

**Child Health Needs Assessment:
A Review of Data Sources to Measure Child Health Status**

A Technical Resource Brief

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for the

**Maternal and Child Health Bureau
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**Child Health Needs Assessment: A Review of Data Sources to Measure Child Health Status.
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The **Child and Adolescent Health Policy Center (CAHPC)** at the Johns Hopkins University was established in 1991 by the federal Maternal and Child Health Bureau as one of two Centers to address new challenges found in amendments to Title V of the Social Security Act (MCH Services Block Grant) enacted in the Omnibus Budget Reconciliation Act (OBRA) of 1989. The purpose of the Center is to draw upon the science base of the university setting to help identify and solve key MCH policy issues regarding the development and implementation of comprehensive, community-based systems of health care services for children and adolescents. Projects are conducted to provide information and analytical tools useful to both the federal MCH Bureau and the State Title V Programs as they seek to meet the spirit, intent and content of the Title V legislation and the challenges of addressing the unique needs of MCH populations and programs in health care reform.

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INTRODUCTION

The shape that health care reform may take in the next decade and beyond is unknown. Yet, under most scenarios, the role of the public health sector in the health care system will likely undergo considerable change. While it seems appropriate for public health agencies to take a greater role in accountability and monitoring of health services and the health of the population, both capacity and methodologies need to be developed in order to effectively achieve this role. Assessment of the need for health services and assurance that needed and effective services are available, accessible and utilized by a population are critical public health functions that are vitally important to Maternal and Child Health (MCH).

To date, attempts at characterizing the health of the maternal and child health population have been eclectic at best. Too frequently, data are pieced together from available sources that have few commonalities, such as similar at-risk populations or standard definitions. The picture that emerges from these data does not provide a systematic account of the health status or health needs of children in the population. The most frequent problems faced by children and families and their actual health needs are seldom described.

This paper is the first of a technical series describing data sources and methodologies for state needs assessments for the child population. Its major focus is a discussion of several potential sources of data that may be particularly useful in supplementing current efforts to develop an integrated picture of child health status. The development of these databases is a high priority because they provide information useful for planning for population-based services and for carrying out the core public health functions of assessment, assurance and policy development. We also present the results of a review of the needs assessments for child health in the FY 1993 state Title V Block grant applications, and offer a number of indicators that can be used to measure health status.

This paper is organized into several parts. First, we briefly describe our analysis of current state efforts to measure the health status of children and the results of this analysis as a prelude to a discussion of supplemental data sources. A description is then presented of data sources that could be used to supplement current needs assessment efforts, and that may be particularly useful for states for developing population-based services and for evaluating health care reform. In this section, we cover the scope of the data that can be used to measure child health status from each source. The paper ends with a discussion of the priorities in achieving an integrated set of databases useful in measuring health status of children.

REVIEW OF STATE EFFORTS

A review of the needs assessments for the child health component of the FY 1993 state applications for Title V Block Grant funds was conducted to gather background information for this technical report. Information was abstracted from the needs assessment for each state, including indicators and sources of data used to measure health status, use of health care, and the availability of health care resources for children.¹ Two tables were generated for this information. Table 1 lists indicators of child health status by data source and Table 2 lists the advantages and disadvantages of these data sources for needs assessment. These tables are included in the Appendix.

DATA SOURCES AND INDICATORS USED BY STATE PROGRAMS

An array of data sources are currently used by state MCH Programs to measure health status including vital records, reportable diseases data, hospital discharge data, registries, screening program data, Title XIX data, the CDC Pediatric Nutrition Surveillance data, data from the Departments of Education and Social Services, and community survey data. Figure 1 classifies these data sources by their frequency of use among states and by the potential quality of the data available from each source. *Use* means that more than a third of the state MCH programs used the data to measure health status of children, even if only on a limited basis. *Quality* of the data source was defined using four criteria. The data source was determined to be of reasonable quality if it: is population-based; provides the opportunity to obtain accurately reported information in terms of completeness of coverage and content; includes information about serious health problems or problems in need of treatment; and identifies the scope of health problems to be addressed. Our application of the criteria for quality is based on the potential of the data source to meet the criteria.

Vital records data are widely used by state MCH programs and meet the criteria for reasonable quality, as defined above. They will not be discussed further here except to make a few comments on their use. Because these data are population-based and universally available in all states, they are used in some manner to measure health status in all states. Data available from vital records includes measures of the health status of the newborn, such as birth weight and Apgar scores, from birth certificates and data on cause of death from death certificates. While these data provide important information on the causes of death in children, they must be

¹ Abstraction of the data from the reports was performed by three abstractors who cross-checked their work before beginning the extensive review process. The abstracted data were entered into a personal computer based on whether or not the indicator was used to measure health status, the use of health services or the availability of health care resources. The indicators and data sources were then listed by these three content areas separately for each state, and were used to make a running list of all indicators and data sources used by all states. This running list was, then, organized by data source and compiled into a table outlining an unduplicated, master list of indicators used by the state MCH programs to measure health status, the use of health services and the availability of health care resources.

Figure 1

**Sources of Data on Health Status of Children
by Quality of the Data and Use by State MCH Programs**

		QUALITY OF DATA	
		Meet Criteria	Do Not Meet Criteria
USE	Widely Used by State Programs	Birth Records Death Records	Reportable Diseases Department of Social Services Department of Education
	Less Widely Used by State Programs	Hospital Discharge Data Registries Community Surveys	Title XIX Data CDC Pediatric Nutrition Surveillance Screening Program Data

combined with data from other sources in order to assess the full range of health problems experienced by children in a population.

Data on reportable diseases are also widely used by states, but these data do not meet the criteria for reasonable quality, as defined for this paper. They are incompletely reported, but, unlike many other sources for which incompleteness is a problem, the selective nature of the under-reporting of reportable diseases seriously affects the conclusions that can be made about population groups at risk for these diseases. Moreover, the amount of effort that would be needed to improve the quality reporting is likely to outweigh the value gained from improved data.

Data from the Departments of Education and Social Services also do not meet the criteria for quality, although they are widely used by most states. Few of the indicators that are obtained from these data actually measure health status. Thus, they do not meet the fourth criteria that the scope of health problems are identified by the data source. Moreover, the data from Social Services about child abuse and neglect are not only markedly under-reported, but also are selectively reported for minority and low income groups. Screening program data may also be selectively reported depending on the extent to which the screening program is universally implemented in a community.

There are other data sources that are used by some MCH programs, although not by a majority, which do not meet the criteria for quality. They include Title XIX data and the CDC Pediatric Nutrition Surveillance (PNS) data system. The CDC PNS data are not population-based. The diagnostic data available from Title XIX are a potential source of data about the health status of the Medicaid enrolled population. These data, however, are population-based only to the extent that Medicaid enrollment is universal among the eligible population. Thus, these data may not only be incomplete but they may also not be accurately reported because of their link to Medicaid reimbursement.

The final group of data sources are sources that are not widely used by state MCH programs, but which approach the criteria for potential quality. Some, like hospital discharge data and the adolescent risk behavior survey, have been used effectively in some states. These data sources also include registries and other community surveys, both of which have the potential to provide reasonably complete data, if properly designed. Their usefulness is explored more fully in the following sections.

RECOMMENDED DATA SOURCES FOR EXPANDING NEEDS ASSESSMENTS

The data sources described below can be used to provide a more integrated picture of the health care needs of children in the population than is currently available through the piecing together of routinely available data sources. Each data source is explored separately to evaluate its potential advantages and disadvantages and the type of data that could be used to form a more complete picture of child health care needs. In this discussion, we stress the usefulness of these data sources to measure health status. Many sources may also be useful in measuring use of services and resources, and will be discussed further in later papers in this series of technical resource briefs.

The data sources that are recommended include: hospital discharge data to obtain information about the reasons for hospital admissions among children; registry data to obtain information about rare events such as birth defects and cancer among children for whom the costs in terms of dollars and human suffering may be high; ambulatory care surveys to obtain information about the common problems for which families seek health care for their children; and special population surveys to obtain information about the need for population based services that are not addressed in the personal health care system.

Hospital Discharge Data

The first potentially useful source of data for measuring health status of children are hospital discharge data. These data are used by about twenty percent of state MCH programs to measure the conditions for which children are hospitalized, often with special focus on injuries. Table 1 in the Appendix shows the indicators that are used by state MCH program staff.

Hospital discharge data have been collected in the United States since 1965 through a continuous nationwide sample survey of short stay hospitals (Graves, 1986, 1989, 1992, 1994; NCHS, 1988; Simmons, 1970). These data provide information about diagnoses and multiple diagnoses, procedures and multiple procedures, and average length of stay for hospital in-patient admissions. A uniform abstraction form is used to transcribe data from the discharge summary face sheet of the hospital record, with abstraction done either by hospital staff or representatives of the National Center for Health Statistics (NCHS). Since 1985, an computerized method has also been available to hospitals (Kovar, 1989). The importance of the national data is that they provide a uniform source of comparative data as well as a resource for state MCH programs for the technical procedures used in data collection and estimation.

Hospital discharge data may be collected at the state level through a complete census of the discharges from hospitals in smaller states such as Rhode Island, while in larger states, sampling of hospitals or records within hospitals is probably a more cost efficient approach. Automation of hospital records has greatly enhanced the potential to obtain discharge data, although the data specific to children must be separated from the data for all discharges. The usefulness of these data to measure the health status of children in the population depends largely on the extent to

which either a complete census or representative sample of hospital discharges can be obtained within a community. If this approach is not possible, then the characteristics of nonparticipating, eligible hospitals should, at the very least, be taken into account when using the data in states where reporting is completely voluntary and no systematic sampling is performed.

A major advantage of hospital discharge data is that they provide information about the most common diagnoses for which children are hospitalized. Because of the expense and potentially traumatic effect of hospitalization for children, this information is particularly important in assessing health care needs. Moreover, it provides the state program with information about serious morbidity in addition to the data available from vital records about the common causes of death. Hospital discharge data are particularly useful in looking at injuries, because they represent the most common reason for hospitalizations of children over the age of one. The international classification of disease (ICD) is most commonly used to classify the discharge diagnoses; this classification system includes codes for injuries and other external causes.

Hospital discharge data can be used to compute rates of hospitalization by diagnosis, using the discharge numbers in the numerator and census data for the catchment population in the denominator. Herein, however, lies one of the disadvantages of hospital discharge data. Hospital discharge data, even though they may include all or a representative sample of discharges, may not be easily related to a population of children. They may not include all children who are hospitalized from a specific catchment population or may include children who are not from the catchment population. Accordingly, it is important to collect data about area of residence when developing a hospital discharge database. If residence data are not available, the estimates of rates must be made with caution and with some understanding of the usage patterns of hospitals in the geographic area.

Hospital discharge data have other disadvantages. They are based on the diagnoses reported on discharge summaries, which may be inaccurately reported because of their link to reimbursement. As noted above, some uniformity of the data can be achieved if the ICD codes are routinely used by hospitals. A second disadvantage is that the discharge data are confined to inpatient admissions and, thus, do not cover the full range of morbidities that children experience. Other data sources described below more adequately cover this range.

Registries

The next data source potentially useful to state MCH programs is registries. Three registries may be particularly useful for different reasons: birth defects, tumor and trauma registries. Birth defects and tumor registries are important because they include conditions that are rare, but for which the medical care costs and personal costs to the family may be great. The number of children with these rare conditions is likely to be very small using other data sources, and estimates of their prevalence will, accordingly, be unstable. The trauma registries are important because of the prominence of injuries as a major cause of morbidity and mortality among children.

In addition to providing numerator data for prevalence rates of birth defects, cancer or trauma among children, registries are particularly useful as a sampling frame for more detailed studies. These more detailed studies include not only studies of the etiology of conditions, but, more importantly, for MCH state programs, the possible reasons for geographic or subgroup variation in prevalence rates. This latter purpose is an important reason for developing a trauma registry. There are other data sources that can be used to estimate the extent of injuries in the population such as hospital discharge data and data from ambulatory care surveys.

There are three major drawbacks of registries. The first is that they are narrow in focus, and, as a result, provide useful data about a limited number of problems for children. As noted above, for rare problems, however, registries may be the only valid source of data. Second, they require considerable start up costs in terms of manpower time and should have some element of active surveillance by a health department or related team to assure validity, which necessitates on-going manpower costs. A third drawback is that more passive registry systems require the active participation of health care providers in the community. Incentives for their participation and assurances of feedback of the information from the registry must be developed for providers in order to insure that these more passive systems work effectively. Several states² have considerable experience with the use of registries that can be drawn upon to facilitate their development or to improve their quality in other states.

Ambulatory Care Surveys

A third potential source of data for assessment of health status of children is ambulatory care surveys. These surveys are conducted on a sample of providers in a given area about the conditions for which individuals seek out-patient care, and are based on compilation of data about patient encounters. There is considerable national experience with these surveys for, at least, office-based physicians, who comprise the largest source of ambulatory care in the United States (Bryant & Shimizu, 1988; McCaig, 1994; Tenney, White, & Williamson, 1974; Schappert, 1992, 1993, 1994). The national survey was extended to hospital outpatient and emergency departments in 1991 (McCaig, 1994). Data collection instruments and sampling procedures are available through publications of NCHS (Nelson & McLemore, 1988; McCaig & McLemore, 1994).

The ambulatory care survey data are an important source of information about physicians' diagnoses and patient symptoms noted during physician-patient encounters. They are, perhaps, the only source of data that directly measure the need for primary care among children, except for population-based surveys such as the National Health Interview Survey (NHIS). If the ambulatory care surveys are combined with estimates of the number of children who receive care from providers in the survey, then they can be used to estimate prevalence rates of conditions among children for which primary care will be needed.

² California and North Carolina have considerable experience with birth defects registries while Connecticut and New Mexico have experience with cancer registries.

There are a number of limitations of the ambulatory care surveys. The first is that they are based on data about encounters, not patients. Thus, some attempts must be made to translate the encounter data into estimates for individual children. The second is that the survey is based on the cooperation of individual providers in completing abstraction forms about encounters during a short sampling period. Although these forms take only a few minutes to complete per encounter, they are still a burden to the provider, and may not be completed by the very providers from whom the data may be most important to collect. In the case of the national survey, response rates have been of the order of 70 percent (Tenney, et al., 1974; Schappert, 1994).

The third limitation of these surveys, and perhaps the most important, is that they are based on data obtained from health facilities, and do not include information about children with health problems for whom health care was not sought. Again, these children are likely to be the very ones for whom the MCH state program will have the most difficulty in assuring access to health care. This problem may become increasing more important as states approve policies such as proposition 187 in California. A final limitation of these data is that they are unlikely to capture much information about children with special health care needs unless a large sample of encounters is taken. This is a costly way to obtain information about children with special health care needs.

Community Surveys

A final source of data for measuring health status of children are community surveys. They are periodic surveys conducted on the entire child population or subgroups within a community or state. Although they can provide potentially important information about health problems for all children as well as problems for which primary care may not be the specific focus, they are particularly important for providing data about the need for population-based services such as health or family life education, ancillary services, etc. The adolescent risk behavior surveys noted in Tables 1 and 2 are a good example of surveys with the latter purpose. Moreover, NCHS is currently considering sampling for the NHIS within states so that the data collected through the national survey can be made more useful to them.

Community surveys have a number of advantages. They permit state programs to periodically undertake an assessment of problems that are emerging as well as ones that continue to be of concern. If properly planned, they can yield reliable estimates of health conditions and problems for a representative sample of the population. On the other hand, these surveys can be quite costly if a high degree of precision is needed or if the survey requires a large sample to assess more rare conditions in a population (such as with assessments of children with special health care needs). They may require potentially more resources than other approaches as well as considerable forethought about what to do with the data, once obtained. The analysis of the data is often the nemesis of these surveys because an analysis plan was not considered at the time of survey development.

Other Data Sources

One other type of data source warrants mention here; they are qualitative data sources such as focus groups and in-depth interviews with key informants. These data sources have the advantage of providing a richness of information about health problems and health care access, in particular, from a small number of people that can not be obtained from the more population-based data described above. They are, nevertheless, limited with regard to assessment of health status in a population because of the small numbers of individuals who are evaluated. They have considerable importance, however, in the development of client friendly health services. Their use for this purpose will be emphasized in subsequent papers in this technical series.

A less costly alternative to the ambulatory survey or a household survey that has immediate results are small surveys that address a limited number of health problems for a defined geographic area. These surveys require less ongoing resources than their larger relatives, and are particularly useful for addressing emerging problems. Sampling of respondents can also be planned to reduce the problems with generalizability of the data that often arise with more qualitative approaches to data collection, like focus groups.

ESTABLISHING PRIORITIES FOR THE COLLECTION OF DATA TO MEASURE CHILD HEALTH STATUS

The above data sources, if collected by a state MCH program and when supplemented with data from vital statistics and other high quality routinely available data sources, could provide a more integrated picture of the health status needs of children in a population than is currently available through the eclectic use of available data by state MCH programs. Collection of the data will require a commitment by many state programs to their development in terms of new staff and resources and a systematic plan for their periodic collection. While registries are collected on an on-going basis, survey data can be collected at periodic intervals; all do not need to be collected each year. In fact, systematic, incremental data collection which assures that related databases can still be linked closely in time will likely result in the most efficient use of state resources and staff.

The development of an integrated data system to assess the health status of children does not mean that the data sources mentioned above need to be collected by or housed in one agency. It can also mean coordination of data collection efforts between relevant agencies, with sharing of data among these agencies. Indeed, if this sharing of data means that additional resources available for the collection of each data source above that which can be provided by one agency alone, then it is a cost efficient way of obtaining quality data for each agency.

The development of an integrated data system has been compromised in state MCH programs because of insufficient resources and expertise and competing priorities between service provision and database development. In order to increase the likelihood that state MCH programs continue to play a key role in reform initiatives, they will increasingly need to be visibly performing relevant data functions. Development of an integrated database for child

health status will be important in securing a visible role of MCH programs in health reform. It will place the MCH program as the lead agency for monitoring the health status of the population. As such, it will also have an important role in monitoring the health care of children, and in making recommendations for changes in services for a population.

Development of an integrated database does not need to happen tomorrow. Incremental development of these databases is a practical approach. Once the commitment is made, the decision must be made regarding which data bases to develop first. Hospital discharge data may be the most cost efficient data source to develop first. Several states already use these data effectively to measure the health status of children³. Even in states where they are not currently being used, a system may already be in place or could be more easily developed for the collection of hospital discharge data than for the other data bases. These data also should take less staff and resources to develop than registries.

The second priority for database development is the ambulatory care survey. A major rationale for this priority is that this database is also useful for developing an inventory of resources available to children in a geographic area, which will be discussed in the next paper in this technical series. In order to conduct the ambulatory care survey, a listing of office-based physicians, free standing clinics, hospital outpatient departments and other ambulatory care providers is needed. This listing is useful in estimating resources available for children in the community. Another reason why the ambulatory care survey should receive priority consideration is that it gives a good approximation of the demand for health care, based on the conditions for which children currently receive care. When combined with the hospital discharge data, the two databases form a reasonably complete, although health facility based, look at the health needs of children. More systematic collection of data from screening programs would also be a good adjunct to these data.

These recommendations for database development are based on current databases available to most MCH programs. More optimal, but, perhaps, more costly, alternatives exist for database development. One such alternative is periodic household surveys of the maternal and child health population either as a primary focus or through an MCH supplement to an on-going household survey. This survey can include the data collected in other community surveys combined with questions about health care use as an alternative to the ambulatory care survey. It may be a more efficient approach to collection of data on the MCH population. It may be possible if the NHIS data become available within states to piggy-back data collection with NCHS; this collaboration will be feasible only if NCHS develops a more state-oriented approach to sampling for the NHIS. A major advantage of collecting data through a household survey is that it provides information about the individual and the family, rather than about visits or

³ Rhode Island has had considerable experience in using this data base to estimate rates of hospitalization for a variety of conditions.

admissions. With a few exceptions⁴, however, most states have not reached the point in prioritizing data collection where a household survey is feasible.

One final issue warrants comment here. The data sources described above will not adequately address the needs for children with special health care needs. The primary reason for their inadequacy is that the conditions that cause children to have special health care needs are usually so rare that they can not be validly measured in most data sources where sampling is performed. At the very least, there should be some consideration of approaches to measuring the number of children with special health care needs. One interesting approach has been used by Palfrey and her colleagues (1991, 1994) to obtain lists of children with special health care needs from a variety of sources of data and using capture re-capture techniques to estimate the number of children with specific conditions. This approach is useful for selected "marker" conditions that may have special policy relevance due to associated cost and service system implications. The reader is referred to their work for this methodology.

CONCLUSIONS

In this paper, we described the data sources used most frequently by MCH state programs to measure child health status. These data sources generally provide a limited, often eclectic picture of the health status of children in a population. Alternative data sources for measuring child health status include hospital discharge data, ambulatory care surveys, other community surveys and registries. These databases, when systematically implemented and coordinated, can provide a more integrated picture of the health status of children and may also be useful in assessing the demand for available resources in the community. Incremental development of these databases is recommended to help secure a place at the table for MCH programs in the discussions concerning health care reform.

⁴ Wisconsin has conducted periodic ambulatory care surveys in 1984, 1986, and 1989, but has recently decided to obtain data from a child health supplement of a household survey.

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APPENDIX: TABLE 1

Data Sources and Health Status Measures Used in FY 1993 Maternal and Child Health Services Block Grant Applications

Data Source	Health Status Measures
Routine Data Sources	
Birth Records	Number and Percent of very low birth weight (VLBW) births by maternal characteristics Number and Percent of low birth weight (LBW) births by maternal characteristics Number and Percent of preterm births
Birth Records (since 1989 revision)	Number and Percent of women with complications of pregnancy Number and Percent of women with less than recommended weight gain during pregnancy Number and Percent of women who smoke during pregnancy Births with congenital anomalies Denominator for infant, neonatal and post-neonatal mortality rates
Death Records	Numerators for infant, neonatal, and post-neonatal mortality rates Number of deaths by age by cause of death: SIDS, Injuries, Homicides, Suicides, Disease groupings Numerators for childhood mortality rates Number of maternal deaths Number of deaths by race/gender Number and Percent of deaths due to Sudden Infant Death Syndrome (SIDS)
Linked Birth and Death Records	Infant, neonatal, post-neonatal mortality rates by: birthweight, maternal age, parity, maternal education, and use of prenatal care, etc.

Reportable Diseases	Numbers and numerators for rates of cases of: gonorrhea, syphilis, chlamydia, AIDS, vaccine-preventable diseases, enteric diseases, tuberculosis (TB), hepatitis B, and congenital syphilis
Hospital Discharge Data (Hospital Association Database)	Most frequent discharge diagnosis Numerators for rates of overnight hospital admissions for children less than 5 for major diagnostic groups Number of children discharged from hospitals with an injury by type: burns, poisonings, accidents, head injuries, major chest trauma, injuries to extremities, skin injuries and conditions, multiple trauma, alcohol and drug effects Numerators for rate of hospital discharge for injuries Number of children discharged from hospital with a diagnosis of congenital anomalies or malformations Number of children discharged from hospital with a diagnosis of Failure to Thrive, ages 0-5
CDC Pediatric Nutrition Surveillance of the WIC Program	Number and Percent of children with anemia Number and Percent of children below 5% of NCHS/CDC growth reference for height Number and Percent of children below 5% of NCHS/CDC growth reference for weight for height Number and Percent of children above 95% of NCHS/CDC growth reference for height Number and Percent of children above 95% of NCHS/CDC growth reference for weight for height Prevalence of growth retardation
Title XIX (Medical Assistance) Data	Anemia rates in EPSDT population
Newborn Screening Programs	Number of infants at risk of hearing defects Number and Percent of infants at risk of hearing defects Number of newborns with screened disease

Data Source	Health Status Measures
Registries	Burn/Trauma: Number of injuries requiring hospital admission by type Birth Defects: Number of newborns diagnosed with Fetal Alcohol Syndrome (FAS) or Drug Dependency Number of newborns diagnosed with or treated for disabilities
Department of Education	Handicapping conditions requiring special education by condition Number and Percent of third graders demonstrating standard literacy skills (reading at or above grade level) Number and percent of children who graduate from high school High school attrition rate (number graduating from number enrolled as freshmen)
Social Services/ Children and Youth/Juvenile Justice/Mental Health	Reported cases of child abuse Reported cases of child neglect Average number of Child Protective Services referred per month Number of juvenile commitments Rate of juvenile commitments Number and Percent of crimes committed by youth Number and Percent of children in need of foster care Number of children in foster care Number of children and adolescents estimated to be in need of sexual abuse treatment services Number and Percent of children at risk of emotional or behavioral problems Number and Percent of children who experience serious emotional problems Number of runaway youth referred per month Number of children estimated to be homeless Number of children estimated to be in need of mental health services Number of out-of-home mental health placements for children Number and Percent of children and adolescents with a mental health problem classified as "mild" or "moderate to severe"

<p>Transportation/ Highway</p>	<p>Rate of motor vehicle crashes related to DWI Number of motor vehicle and other wheel-driven injuries among youth</p>
<p>Special Surveys</p>	
<p>CDC Youth Risk Behavior Survey/Teen Wellness Check</p>	<p>Number and Percent of youth reporting: use of alcohol ever; use of alcohol in the last month; use of alcohol in the previous year by grade; use of steroids ever; use of steroids in the last 12 months; use of smokeless tobacco; use of cocaine; use of heroin; use of needles to inject illegal drugs Frequency of use of substances (as named above) Age of onset of use of substances (as named above) Number and Percent of youth eating breakfast fewer than four times/week Number and Percent of youth on a diet Number and Percent of youth that eat junk food daily Number and Percent of youth that eat fatty food daily Number and Percent of youth who are overweight Number and Percent of youth 20% or more above ideal weight Number and Percent of youth that do aerobic or other exercise less than three times/week Number and Percent of youth that never wear helmet when riding a bicycle Number and Percent of youth that often or sometimes feel life is not worth living Number and Percent who have seriously thought about attempting suicide in the past 12 months Number and Percent that have engaged in sexual intercourse Number and Percent having contracted a sexually transmitted disease Number and Percent having engaged in unprotected sexual activity Number and Percent of females reporting sexual abuse Number and Percent having carried a weapon for protection Number and Percent having been in a fight in which at least one participant required medical attention Number and Percent of youth having been in a fight more than twice in the past year</p>

Data Source	Health Status Measures
PRAMS	<p>Number and Percent of women reporting substance use during pregnancy</p> <p>Number and percent of women with short birth intervals by: maternal age, trimester of care, location of care, intentions, and source of family income</p> <p>Number and Percent of women with unintended pregnancies by: trimester of care and source of family income</p> <p>Number and Percent of women reporting smoking during pregnancy</p> <p>Number and Percent of women reporting alcohol consumption by: education, race, age, marital status, smoking</p> <p>Distribution of weight gain during pregnancy by birthweight</p> <p>Number and Percent of women with low birth weight by their birthweight</p> <p>Breastfeeding duration</p> <p>Number and Percent of women reporting domestic violence</p>
Lead Screening Studies	Number and Percent of children with elevated lead levels
Dental Health Surveys	Prevalence of decayed, filled, and missing teeth

APPENDIX: TABLE 2

Advantages and Disadvantages of Data Sources for Health Status Measures

Data Source	Advantages	Disadvantages
Routine Data Sources		
Birth Records	<p>Available for the entire population Available on a continuous basis Available on a county basis and at times, for smaller geographic areas Provide measures of newborn morbidity: length of pregnancy; birth weight; and Apgar scores Provide information on complications of pregnancy</p>	<p>Often are not timely Newborn measures are limited to the condition of the infant at birth Quality of "complications of pregnancy" data is questionable before recent changes in the birth certificate</p>
Death Records	<p>Available for the entire population Available on a continuous basis Available on a county basis and at times, for smaller geographic areas Provide data for numerators of death rates Include age of death; cause of death and race</p>	<p>Only signals the most severe problems May not capture the most prevalent morbid conditions Of limited value for ages where rates are low, (i.e., school-age children) Provide limited information other than cause of death Often are not timely</p>
Linked Birth and Death Records	<p>[Same advantages as for birth and death records] Can look at infant mortality rates by birth weight, maternal characteristics, and other data from birth certificates Can compute cohort rates</p>	<p>[Same disadvantages as for birth and death records] Often not available for several years after the birth occurred</p>

Data Source	Advantages	Disadvantages
Reportable Diseases	Provide numerators for: rates of STDs; rates of vaccine preventable diseases; rates of other important infectious diseases (e.g., TB)	Most diseases are not completely reported Systematic reporting biases Cover only a limited number of conditions
Hospital Discharge Data (Hospital Association Database)	Provide measures of the most common diagnoses for hospitalizations among children Frequently used to look at injury morbidity Relatively untapped data source	User must rely on discharge diagnosis reported by the institution Limited to in-patient admissions In some states, reporting is voluntary
CDC Pediatric Nutrition Surveillance of the WIC Program	Includes information to monitor children's: -growth (height; weight; height for weight) -nutritional status (e.g., anemia; nutrition risk)	Collected only on users of the WIC Program
Screening Programs	Provide data on number of detected cases Provide data on children with vision or hearing losses	Many diseases for which screening is done are very rare
Registries	Specific criteria established to define reported diseases and conditions Specific reporting forms or audits used to obtain the data Can be used as a sampling frame to launch more in-depth studies or analyses	Require some elements of active surveillance or monitoring to assure complete reporting May be narrow in perspective

<p>Title XIX Claims Records</p>	<p>Provide information to assess children's health status: diagnosis on submitted claims; hospitalization rates; length of hospitalization (NICU, etc.)</p>	<p>Diagnoses are tied to claims/reimbursement Data are seldom available in the needed format Only pertain to users for whom a claim was submitted Claims may not be complete for any given children Difficulty determining the population for analysis</p>
<p>Department of Education</p>	<p>Provide data on handicapping conditions requiring special education; literacy skills of students; school drop-out/high school attrition</p>	<p>Except for special education data, data do not include measures of health status Numbers are often compiled for educational purposes not for health purposes</p>
<p>Social Services/Children and Youth/Juvenile Justice/Mental Health</p>	<p>Provides data on: reported cases of child abuse and neglect; foster care placements; juvenile commitments; runaway youth; mental or behavioral problems in children</p>	<p>Distinction between suspected and confirmed cases Unreported cases are a tip of the iceberg Systematic bias in reported cases</p>

Data Source	Advantages	Disadvantages
Community Surveys	<p>Direct query about specific problems/needs and causes/risk factors</p> <p>If properly planned and implemented, yield reliable data for a representative sample of the population</p> <p>Flexible approach</p> <p>Can be combined with other approaches</p> <p>Provide supplementary information to that available from routine data sources</p> <p>Can be periodically repeated to assess changes/trends</p>	<p>Can be very costly if a high degree of precision is needed</p> <p>May be lengthy to conduct from formulation to analysis</p> <p>More resources are needed than for other approaches</p> <p>Only permit assessment of current problems</p> <p>Plan of analysis is seldom well formulated</p>
Pregnancy Risk Assessment Monitoring System (PRAMS)	<p>Captures data on all women</p> <p>Can be tailored to the specific needs of a state/area</p> <p>If handled as a spot survey, can be of reasonable cost</p>	<p>Objectives of survey may not be well formulated</p> <p>Limited technical assistance available</p> <p>Sampling, as suggested by CDC, may be very complex</p> <p>Analysis of data can be complex</p>
Youth Risk Behavior Surveys	<p>Captures data on all students</p> <p>Can be tailored to the specific needs of a state/area</p> <p>Can be completed in school at a reasonable cost</p>	<p>Objectives of survey may not be well formulated</p> <p>Limited technical assistance available</p> <p>Sampling, as suggested by CDC, may be very complex</p> <p>Analysis of data can be complex</p> <p>Miss high risk individuals: those who are no longer in school or with frequent absences</p> <p>Requires excellent working relationship with schools</p> <p>In some states, parents must give approval for their child to participate</p>

Appendix: Table 2