high levels of social stress; and children otherwise disenfranchised, including the homeless and those in foster care, all differ from the general pediatric population with respect to baseline health status, measurement issues relating to functional status, and needs for care and services. Within all of the research areas mentioned in this article, special and separate attention should be given to these high-risk children and their families.

## REFERENCES

Adesman, A. R., and G. A. Walco. 1993. "Validation of the Charleston Pediatric Pain Pictures in School-Age Children." *Journal of Clinical and Child Psychology* 21 (1): 10–13.

Alonso, J., J. M. Anto, M. Gonzales, J. A. Fiz, J. Izquierdo, and J. Morera. 1992. "Measurement of General Health Status of Non-Oxygen-Dependent Chronic Obstructive Pulmonary Disease Patients." *Medical Care* 30 (1): MS125–MS135.

American Institutes for Research. 1984. *Air Power: Self-Management of Asthma Through Group Education.* Pub. No. (NIH) 85-2362. Washington, DC: Government Printing Office.

American Medical Association. 1992. *Healthy Youth by the Year 2000.* Chicago: AMA.

Baribeau, P., D. Berger, A. Jette, S. Kairys, A. Keller, J. Landgraf, G. Wasson, and J. Masson. 1992. *COOP Functional Health Status Charts for Children and Adults: A System to Measure Functional Health Status in Physicians' Offices.* Final Report to the Henry J. Kaiser Family and the W. T. Grant Foundations. Dartmouth Medical School, 1991.

Bauman, L. J. 1994. "Discussant Section." *American Journal of Respiratory Critical Care Medicine* 149 (Supplement: *Asthma Outcome Measures*): S40–S43.

Boyle, M. H., D. R. Offord, H. G. Hoffman, G. P. Catlin, J. A. Byles, D. T. Cadmun, J. W. Crawford, P. S. Links, N. I. Rap-Grant, and P. Szatmani. 1987. "Ontario

Child Health Study: I. Methodology." *Archives of General Psychiatry* 44 (7): 826–31.

Brent, D. A. 1993. "Depression and Suicide in Children and Adolescents." *Pediatrics in Review* 14 (10): 380–88.

Bungay, P. S., and J. E. Ware, Jr. 1993. *Measuring and Monitoring Health-Related Quality of Life.* Kalamazoo, MI: Upjohn.

Bunker, J. P., H. S. Frazier, and F. Mosteller. 1995. "The Role of Medical Care in Determining Health: Creating an Inventory of Benefits." In *Society and Health,* edited by B. C. Amick, S. Levine, A. R. Tarlov, and D. C. Walsh, pp. 305–41. New York: Oxford University Press.

Children's Health Insurance Program. P.L. 105-34. The Revenue Reconciliation Act of 1997.

Columbia University Department of Pediatrics. 1984. *Open Airways/Respiro abierto.* Pub. No. (NIH) 84-2365. Washington, DC: National Institutes of Health.

Creer, T. L., R. J. Marion, and P. P. Crer. 1983. "Asthma Problem Behavior Checklist: Parental Perceptions of the Behavior of Asthmatic Children." *Journal of Asthma* 20 (1): 97–104.

Creer, T. L., M. Backial, K. L. Burns, P. Leung, R. J. Marion, D. R. Miklich, C. Morrill, P. S. Joplin, and S. Ullman. 1988. "Living with Asthma: Genesis and Development of a Self-Management Program for Childhood Asthma." *Journal of Asthma* 25 (6): 335–62.

Creer, T. L., J. K. Wigal, H. Kotses, and J. C. Hatala. 1992. "A Life Activities Questionnaire for Childhood Asthma." Department of Psychology, Ohio University.

Deyo, R. A., and W. B. Carter. 1992. "Strategies for Improving and Expanding the Application of Health Status Measures in Clinical Settings." *Medical Care* 30 (2): MS176–MS196.

Davis, A. R., and J. E. Ware. 1991. *Consumer Satisfaction Survey and User's Manual.* Washington, DC: Group Health Association of America.

Egbuonu, L., and B. Starfield. 1982. "Child Health and Social Status." *Pediatrics* 69 (5): 550–57.

Eisen, M., J. E. Ware, and C. Donald. 1979. "Measuring Components of Children's Health Status." *Medical Care* 17 (9): 902–21.

Eisen, M., C. Donald, J. E. Ware, R. Brook. 1988. *Conceptualization and Measurement of Health for Children in the Health Insurance Study.* Pub. No. R-2313-HEW, Santa Monica, CA: RAND.

Ellis, E. 1983. "Asthma in Childhood." *Journal of Allergy and Clinical Immunology* 72 (5, Part II): 526–39.

Enright, P. L., M. D. Lebowitz, D. W. Cockroft. 1994. "Physiologic Measures: Pulmonary Function Tests, Asthma Outcome." *American Journal of Respiratory Critical Care Medicine* 149 (Supplement: *Asthma Outcome Measures*): S9–18.

Evans, R. G., and G. L. Stoddart. 1994. "Producing Health, Consuming Health Care." In *Why Are Some People Healthy and Others Not?,* edited by R. G. Evans, M. L. Baarer, and T. R. Marmor, pp. 17–64. New York: Aldine De Gruyter.

Forrest, C. B., B. Starfield, A. W. Riley, and M. Kang. 1997. "The Impact of Asthma on the Health Status of Adolescents." *Pediatrics* 99 (2): *URL:http://www.pediatrics.org/cgi9/*content/full/99/2/e1.

French, D. J., M. J. Christie, and A. J. Sowden. 1994. "The Reproducibility of the Childhood Asthma Questionnaires: Measures of Quality of Life for Children with Asthma Aged 4–16 Years." *Quality of Life Research* 3 (3): 215–24.

Garmezy, N. 1991. "Resilience in Children's Adaptation to Negative Life Events and Stressed Environments." *Pediatric Annals* 20 (9): 459–66.

Gibson, H. B., H. Silverston, B. Gandevia, and G. J. L. Hall. 1969. "Respiratory Disorders in Seven-Year-Old Children in Tasmania: Aims, Methods and Administration of the Survey." *Medical Journal of Australia* 2 (July): 201–205.

Greenfield, S., and E. C. Nelson. 1992. "Recent Developments and Future Issues in the Use of Health Status Assessments in Clinical Practice." *Medical Care* 30 (5, Supplement): MS23-MS41.

Guyer, B., D. M. Strobino, S. J. Ventura, M. MacDorman, and J. A. Martin. 1996. "Annual Summary of Vital Statistics, 1995." *Pediatrics* 98 (6, Part I): 1007–1019.

Hindi-Alexander, M., and G. J. Cropp. 1981. "Community and Family Programs for Children with Asthma." *Annals of Allergy* 46 (3): 143–48.

Jessop, D. J., and R. K. Stein. 1995. "Consistent but Not the Same: Effect of Method on Chronic Condition Rates." *Archives of Pediatrics and Adolescent Medicine* 149 (10): 1105–110.

Juniper, E. F., G. H. Guyatt, D. H. Feeny, P. J. Ferrie, L. E. Griffith, and M. Townsend. 1996. "Measuring Quality of Life in the Parents of Children with Asthma." *Quality of Life Research* 5 (1): 27–34.

———. 1996. "Measuring Quality of Life in Children with Asthma." *Quality of Life Research* 5 (1): 35–46.

Kiechkhefer, G. 1987. "Testing Self-Perception of Health Theory to Predict Health Promotion and Illness Management Behavior in Children with Asthma." *Journal of Pediatric Nursing* 2 (6): 381–91.

Landgraf, J. M., and L. N. Abetz. 1994. *The Infant/Toddler Quality of Life Questionnaire: Conceptual Framework, Logic, Content, and Preliminary Psychometric Results.* Final Report to Schering-Plough Laboratories and Health Technology Associates, New England Medical Center, Boston.

———. 1996. "Measuring Health Outcomes in Pediatric Populations: Issues in Psychometrics and Application." In *Quality of Life and Pharmacoeconomics in Clinical Trials*, 2d. ed., edited by B. Spilker, ch. 83, pp. 793–802. Philadelphia: Lippincott-Ravin Publishers.

Landgraf, J. M., L. Abetz, and J. E. Ware. 1996. *Child Health Questionnaire (CHQ): A User's Manual.* Boston: The Health Institute, New England Medical Center.

Lerner, D. J., and S. Levine. 1994. "Health-Related Quality of Life: Origins, Gaps, and Directions." *Advances in Medical Sociology* 5 (1): 43–65.

Lewis, C. C., D. E. Scott, R. H. Pantell, and M. H. Wolf. 1986. "Parent Satisfaction with Children's Medical Care." *Medical Care* 24 (3): 209–15.

Lewis, C. C., R. H. Pantell, and G. M. Keickhefer. 1989. "Assessment of Children's Health Status: Field Test of New Approaches." *Medical Care* 27 (1, Supplement): S54–S65.

Lewit, E. M., and L. Schuurmann Baker. 1996. "Children as Victims of Violence." *The Future of Children* 6 (3): 147–56.

McCormick, M. 1983. "The Contribution of Low Birthweight Infant Mortality and Childhood Morbidity." *The New England Journal of Medicine* 312 (1): 82–90.

McCormick, M. C., S. Shapiro, and B. Starfield. 1984. "High-Risk Young Mothers: Infant Mortality and Morbidity in Four Areas in the United States, 1973–1978." *American Journal of Public Health* 74 (1): 18–23.

McCormick, M. C., K. Workman-Daniels, and J. Brooks-Gunn. 1996. "The Behavioral and Emotional Well-Being of School-Age Children with Different Birth Weights." *Pediatrics* 97 (1): 18–25.

Meterko, Nelson, and Rubin. 1990. "Patient Judgments of Hospital Quality." *Medical Care* 28 (9, Supplement): 51–56.

Mishler, E. G. 1981. *Social Contexts of Health, Illness, and Patient Care.* Cambridge, MA: Cambridge University Press.

Mitchell, C., and J. Miles. 1983. "Lower Respiratory Tract Symptoms in Queensland School Children: The Questionnaire, Its Reliability and Validity." *Australian and New Zealand Journal of Medicine* 13 (3): 264–69.

National Center for Health Statistics. 1986. "Current Estimates from the National Health Interview Survey, U.S., 1985." *Vital and Health Statistics.* Series 10, No. 160. Hyattsville, MD: U.S. Dept. of Health and Human Services, September.

———. 1990. *Health, United States, 1989 and Prevention Profile.* DHHS Pub. No. (PHS) 90-1232. Hyattsville, MD: Dept. of Health and Human Services.

National Health Interview Survey. 1988. "Current Estimates from the National Health Interview Survey." *NHIS Child Health Supplement.*

National Highway Traffic Safety Administration. 1988. *Fatal Accident Reporting System, 1987.* Washington DC: U.S. Department of Transportation.

Newacheck, P. W. 1994. "Poverty and Childhood Chronic Illness." *Archives of Pediatric Adolescent Medicine* 148 (11): 1143–49.

Newacheck, P. W., and B. Starfield. 1988. "Morbidity and Use of Ambulatory Care Services Among Poor and Nonpoor Children." *American Journal of Public Health* 78 (8): 927–33.

Newacheck, P. W., and J. J. Stoddard. 1994. "Prevalence and Impact of Multiple Childhood Chronic Illnesses." *Journal of Pediatrics* 124 (1): 40–48.

Newacheck, P. W., and W. R. Taylor. 1992. "Childhood Chronic Illness: Prevalence, Severity, and Impact." *American Journal of Public Health* 82 (3): 364–71.

O'Connor, G. T., and S. T. Weiss. 1994. "Clinical and Symptom Measures." *American Journal of Respiratory Critical Care Medicine* 149 (Supplement: *Asthma Outcome Measures*): S21-S28.

Perrin, E. C., P. Newacheck, I. B. Pless, D. Drotar, S. L. Gortmaker, J. Leventhal, J. M. Perrin, R. E. Stein, D. K. Walker, and M. Weitzman. 1993. "Issues Involved in the Definition and Classification of Chronic Health Conditions." *Pediatrics* 91 (4): 787–93.

Richards, J. M., and M. P. Hemstreet. 1994. "Measures of Life Quality, Role Performance, and Functional Status in Asthma Research." *American Journal of Respiratory Critical Care Medicine* 149 (Supplement: *Asthma Outcome Measures*): S31-S39.

Rifkin, L., M. H. Wolf, C. C. Lewis, and R. H. Pantell. 1988. "Children's Perceptions of Physicians and Medical Care: Two Measures." *Journal of Pediatric Psychology* 13 (2): 247–54.

Rosenbaum, S., C. Layton, and J. Liu. 1991. *The Health of America's Children.* Washington DC: Children's Defense Fund.

Salome, C. M., J. K. Peat, W. J. Britton, and A. J. Woolcock. 1987. "Bronchial Hyperresponsiveness in Two Populations of Australian Schoolchildren." *Clinical Allergy* 17 (4): 271-81.

Schor, E. L., and E. G. Menaghan. 1995. "Family Pathways to Child Health." In *Society and Health,* edited by B. C. Amick, S. Levine, A. R. Tarlov, and D. C. Walch. New York: Oxford University Press.

Schor, E. L. 1995. "The Influence of Families on Child Health." *Pediatric Clinics of North America* 42 (1): 89–102.

———. 1997a. "Children's Health and the Assessment of Health Related Quality of Life." In *Measuring Health-Related Quality of Life in Children and Adolescents,* edited by D. Drotar, pp. 25–37. Mahwah, NJ: Erlbaum Associates.

———. 1997b. "Measurable Development in Parents: A Goal of Effective Primary Pediatric Care." *Zero to Three.* June/July: 41–43.

Simonian, S. J., K. J. Tarnowski, A. Park, and P. Bekeny. 1993. "Child, Parent, and Physician Perceived Satisfaction with Pediatric Outpatient Visits." *Journal of Developmental Behavior Pediatrics* 14 (1): 8–12.

Singh, G. K. S., K. D. Kochanek, and M. S. MacDorman. 1996. "Advance Report of Final Mortality Statistics, 1994." *Vital Statistics Report* 45 (30 September): 1–33.

Starfield, B. 1973. "Health Services Research: A Working Model." *The New England Journal of Medicine* 289 (3): 132–36.

———. 1985. *The Effectiveness of Medical Care: Validating Clinical Wisdom. Baltimore,* MD: The Johns Hopkins University Press.

———. 1987. "Child Health Status and Outcome of Care: A Commentary on Measuring the Impact of Medical Care on Children." *Journal of the Chronicals of Disease* 40 (1, Supplement): 109S–115S.

———, 1991a. "Primary Care and Health: A Cross-National Comparison." *Journal of the American Medical Association* 266 (16): 2268–71.

———. 1991b. "Childhood Morbidity: Comparisons, Clusters, and Trends." *Pediatrics* 88 (3): 519–26.

———. 1992. "Effects of Poverty on Health Status." *Bulletin of New York Academic Medicine* 68: 17–24.

Starfield, B., A. W. Riley, B. F. Green, M. E. Ensminger, S. A. Ryan, K. Kelleher, S. Kim-Harris, D. Johnston, and K. Vogel. 1995. "Adolescent Child Health and Illness Profile: A Population-Based Measure of Health." *Medical Care* 33 (5): 553–66.

Starfield, B. and P. P. Budetti. 1985. "Child Health Status and Risk Factors." *Health Services Research* 19 (6, Part II): 817–86.

Starfield, B., M. Bergner, M. Ensminger, A. Riley, S. Ryan, B. Green, and M. McGauhey. 1993. "Adolescent Health Status Measurement: Development of the Child Health and Illness Profile." *Pediatrics* 91 (2): 430–35.

Stein, R. E. K., E. C. Perrin, I. B. Pless, S. L. Gortmaker, J. M. Perrin, D. Klein Walker, and M. Weitzman. 1987. "Severity of Illness: Concepts and Measurements." *The Lancet* 26 (December): 1506–509.

Stein, R. E. K., and D. J. Jessop. 1990. "Functional Status II (R): A Measure of Child Health Status." *Medical Care* 28 (9): 1041–55.

Streiner, D. L., and G. R. Norman. 1989. *Health Measurement Scales: A Practical Guide to Their Development and Use.* New York: Oxford University Press.

Tarlov, A. R., J. E. Ware, S. Greenfield, E. C. Nelson, E. Perrin, and M. Zubkoff. 1989. "The Medical Outcomes Study: An Application of Methods for Monitoring the Results of Medical Care." *Journal of the American Medical Association* 262 (7): 925–29.

U.S. Department of Health and Human Services [DHHS]. 1990. *Healthy People 2000: National Health Promotion and Disease Prevention Objectives.* Washington, DC: DHHS.

Usherwood, T. P., A. Scrimgeour, and J. H. Barber. 1990. "Questionnaire to Measure Perceived Symptoms and Disability in Asthma." *Archives of Diseases in Children* 65 (7): 779–81.

Valdez, R. B., R. H. Brook, W. H. Rogers, J. E. Ware, Jr., E. B. Keeler, C. A. Sherbourne, R. N. Lohr, G. A. Goldberg, P. Camp, and J. P. Newhouse. 1985. "Consequences of Cost-Sharing for Children's Health." *Pediatrics* 75 (5): 952–61.

Valdez, R. B., J. E. Ware, W. G. Manning, R. H. Brook, W. H. Rogers, G. A. Goldberg, and J. P. Newhouse. 1989. "Prepaid Group Practice Effects on the Utilization of Medical Services and Health Outcomes for Children: Results from a Controlled Trial." *Pediatrics* 83 (2): 168–80.

Wilson, I. B., and P. D. Cleary. 1995. "Linking Clinical Variables with Health-Related Quality of Life: A Conceptual Model of Patient Outcomes." *Journal of the American Medical Association* 273 (1): 59–65.

Wilson, S. R. 1991. *Wee Wheezers Asthma Education Program: Parent's Enrollment Form.* Palo Alto, CA: American Institutes for Research.

Wilson, S. R., D. Latini, N. J. Starr, L. Fish, L. M. Loes, A. Page, and P. Kubic. 1996. "Education of Parents of Infants and Very Young Children with Asthma: A Developmental Evaluation of the Wee Wheezers Program." *Journal of Asthma* 33 (4): 239–54.

Wise, P. H., M. Kotelchuck, M. L. Wilson, and M. Mills. 1985. "Racial and Socioeconomic Disparities in Childhood Mortality in Boston." *The New England Journal of Medicine* 313 (6): 360–66.

World Health Organization. 1948. *World Health Organization Constitution.* In *Basic Documents,* Geneva: WHO.