Data Sources & Tools for Measuring Adolescent Health Status

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Family Health Outcomes Project
University of California San Francisco

DATA SOURCES & TOOLS FOR MEASURING ADOLESCENT HEALTH STATUS

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ASSESSING ADOLESCENT HEALTH STATUS:
INDICATORS, DATA SOURCES AND TOOLS

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INTRODUCTION

For decades, public health professionals have attempted to monitor the health status of youth and to evaluate the outcomes of their program interventions. Both the lack of population-based data relevant to the adolescent age group and the lack of well-defined and measurable indicators of adolescent functional and mental health status have hindered efforts. Past primary data collection efforts have been few and costly. However, budget and policy decisions over the past decade have refocused priorities to include timely identification of needs and accountability of dollars spent. Budget cuts in publicly funded health programs, hiring freezes in public health and social service agencies, consolidating funds in the form of block grants and the implementation of Welfare Reform have greatly altered the amount and the type of resources available through public agencies. These changes have resulted in fewer staff to perform public health function. Further, the initiation of term limits for many state legislatures have resulted in less experienced officials making vital decisions about how to allocate an increasingly smaller pot of block-granted health care dollars. Undoubtedly, the disintegration of this publicly funded safety net will impact the health of adolescents.

In addition, the transition of most public and privately funded health insurance beneficiaries into managed care models has raised concern among advocates of adolescent health regarding the impact on the quantity and the quality of adolescent care. Existing performance measures required by the National Committee on Quality Assurance (NCQA) for plan accreditation, such as The Health Plan Employer Data and Information Set (HEDIS)[1], include only a few measures specific to youth. The lack of adolescent performance measures at the federal level and the impact of budget, policy and insurance coverage changes brings an increased sense of urgency to selecting appropriate adolescent health indicators and the collection and analysis of these data.

Given the importance of data for policy and budgetary decision making in the current environment, those responsible for the public's health as well as for the personal health care of adolescents must develop a strategic plan with timely and reliable data on clearly defined outcomes to:

- Document health status and needs of adolescents
- Identify systematic differences in sub-populations
- Allow monitoring of well-defined indicators of adolescent health and well-being that may reflect the effects of changes in the health care delivery system
- Document the effectiveness of program interventions

This monograph will present and discuss a set of "traditional" health indicators for youth, covering the more common areas of morbidity, mortality, and health service utilization. A summary of the advantages and limitations of existing population-based data sets relevant to these health indicators is also presented. We will then discuss some of the new thinking with regard to monitoring adolescent health. We will also summarize the content of some of

the available, well tested, primary data collection instruments, which could be useful for primary data collection on additional indicators. Further, we will identify some of the ongoing population-based surveys containing state level data on additional indicators. It is hoped that this information is useful to those individuals and agencies documenting health conditions of adolescents as well as to those monitoring the quality of services delivered to them.

BACKGROUND

Following the Omnibus Budget Reconciliation Act of 1989 (OBRA 89), state Title V Maternal and Child Health agencies were asked by the federal Maternal and Child Health Bureau (MCHB) to take on core public health functions of assessment, policy development and assurance for their target populations by reporting on 18 health indicators[2]. Eight of these indicators were specific to adolescents. During 1997, in response to the Office of Management and Budget (OMB) mandate that all federal programs implement conditions of the 1992 Government Performance and Results Act, MCHB changed its reporting requirements. States receiving MCH Block Grant funding must now report on 18 Performance Objectives, in which only two are specific to adolescents though others include adolescents as part of a larger age group. Likewise, in 1999 MCHB added a mandate to the Title V Guidance requiring grantees to also report on 18 needs indicators of which only 5 are specific to youth. Appendix I compares these measures.

In 1993, The National Committee for Quality Assurance, with input from these sectors, developed the Health Plan Employer Data and Information Set (HEDIS)[1]. The currently operational HEDIS version 3.0 includes a set of standardized measures for quality of care, member access and satisfaction, membership, utilization, finance, health plan management and activities. Of the quality measures, only three apply specifically to adolescents and are limited to process, not health status or outcomes (see Appendix I).

Many state and local public agencies recognize the importance of monitoring the adolescent age group, who accounts for a higher proportion of the morbidity, mortality and health care costs than any childhood age group, excluding newborns[2, 3]. High rates of mortality from intentional and unintentional injuries, unintended pregnancy and birth, sexually transmitted diseases, unemployment, crime, substance abuse, mental health, untreated severe dental conditions and nutritional disorders are only some of the issues demanding attention[2, 4, 5]. Findings from a 1997 report published by the National Center for Adolescent Health, America's Adolescents: Are They Healthy?, indicated that most of the observed adolescent morbidity and mortality can be attributed to preventable risk factors[6]. For example, the highest numbers of adolescent deaths were due to accidents, unintentional injuries, homicide, and suicide. Results also showed the prevalence of risky health behaviors increasing at earlier ages. Cigarette smoking and drug-use were increasing among adolescents. Three-quarters of high school age youth reported consuming alcohol whereas two-thirds were sexually active by their senior year. However, though the majority of adolescent morbidity and mortality is preventable, adolescents have

the lowest utilization of health care services of any age group and are the least likely to have health insurance. (Appendix II for executive summary of America's Adolescents: Are They Healthy?).

Given the current upheaval in health and social service systems and its potentially negative impact on adolescents, it is imperative to identify or develop a comprehensive set of health indicators for youth. By regularly monitoring these indicators, policy makers will be alerted to the health needs of youth, and thus able to better allocate their resources and develop effective health policies. In order to execute these steps, standardized and validated approaches to measuring these indicators must be identified.

TRADITIONAL ADOLESCENT INDICATORS

In 1995 The Family Health Outcomes Project (FHOP) at the University of California, San Francisco was funded by MCHB to develop a set of population-based measures assessing the impact of changes in the health care delivery system on the MCH population[7]. FHOP reviewed available health reports and peer reviewed literature on adolescent health status to identify useful measures. The resulting monograph, Selecting Health Indicators for Public Health Surveillance in a Changing Health Care Environment, includes indicators specific to adolescents (Appendix III). Each indicator is precisely defined with numerator and denominator specified in table format. See Appendix I for a comparison of these indicators with the HEDIS and Title V performance measures.

NEW DIRECTIONS

A considerable interest has been generated in the past few years about looking at functional health status and recent national reports have included functional health status measures as well as traditional health indicators[8, 9]. These measures include: physical activity level or fitness, limitations of physical activity due to acute or chronic illness, school absenteeism, degree of participation in sports or other activities. An advantage to the functional status approach is that it gives us rich information on a much larger group of adolescents who are either "disease free" but potentially at risk for later pathologies or chronically ill but not severely affected enough to appear in hospital discharge or mortality data. These measures can give us an idea about the adequacy of systems of care for children with special health care needs. It can also help to focus program attention on earlier prevention and intervention efforts and highlight changes in desirable activities such as increasing physical fitness.

The other major trend that has developed within the past 10 years is the assets model. Part of the impetus for this change is a reaction to the perceived emphasis of traditional indicators on measuring negative outcomes and risk behaviors. The work conducted by The Search Institute of Minneapolis, Minn. has reframed assessment of youth in a positive light. The Search Institute developed a 156-item questionnaire assessing 40 assets[10] (see

Appendix IV for a list of the assets). Over 300 local health communities are using this instrument to survey their teen population. Some have even substituted the Search instrument for the Youth Risk Behavior Surveillance System developed by the Centers for Disease Control and Prevention in order to promote a more positive approach.

However, the Search Institution's approach has been questioned on a number of scientific grounds[11]. Samples employed are not random or representative of the range of urban and suburban youth populations of America and instead focus on limited regions of the Midwest. In addition, this instrument has been tested with middle-class white populations and as such, may not demonstrate cross-cultural validity. Although many of the items were culled from reliable and valid instruments, internal reliability (a method used to determine the extent to which all items on a given test are measuring the same skill, that a test is consistently measuring the same skill) was not established in 19 (47.5%) of the 40 assets. For example, accepted limits of internal consistency are not met for 6 of the 27 tested assets (coefficient alpha less than .50). Likewise, internal reliability was not computed for 13 assets. Test –retest reliability also has not been established. Further, 13 of the 40 assets (32.5% of all assets) are assessed by only 1 item on the questionnaire. This is highly questionable unless each item has been statistically tested and found to be a valid predictor, which has not been substantiated by the Institute. Current research by The Search Institute is underway to address some of the identified scientific weaknesses of the survey.

The other approach that has begun to be discussed is the holistic model. This model looks at the adolescent in context and attempts to measure aspects of family or community life, which are associated with better outcomes. The Search Institute is incorporating this approach into their assets measurement model. The Search Institute instrument identifies two domains of assets, internal and external, to distinguish individual level characteristics from characteristics of family, school or community. Within each domain are 20 assets assessing 4 categories. Assets were identified via an extensive literature review in which much empirical literature was found to be supportive of these 8 categories. Though much empirical literature exists on these categories, to date, no research has shown that intervention efforts to increase assets will yield better health outcomes.

ADOLESCENT DATA SOURCES

When assessing adolescent health status from a public health perspective, existing population-based data sources should be used wherever possible to allow comparisons with other states and with national data. However, there are few population-based data sources available for assessing the general health status and well being of adolescents. The indicator table (Appendix III) specifies possible data sources for each indicator. These include population-based data, at the national level, collected from vital records, disease surveillance, hospital discharge abstracts or regularly administered surveys.

However, there are limitations to these data sources. Ozer, et al. states the most significant and pervasive problem is that adolescents are aggregated to a larger age group, thus conditions specific to the adolescent group may get over- or under-represented in resulting computations. In many national surveys, respondents are classified into age groups of children (under 15 or 18 years), young adults (15 to 24 years), and older adults (25 to 44 years). Therefore, trends for adolescents cannot be separated out from those for children or young adults. Likewise, inconsistency in age ranges used to define adolescence presents an additional dilemma, particularly when trying to link or to compare different data sources[11].

Another methodological issue with the listed data sources is the aggregation of race/ethnic subgroups into larger groups. Various subgroups of Hispanics (Mexican, Central American, Cuban, etc.) are grouped into Hispanic. Similarly, Asian subgroups (Chinese, Japanese, Laotian, Vietnamese, Hmong, etc.) are grouped into Asian. Even worse, Hispanic, Asian, Native American and Pacific Islander adolescents are commonly grouped into one category as "Other." Again, this practice of aggregation wipes out differences that may exist among subgroups thus giving an inaccurate picture of the health status of larger groups. Whereas these groupings are often done to circumvent the problem of small sample size, cultural differences and effects of socioeconomic status, both greatly impacting health status, are lost. In addition, as race is often mistakenly used as a "proxy" for socioeconomic status[11], it is important to fully understand the implications and potential outcomes of such groupings.

Appendix V presents the advantages and disadvantages of data sources identified in Appendix III in table format. This list can serve as a guide in selecting appropriate databases for a particular health jurisdiction. Appendix VI, "Barriers to the Measurement of Public Health Indicators" is a more generic and comprehensive discussion of the limitations of available population-based data sources.

With sampling methods being too limited, national surveys are often non-representative of many state or local populations. However, many public health agencies use these instruments to survey a larger population in their particular jurisdiction. This is advantageous for the agencies as it allows them to compare their results to a national group. A number of regularly administered, validated instruments surveying adolescents on

their health and health behaviors are available for analysis or to use to collect larger samples. The following are some examples of such surveys:

- Adolescent Health Survey (AHS)
- National Health and Nutrition Evaluation Survey (NHANES)
- National Health Interview Survey (NHIS)
- National Longitudinal Survey of Youth (NLSY)
- National Survey of Adolescent Males (NSAM)
- National Survey of Family Growth (NSFG)
- Youth Risk Behavior Surveillance System (YRBSS)

Appendix VII contains descriptions of these instruments and information on contacts for obtaining either the raw data or the instruments.

In addition, many public agencies fund special studies or maintain program data sets that are in the public domain. These existing data sources at the federal, state, and local levels should be thoroughly reviewed before embarking on any new data collection efforts. Inventories of these data sets are available through the national MCH Clearing House, Maternal Child Health Bureau (MCHB), Center for Disease Prevention and Control (CDC) and HRSA publications as well as through the Adolescent Resource Centers funded by MCHB.

PRIMARY DATA COLLECTION INSTRUMENTS

When no population-based data source exists, a standardized primary data collection tool can be used. Selected instruments should meet the following criteria:

- Have established validity and reliability
- Be developmentally appropriate
- Be culturally sensitive
- Be meaningful across populations
- Be proven useful in a similar setting (shows replicability)

Documentation of reliability and validity testing should include mention of internal consistency, test-retest reliability, inter-rater reliability, content validity, construct validity, and criterion-related validity. Standardized data collection instruments should allow for modifications, for example – that population subgroups can be examined, such as race/ethnic groups of interest or children with special health care needs. Both standardized numerators and denominators should be employed in order to facilitate both longitudinal

and comparative studies. Data reporting should be done in a culturally competent manner and affected communities made privy to results.

Instruments are often accompanied with manuals and scoring sheets as well as access to consultants with measurement expertise. Incorporating survey tools to assess representative samples of a given population at regular intervals can be part of a larger assessment process for a reasonable cost. Many tools can be administered in alternative ways, such as via telephone interviews or by teachers in a classroom setting.

Be aware that available surveys may not meet all specific needs. Newacheck and Starfield note the following limitations of adolescent surveys[12]:

- There is a lack of information about types of health services sought and provided as well as the perceived outcomes of these services.
- Tracking trends of health service use and health status over time is difficult, as most surveys are cross-sectional.
- The estimated number of adolescents suffering from chronic conditions and acute disability could be inaccurate, as there are limited questions on chronic illness.
- Mental health symptoms are often treated as distinct from physical symptoms.

Over the past two decades, a number of very reliable and carefully validated instruments have been developed to measure health status and outcomes among children. A number of such instruments have been adapted for use with adolescents. After reviewing these tools and consulting with experts at the Center for Adolescent Health Research, the following surveys are recommended:

- The Child Health and Illness Profile-Adolescent Edition (CHIP-AE)
- Child Health Questionnaire (CHQ) (Wehr)
- The Commonwealth Fund Survey of the Health of Adolescent Girls and Boys (CFS)
- Prevention Minimum Evaluation Data Set (PMEDS)
- Reynolds Adolescent Depression Scale (RADS)
- Rosenberg Self-Esteem Scale (Rosenberg SE)
- Short Form 36 from the Medical Outcomes Study (SF-36)
- Teen Health Risk Survey (THS)
- Teen Questionnaire (TQ)
- Youth Health Provider (YHP)

Appendix VII, the Annotated Resource List, describes validated instruments in more detail and where available, information on acquiring these instruments.

As many tools and surveys exist, it is unlikely an entirely new instrument needs to be developed, and such an arduous task is not recommended. A more practical approach is to ensure that the instrument of interest has met acceptable levels of reliability and validity as well as demonstrating cross-culturally competency. Likewise, it is possible to select subscales from instruments that are more relevant to your purposes, including only items that are critical. For example, isolating the Discomforts section of the CHIP-AE and combining it with selected questions from the Youth Risk Behavior Surveillance System could provide information on the prevalence of mental health problems in a population.

SUMMARY

During this period of rapid changes in the health care delivery system, it is important to develop a standard approach to assessing the impact of these changes on the health status of adolescent population. Critical to this process is the identification of health status/outcome indicators that measure risks, assets and psychological characteristics more relevant to adolescents. A number of very good survey databases and reliable and well-validated primary data collection instruments are available to assist in this effort. Careful selection of existing data sets and tools can provide the needed information to develop a more comprehensive profile of adolescents within a particular health jurisdiction. These data can be used for needs assessment as well as quality assurance functions.

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APPENDIX I. COMPARISON OF CURRENTLY RECOMMENDED MEASURES RELEVANT TO ADOLESCENTS

PERFORMANCE MEASURE	TITLE V	HEDIS	FHOP MEASURE
ADOLESCENT			
The rate per 100,000 of deaths due to suicide in youth ages 14 through 17 years	x		x
The birth rate (per 1,000) for teenagers ages 15 through 17 years	x		x
The rate of deaths to children ages 1-14 years caused by motor vehicle crashes per 100,000 children			x
Teen Immunization		x	x
Teen well-care visits		x	x
Annual dental visit, ages 4-21 years		x	x
ALL AGE GROUPS			
The percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the State Children with Special Health Care Needs (CSHCN) Program	x		
The degree to which the State CSHCN Program provides or pays for specialty and subspecialty services, including care coordination, not otherwise accessible or affordable to its clients	x		
The percent of CSHCN in the State who have a "medical home"	x		
Percent of CSHCN in the State CSHCN program with a source of insurance for primary and specialty care	x		
Percent of children without health insurance	x		x
Percent of potentially Medicaid eligible children who have received a service paid by the Medicaid Program	x		
Patient Satisfaction - Pediatric CAPHS Scales	x	x	

APPENDIX II. EXECUTIVE SUMMARY: AMERICA'S ADOLESCENTS: ARE THEY HEALTHY?

Ozer, Elizabeth M.; Brindis, Claire D.; Milstein, A.; Knopf, David K.; Irwin Jr., Charles E.

National Adolescent Health Information Center, Division of Adolescent Medicine, Department of Pediatrics and Institute for Health Policy Studies, School of Medicine, University of California, San Francisco, January 1998

EXECUTIVE SUMMARY

Adolescence is a unique developmental stage distinct from both childhood and adulthood. The second decade of life has special vulnerabilities, health concerns and barriers to accessing health care. Most of the health problems of adolescents have their origins in environmental and behavioral factors. Injury and violence have replaced illness as the leading causes of death for adolescents, and life conditions and risky behaviors are linked to the major morbidities.

The majority of adolescent morbidity and mortality can be attributed to preventable risk factors. These include unhealthy behaviors, such as sedentary lifestyle, poor nutritional habits, substance use and abuse, unsafe sexual practices, and risky vehicle use. It is well known that many of these same behaviors that begin during the adolescent years are also associated with adult morbidity and mortality.

This monograph presents an overview of the health of adolescents, including:

Demographic Trends

- Increase in number of adolescents, single parent families living in poverty and proportion of minority adolescents
- Blacks make up the majority of minority adolescents; the percentage of Hispanic adolescents is increasing more rapidly

Adolescent Health Care Utilization

- Lowest utilization of health care services of any age group
- Less likely to have health insurance than other age groups

Mortality During Adolescence

- Accidents and unintentional injuries, homicide, and suicide account for the greatest number of adolescent deaths
- Males are dying at a higher rate than females across all races and age groups
- Death rates for White adolescents in 1993 were at or below 1985 levels. Black older adolescent males and females were more likely to die in 1993 than they were in 1987
- Black males 15 to 19 are more than 9 times as likely to die from homicide as White males

Risky Behavior

- Adolescents are increasingly initiating risky health behaviors at earlier ages
- Cigarette smoking among teenagers is now on the rise
- Sixty percent of adolescents who attend high school report having ever tried a cigarette, one third are currently smoking and as many as quarter of these smoke every day
- More than three-quarters of high school age adolescents have consumed alcohol in their lifetime, about half report current alcohol use, and about one quarter report heavy, episodic drinking
- Almost one third of adolescents who use alcohol and are of driving age report driving after drinking in the previous month
- After a decline in illicit drug use among teenagers, drug use has once again begun to increase
- More than one third of high school seniors have used marijuana at some point in their lives
- More than two-thirds of students have had sexual intercourse by their senior year of high school
- Between 1991 and 1994, there was a consistent decrease in birth rates among 15-19 year olds

APPENDIX III. MATRIX OF COMMONLY USED ADOLESCENT HEALTH INDICATORS

YOUTH INDICATORS - AGES 10 THROUGH 19 YEARS

INDICATOR	DEFINITIONS FOR PUBLIC HEALTH SURVEILLANCE	NUMERATOR	DENOMINATOR	DATA SOURCES
ACCESS TO PRIMARY CARE	The percent of youth (or their caretakers) who report having an identified primary care provider	Number of youth in the denominator (or their caretakers) who report having a primary care provider	Total number of youth ages 10-14 and 15-19 years in a defined population	Special Survey
	The percent of youth (or their caretakers) who report having had a well visit to a health care provider within the past 12 months NOTE: Excludes ER visits	Number of youth in the denominator (or their caretakers) who report having a visit in the past 12 months	Total number of youth ages 10-14 and 15-19 years in a defined population	Special Survey
ADEQUACY OF PRIMARY CARE	The percent of providers who report using a well child/youth protocol consistent with recommended guidelines	Number of providers in the denominator reporting use of recommended guidelines	Total number of providers surveyed	Provider Survey
	The percent of youth who have had the recommended number of well visits for their age NOTE: 1994 AAP guidelines, Bright Futures or EPSDT standards preferred	Number of youth in the denominator who received the recommended number of visits	Total number of youth ages 10 through 19 years (by age) in a defined population in a calendar year	Chart Review Clinical Encounter Data EPSDT

YOUTH INDICATORS - AGES 10 THROUGH 19 YEARS

INDICATOR	DEFINITIONS FOR PUBLIC HEALTH SURVEILLANCE	NUMERATOR	DENOMINATOR	DATA SOURCES
HOSPITAL DISCHARGES FOR AMBULATORY CARE SENSITIVE DIAGNOSES	Hospital discharges rate per 1,000 youth (ages 10-14 and 15-19 years) for ambulatory care sensitive (ACS) diagnoses NOTE: 1. HP 2000 Reference Objective 11.1b: Rate per 100,000 hospitalizations for asthma in children 14 years and younger 2. ACS - ICD9 codes - See Appendix C	Number of hospital discharges for ACS diagnoses among youth in the denominator in a calendar year	Total number of youth ages 10-14 and 15-19 years	Census Hospital Discharge Data
IMMUNIZATION **Vaccine-Preventable Conditions**	The number and rate per 100,000 youth (ages 10 – 19 years) of reported cases of vaccine-preventable conditions: diphtheria, tetanus, pertussis, polio, measles, mumps, rubella and hepatitis B; Adapted from HP 2000 Objective 20.1	Number of reported cases of vaccine-preventable conditions, by condition, among youth in the denominator in a year	Total number of youth ages 10 through 19 years in a calendar year	Census Notifiable Infectious Disease Data
	The number and rate per 100,000 youth (ages 10 – 19 years) of hospital discharges for vaccine-preventable conditions (conditions listed above)	Number of hospital discharges for vaccine-prevent-able conditions, by condition, among youth in the denominator in a calendar year	Total number of youth ages 10 through 19 years in a calendar year	Census Hospital Discharge Data

YOUTH INDICATORS - AGES 10 THROUGH 19 YEARS

INDICATOR	DEFINITIONS FOR PUBLIC HEALTH SURVEILLANCE	NUMERATOR	DENOMINATOR	DATA SOURCES
IMMUNIZATION **Vaccine Status**	The percent of youth who have received hepatitis B series, MMR and Td boosters, as recommended by the current AAP/ACIP schedule NOTE: Refer to Appendix D (AAP/ACIP schedule)	Number of youth in the denominator who received the AAP/ACIP recommended immunizations	Total number of youth ages 10 through 19 years in a defined population in a calendar year	CDC Immunization Special Survey Chart Review Clinical Encounter Data EPSDT
	The percent of youth in foster care who received age-appropriate immunizations, by immunization type, as recommended by the current AAP/ACIP schedule NOTE: Refer to Appendix D (AAP/ACIP schedule)	Number of youth in the denominator who received age-appropriate immunizations, by immunization type	Total number of youth in foster care 10 through 19 years of age, by age, in a defined population in a calendar year	Immunization Registry Department of Social Services Data Medicaid Claims Data
INJURIES **Intentional Injuries***	The number, percent and rate per 100,000 youth (ages 10-14 and 15-19 years) of intentional fatalities due to homicide, by cause, including: • Homicide involving youth abuse • Homicide involving sexual assault • Unarmed homicide • Homicide involving firearms • Homicide involving other weapons NOTE: 1. HP 2000 Reference Objectives: Rate	Total number of atalities due to homicide, by cause of homicide (as specified), among youth in the denominator in a calendar year	Total number of youth ages 10-14 and 15-19 years	Census Child Death Review Data Death Certificate Data (E-Codes)

YOUTH INDICATORS - AGES 10 THROUGH 19 YEARS

INDICATOR	DEFINITIONS FOR PUBLIC HEALTH SURVEILLANCE	NUMERATOR	DENOMINATOR	DATA SOURCES
	per 100,000 homicides (7.1a), weapon-related violent deaths (7.3) 2. Report overall rate and rate by cause			Medical Examiner Reports
	The number, percent and rate per 100,000 youth (ages 10-14 and 15-19 years) of fatalities due to suicide NOTE: HP 2000 Reference Objective 6.1: Rate of suicide per 100,000 people	Number of fatalities due to suicide among youth in the denominator in a calendar year	Total number of youth ages 10-14 and 15-19 years	Census Child Death Review Data Death Certificate Data (E-Codes) Medical Examiner Reports
	The number, percent and rate per 100,000 youth (ages 10-14 and 15-19 years) of intentional nonfatal injuries due to: • Physical abuse • Sexual assault NOTE: HP 2000 Reference Objective 7.4: Rate per 1,000 of maltreatment of children less than 18 years	Number of intentional nonfatal injuries among youth in the denominator in a calendar year	Total number of youth ages 10-14 and 15-19 years	Census Dept of Social Services Data Emergency Room Data Law Enforcement Data
	The rate of hospital discharges per 100,000 youth (ages 10-14 and 15-19 years) for intentional nonfatal injuries, by cause, including: • Youth abuse • Sexual assault	Total number of hospital discharges for intentional nonfatal injuries, by cause of injury (as specified), among youth in the	Total number of youth ages 10-14 and 15-19 years	Census Hospital Discharge Data (E-Codes)

YOUTH INDICATORS - AGES 10 THROUGH 19 YEARS

INDICATOR	DEFINITIONS FOR PUBLIC HEALTH SURVEILLANCE	NUMERATOR	DENOMINATOR	DATA SOURCES
	• Unarmed assault • Firearms • Other weapons NOTE: Report overall rate and rate by cause	denominator in a calendar year		Law Enforcement Data
	The number and rate of hospital discharges per 100,000 youth (ages 10-14 and 15-19 years) for suicide attempts NOTE: HP 2000 Reference Objective 7.8: Reduce by 15 percent the incidence of injurious suicide attempts among adolescents ages 14 through 17	Number of hospital discharges for suicide attempt among youth in the denominator in a calendar year	Total number of youth ages 10-14 and 15-19 years	Census Hospital Discharge Data (E-Codes) Mandated State Reports
	The number and rate of emergency room visits per 100,000 youth (ages 10-14 and 15-19 years) for suicide attempts NOTE: HP 2000 Reference Objective 7.8: Reduce by 15 percent the incidence of injurious suicide attempts among adolescents ages 14 through 17	Number of emergency room visits for suicide attempt among youth in the denominator in a calendar year	Total number of youth ages 10-14 and 15-19 years	Census Emergency Room Data Mandated State Reports
INJURIES **Prevention**	The percent of youth reporting use of care passenger restraint systems (CPRS) NOTES: 1. HP 2000 Reference Objective 9.12a: percent of motor vehicle occupants using occupant protection systems	Number of youth in the denominator reporting use of CPRS	Total number of youth ages 10-14 and 15-19 years in a defined population	YRBS

YOUTH INDICATORS - AGES 10 THROUGH 19 YEARS

INDICATOR	DEFINITIONS FOR PUBLIC HEALTH SURVEILLANCE	NUMERATOR	DENOMINATOR	DATA SOURCES
	2. States should develop standards for appropriate CPRS use 3. States should note laws and programs for injury prevention when comparing results from other states			
	The percent of youth involved in injury crashes using CPRS	Number of youth in the denominator using CPRS	Total number of youth ages 10-14 and 15-19 years involved in injury crashes in a defined population	FARS Highway Traffic Safety Data
	HP 2000 Objective 9.13: The percent of youth who ride bicycles and use bicycle helmets	Number of youth in the denominator who report bicycle helmet use	Total number of youth ages 10 through 19 years by age who ride bicycles in a defined population	Special Survey
	The percent of youth who report having received information on injury prevention by source (health care provider, community program, media) NOTES: 1. HP 2000 Reference Objective 9.21: Percent primary care providers who routinely provide age-appropriate counseling on safety precautions to prevent unintentional injury 2. States should note laws and programs for injury prevention when comparing results from other states	Number of youth in the denominator who report having received injury prevention information by source		Special Survey
	The percent of health care providers who routinely provide age-appropriate	Number of health care providers in the	Total number of health care providers in a	Provider Survey

YOUTH INDICATORS - AGES 10 THROUGH 19 YEARS

INDICATOR	DEFINITIONS FOR PUBLIC HEALTH SURVEILLANCE	NUMERATOR	DENOMINATOR	DATA SOURCES
	counseling on safety precautions to prevent unintentional injury according to the American Academy of Pediatrics-TIPP program (or a local equivalent). Topics include: • Bicycle/motorcycle helmet use • Car passenger restraint use • Oral/facial protective devices • Smoke detector use • Sport and work safety equipment • Suicide/depression • Water/pool safety	denominator reporting use of protocols for delivering appropriate injury- prevention counseling	defined population	
INJURIES **Unintentional Injuries***	The number, percent and rate per 100,000 youth (ages 10-14 and 15-19 years) of fatalities due to unintentional injuries, by cause, including: • Motor vehicle crashes • Motor vehicle crashes and substance • abuse • Drownings • Burns (scalds and/or flames) • Poisoning • Falls • Unintentional firearm-related injury • Sports/recreational injury NOTE: 1. HP 2000 Reference Objectives: Rate per 100,000 of deaths due to unintentional injuries (9.1), rate of (9.3a), falls (9.4), drowning (9.5a),	Total number of fatalities due to unintentional injury, by cause of injury (as specified) among youth in the denominator in a calendar year	Total number of youth ages 10-14 and 15-19 years	Census Child Death Review Data Death Certificate Data (E-Codes) FARS Medical Examiner Reports

YOUTH INDICATORS - AGES 10 THROUGH 19 YEARS

INDICATOR	DEFINITIONS FOR PUBLIC HEALTH SURVEILLANCE	NUMERATOR	DENOMINATOR	DATA SOURCES
	deaths due to motor vehicle crashes and fire (9.6a) 2. States are encouraged to document the percent of total fatalities associated with neglect 3. Report overall rate and rates by cause			
	The rate of hospital discharges per 100,000 youth (ages 10-14 and 15-19 years) for unintentional nonfatal injuries, by cause, including: • Motor vehicle crashes • Motor vehicle crashes and substance abuse • Drownings • Burns (scalds and/or flames) • Poisoning • Falls • Unintentional firearm-related injury • Sports/recreational injury NOTE: Report overall rate and rates by cause	Total number of hospital discharges for unintentional nonfatal injuries, by cause of injury (as specified) among youth in the denominator in a calendar year	Total number of youth ages 10-14 and 15-19 years	Census Hospital Discharge Data (E-Codes)
INSURANCE STATUS	The percent of youth (ages 10-14 and 15-19) who lack health insurance coverage	Number of youth in the denominator who lack health insurance coverage	Total number of youth ages 10-14 and 15-19 years in a defined population	Current Population Survey Census

YOUTH INDICATORS - AGES 10 THROUGH 19 YEARS

INDICATOR	DEFINITIONS FOR PUBLIC HEALTH SURVEILLANCE	NUMERATOR	DENOMINATOR	DATA SOURCES
LOW HGB/HCT	The percent of youth (ages 10 through 19 years) with low Hgb/Hct according to CDC age-specific standards	Number of youth in the denominator with low Hgb/Hct, by age	Number of youth ages 10 through 19 years by age in a defined population	Chart Review Clinical Encounter Data EPSDT PedNSS
ORAL HEALTH **Youth with a Dental Exam**	The percent of youth who have received a dental examination within the previous 12 months	Number of youth in the denominator who received a dental exam within the previous 12 months	Total number of youth ages 10 through 19 years by age in a defined population	EPSDT NHIS NHANES NIH or State Oral Health Survey
ORAL HEALTH **Youth with Protective Sealants on Permanent Molar Teeth**	HP 2000 Objective 13.8: The percent of youth 14 years of age with protective sealants on occlusal surfaces of second permanent molars	Number of youth in the denominator with protective sealants on occlusal surfaces of second permanent molars	Total number of youth 14 years of age in a defined population	Dental Encounter Data NHANES NIH or State Oral Health Survey
ORAL HEALTH **Youth with Untreated Dental Caries**	The percent of youth aged 15 with one or more untreated carious permanent teeth NOTE: HP 2000 Reference Objective 13.2: Reduce untreated dental caries so that the proportion of children with untreated	Number of youth in the denominator who have one or more untreated carious permanent teeth	Total number of youth 15 years of age in a defined population	Dental Encounter Data EPSDT NIH or State Oral Health

YOUTH INDICATORS - AGES 10 THROUGH 19 YEARS

INDICATOR	DEFINITIONS FOR PUBLIC HEALTH SURVEILLANCE	NUMERATOR	DENOMINATOR	DATA SOURCES
	caries (in permanent or primary teeth) is no more than 15 percent among youth aged 15			Survey
REPEAT TEEN BIRTHS	The number and rate per 1,000 of repeat births to adolescent females NOTE: Should be reported by age group: under age 15, age 15-17, age 18-19	Number of repeat births among females in the denominator, by age group	Total number of teen births to adolescent females, by age group, in a calendar year	Birth Certificate Data
SUBSTANCE, ALCOHOL AND TOBACCO USE/ABUSE/ EXPOSURE **Exposure**	The percent of youth with current household exposure to alcohol or substance abuse NOTE: 1. Current is defined as daily exposure within the last 6 months 2. Household refers to others in household using substances	Number of youth in the denominator with current household exposure to alcohol or substance abuse	Total number of youth ages 10 through 19 years by age in a defined population	Special Survey
	The percent of youth with current household exposure to tobacco	Number of youth in the denominator with current household exposure to tobacco	Total number of youth ages 10 through 19 years by age in a defined population	Special Survey EPSDT
SUBSTANCE, ALCOHOL AND TOBACCO USE/ABUSE/ EXPOSURE **Prevention**	HP 2000 Objective 4.19: The percent of primary care providers who screen for alcohol and other drug use problems and provide other counseling as needed HP 2000 Objective 3.16: The percent of primary care and oral health care providers who routinely advise cessation	Number of primary care providers in the denominator who provide alcohol and drug use screening/ counseling Number of primary/oral care providers in the denominator who	Total number of primary care providers in a defined population Total number of primary/oral care providers in a defined	Chart Review Provider Survey Chart Review Provider Survey

YOUTH INDICATORS - AGES 10 THROUGH 19 YEARS

INDICATOR	DEFINITIONS FOR PUBLIC HEALTH SURVEILLANCE	NUMERATOR	DENOMINATOR	DATA SOURCES
	and provide assistance for tobacco-using patients	provide cessation advice	population	
	The percent of youth reporting having received advice or education about alcohol or tobacco use by source (health care provider, caretakers, community-based health education program, media)	Number of youth in the denominator who report having received substance advice/ education	Total number of youth ages 10 through 19 years by age in a defined population	Special Survey
SUBSTANCE, ALCOHOL AND TOBACCO USE/ABUSE/ EXPOSURE **Use / Abuse** **1. Alcohol**	The percent of youth reporting any use of alcohol in the previous month, six months, ever, by age NOTE: HP 2000 Reference Objective 4.6: Percent of adolescents ages 12-17 who have used alcohol, marijuana and cocaine in the last month	Number of youth in the denominator reporting alcohol use, by age	Total number of youth ages 10 through 19 years, by age group, in a defined population	Census National Council on Alcoholism Data State and Local Substance Abuse Data YRBS
	The number and rate of hospital discharges for alcohol abuse among youth ages 10-14 and 15-19 years	Number of hospital discharges for alcohol abuse among youth in the denominator in a calendar year	Total number of youth ages 10-14 and 15-19 years	Census Hospital Discharge Data
	The number and rate of emergency room visits for alcohol abuse among youth ages 10-14 and 15-19 years	Number of emergency room visits for alcohol abuse among youth in the denominator in a calendar year	Total number of youth ages 10-14 and 15-19 years	Census Emergency Room Data
SUBSTANCE, ALCOHOL AND TOBACCO	The percent of youth in a defined population reporting any substance use/abuse, by substance, in the previous	Number of youth in the denominator reporting use of substances, by	Total number of youth ages 10 through 19 years, by age group, in	EPSDT Law

YOUTH INDICATORS - AGES 10 THROUGH 19 YEARS

INDICATOR	DEFINITIONS FOR PUBLIC HEALTH SURVEILLANCE	NUMERATOR	DENOMINATOR	DATA SOURCES
USE/ABUSE/ EXPOSURE **Use / Abuse** **2. Substance**	month, six months, ever, by age NOTE: HP 2000 Reference Objective 4.6: Percent of adolescents ages 12-17 who have used alcohol, marijuana and cocaine in the last month	age and by substance	a defined population	Enforcement Data National Council on Alcoholism Data State and Local Substance Abuse Data YRBS
	The number and rate of hospital discharges for substance abuse, by substance, among adolescents ages 10 through 19 years	Number of hospital discharges for substance abuse among youth in the denominator in a calendar year, by substance	Total number of youth ages 10-14 and 15-19 years	Census Hospital Discharge Data
	The number and rate of emergency room visits for substance abuse, by substance, among youth ages 10 through 19 years	Number of emergency room visits for substance abuse among youth in the denominator in a calendar year, by substance	Total number of youth ages 10-14 and 15-19 years	Census Emergency Room Data
SUBSTANCE, ALCOHOL AND TOBACCO USE/ABUSE/	The percent of youth reporting any use of tobacco, by type, in the previous month, six months, ever, by age: • Cigars	Number of youth in the denominator reporting tobacco use, by type, by age	Total number of youth ages 10 through 19 years, by age group, in a defined population	EPSDT State and Local Substance

YOUTH INDICATORS - AGES 10 THROUGH 19 YEARS

INDICATOR	DEFINITIONS FOR PUBLIC HEALTH SURVEILLANCE	NUMERATOR	DENOMINATOR	DATA SOURCES
EXPOSURE **Use / Abuse** **3. Tobacco**	• Cigarettes • Smokeless tobacco NOTE: HP 2000 Reference Objectives: Percent of adolescents initiating and becoming regular cigarette smokers by age 20 (3.5); the percent of adolescents ages 12-17 who have used snuff or chewing tobacco in the previous month; the percent of adolescent males aged 12-24 who have used snuff or chewing tobacco at least 20 times and who currently use snuff or chewing tobacco (3.9); the average age of first use of cigarettes, alcohol and marijuana by adolescents ages 12-17 (4.5).			Abuse Data YRBS
SEXUALLY TRANSMITTED DISEASES	The number and rate per 100,000 youth (by age group) of reportable sexually transmitted diseases, by cause, including: HIV, gonorrhea, chlamydia, Hepatitis B, syphilis) NOTES: HP 2000 Reference Objectives: 1. The rate per 100,000 of gonorrhea (19.1), chlamydia (19.2), primary and secondary syphilis cases (19.3) and repeat gonorrhea (19.8) 2. The number of genital herpes and genital warts (19.5), and hepatitis B	The number of reported cases of specified conditions, by condition, among youth in the denominator, by age group, in a calendar year	Total number of youth in each age group	Census Notifiable Infectious Disease Data

YOUTH INDICATORS - AGES 10 THROUGH 19 YEARS

INDICATOR	DEFINITIONS FOR PUBLIC HEALTH SURVEILLANCE	NUMERATOR	DENOMINATOR	DATA SOURCES
	(19.7) 3. Should be reported in age groups: under age 15, age 15-17, age 18-19			
	The number and rate per 100,000 females (ages 10-14 and 15-19 years) of hospital discharges for Pelvic Inflammatory Disease (PID); Adapted from HP 2000 Objective 19.6	Number of hospital discharges for PID among females in the denominator in a calendar year	Total number of female youth ages 10-14 and 15-19 years	Census Hospital Discharge Data
TEEN BIRTHS **Teen Births***	The number and rate per 1,000 adolescent females of births to adolescent females by age of delivery Note: Should be reported by age group: under age 15, age 15-17, age 18-19	Number of births among adolescent females in the denominator, by age group, in a calendar year	Total number of female adolescents, by age group	Birth Certificate Data Census
TEEN BIRTHS **Teen Fathers**	The number and rate per 1,000 adolescent males of teen fathers by age group NOTE: Should be reported by age group: under age 15, age 15-17, age 18-19	Number of adolescent fathers, by age group, in a calendar year	Total number of adolescent males, by age group	Birth Certificate Data Census
TEEN BIRTHS **Teen Births to Adult Fathers**	The percent of births to female adolescents where the father is over 19 years of age NOTE: Should be reported by age group of father: 20-24, 25-29, 30+	Number of denominator births where the father is over 19 years of age	Total number of births to teen mothers in a calendar year	Birth Certificate Data

YOUTH INDICATORS - AGES 10 THROUGH 19 YEARS

INDICATOR	DEFINITIONS FOR PUBLIC HEALTH SURVEILLANCE	NUMERATOR	DENOMINATOR	DATA SOURCES
TEEN PREGNANCY	The number and rate of fetal deaths, live births and abortions per 1,000 pregnancies to adolescent females by age at delivery; Adapted from HP 2000 Objective 5.1	Number of fetal deaths, live births and abortions among females in the denominator, by age group, in a calendar year	Total number of female youth, by age group	Birth Certificate Data Census Fetal Death Certificate Data Reported Abortion Data

APPENDIX IV. THE SEARCH INSTITUTE: DEVELOPMENTAL ASSETS SURVEY

The Measurement of Developmental Assets Survey was designed by the Search Institute to measure both the assets and risk variables from a variety of standardized and well-validated instruments used in national and state surveys of adolescents and other psycho-social research. There are 156 survey items of which 92 items measure the 40 assets assessing support, empowerment, boundaries and expectations, constructive use of time, commitment to learning, positive values, social competencies and positive identity.

SUPPORT

Family Support: Family life provides high levels of love and support measured by 3 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Positive Family Communication: Young person and her/his parent (s) communicate positively, and young person is willing to seek parent(s) advice and counsel measured by 3 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Other Adult Relationships: Young person receives support from three or more non-parent adults measured by 3 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Caring Neighborhood: Young person experiences caring neighbors measured by 1 item on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Caring School Climate: School provides a caring, encouraging environment measured by 3 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Parent Involvement in Schooling: Parent(s) are actively involved in helping young person succeed in school measured by 4 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

EMPOWERMENT

Community Values Youth: young person perceives that adults in the community value youth measured by 4 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Youth as Resources: Young people are given useful roles in the community measured by 3 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Service to Others: Young person serves in the community 1 hour or more per week measured by 1 item on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Safety: Young person feels safe in home, school, and the neighborhood measured by 3 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

BOUNDARIES & EXPECTATIONS

Family Boundaries: Family has clear rules and consequences and monitors the young person's whereabouts measured by 3 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

School Boundaries: School provides clear rules and consequences measured by 3 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Neighborhood Boundaries: Neighbors take responsibility for monitoring young people's behavior measured by 1 item on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Adult Role Models: Parent(s) and other adults model positive, responsible behavior measured by 3 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Positive Peer Influence: Young person's best friends model positive, responsible behavior measured by 4 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

High Expectations: Both parents and teachers encourage the young person to do well measured by 2 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors

CONSTRUCTIVE USE OF TIME

Creative Activities: Young person spends 3 or more hr per week in lessons or practice in music, theater, or other arts measured by 1 item on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Youth Programs: Young person spends 3 or more hr per week in sports, clubs, or organizations at school and/or in community organizations measured by 3 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Religious Community: Young person spends 1 or more hour per week in activities in a religious institution measured by 1 item on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Time at Home: Young person is out with friends "with nothing special to do" 2 or fewer nights per week measured by 1 item on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

COMMITMENT TO LEARNING

Achievement Motivation: Young person is motivated to do well in school measured by 3 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

School Engagement: Young person is actively engaged in learning measured by 4 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Homework: Young person reports 1 or more hr of homework every school day measured by 1 item on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Bonding to School: Young person cares about her/his school measured by 1 item on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Reading for Pleasure: Young person reads for pleasure 3 or more hr per week measured by 1 item on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

POSITIVE VALUES

Caring: Young person places high value on helping other people measured by 3 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Equality and Social Justice: Young person places high value on promoting equality and reducing hunger and poverty measured by 3 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Integrity: Young person acts on convictions and stands up for her or his beliefs measured by 2 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Honesty: Young person "tells the truth even when it is not easy" measured by 1 item on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Responsibility: Young person accepts and takes personal responsibility measured by 2 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Restraint: Young person believes it is important not to be sexually active or to use alcohol or other drugs measured by 2 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

SOCIAL COMPETENCIES

Planning and Decision-Making: Young person knows how to plan ahead and make choices measured by 2 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Interpersonal Competence: Young person has empathy, sensitivity, and friendship skills measured by 3 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Cultural Competence: Young person has knowledge of and comfort with people of different cultural, racial, ethnic backgrounds measured by 3 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Resistance Skills: Young person can resist negative peer pressure and dangerous situations measured by 2 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Peaceful Conflict Resolution: Young person seeks to resolve conflict nonviolently measured by 1 item on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

POSITIVE IDENTITY

Personal Power: Young person feels he or she has control over "things that happen to me" measured by 2 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Self-Esteem: Young person reports having high self-esteem measured by 4 items on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Sense of Purpose: Young person reports "my life has a purpose" measured by 1 item on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

Positive View of Personal Future: Young person is optimistic about her or his personal future measured by 1 item on the Search Institute's Profiles of Student Life: Attitudes and Behaviors (PSL-AB)

APPENDIX V. POTENTIAL DATA SOURCES: ADVANTAGES AND DISADVANTAGES

The following table identifies advantages and disadvantages of state and federal data sources recommended for use in measuring selected indicators. State data sources are presented first. Federal data sources are grouped by the sponsoring agency or organization, such as the Centers for Disease Control and Prevention (CDC). The federal agency or department from which the data are disseminated and, where available, the World Wide Web page address are noted.

STATE DATA SOURCES

DATA SOURCE	ADVANTAGES	DISADVANTAGES
VITAL STATISTICS • Birth Certificates • Birth/Death Cohort File	Ongoing data collection and availability Inexpensive Standardized manner of data collection Near complete coverage of vital events Many natality and mortality indicators may be derived from this source	Risk behavior, pregnancy condition and neonatal outcome data may be incomplete Availability of risk behavior, pregnancy condition and neonatal outcome data varies from state to state 1 to 2 year delay in availability of cohort file following data collection
VITAL STATISTICS • Death Certificate	Ongoing data collection and availability Inexpensive Standardized manner of data collection Near complete coverage of vital events	Cause of death may be coded inconsistently

FEDERAL DATA SOURCES

DATA SOURCE	ADVANTAGES	DISADVANTAGES
CENTERS FOR DISEASE CONTROL AND PREVENTION **Behavioral Risk Factor Surveillance System (BRFSS)** Behavioral Surveillance Branch, National Center for Chronic Disease Prevention and Health Promotion http://www.cdc.gov/nccdphp/brfss/brfsques.htm	Ongoing data collection and availability Rich data source for health and nutrition information adult population 18 years if age or older living in households Injury module added in 1988, in 1993 injury items on child/adolescent safety added to core questionnaire Data available on CD 6 to 9 months after collection	No direct method of compensating for non-telephone coverage is employed by the BRFSS (may be missing people of lower socioeconomic status without telephones) Unknown amount of measurement error due to self-report For injury module, sample size may limit data analysis
CENTERS FOR DISEASE CONTROL AND PREVENTION **Fatal Accident Reporting System (FARS)** Fatal Accident Reporting System Branch, National Highway Traffic Safety Administration, Department of Transportation	Ongoing data collection and availability Data collected on all persons involved in the fatal motor-vehicle crash, on circumstances surrounding the crash including weather and type of road, location and all motor-vehicles involved in crash Work-related fatalities for persons working in transportation industry are included Data are standardized state to state and are valid for national, state, county and local totals.	Includes only motor-vehicle, traffic-related deaths occurring within 30 days of the crash Race/ethnic of persons is not included No E-coding of injuries is included Only medical information included on survivors is injury severity and if taken to a medical facility Injury severity index used by police is broadly defined (e.g., killed, incapacitated, non-incapacitating injury, possible injury, no injury,

FEDERAL DATA SOURCES

DATA SOURCE	ADVANTAGES	DISADVANTAGES
http://www-fars.nhtsa.dot.gov/		unknown)
CENTERS FOR DISEASE CONTROL AND PREVENTION **Healthcare Cost Utilization Project (HCUP)** Hospital discharge abstracts into 2 data sets: • SID • NIS Agency for Healthcare Research and Quality, Healthcare Cost Utilization Project http://www.ahcpr.gov/data/hcup/	Ongoing data collection and availability Valuable for monitoring use and cost of hospital services Detailed information on diagnosis, procedures and external cause may be used to measure morbidity and injuries	**General:** Unduplicated count may be difficult to determine if data set contains no individual identifiers Often a two-year lag between data collection and data availability for analysis **Specific:** SID: application process and fee, data for 22 states only NIS: short application process, data is drawn from SID but only approximates 20% sample of all U.S. community hospitals
CENTERS FOR DISEASE CONTROL AND PREVENTION **National Health and Nutrition Examination Survey (NHANES)** Division of Health	Ongoing data collection and availability Rich data source for health and nutrition information for women and children	2 to 5 year delays in data availability Weighting software needed to obtain national estimates from survey data

FEDERAL DATA SOURCES

DATA SOURCE	ADVANTAGES	DISADVANTAGES
Examination Statistics, National Center for Health Statistics http://www.cdc.gov/nchsww/nchshome.htm		
CENTERS FOR DISEASE CONTROL AND PREVENTION **National Health Interview Survey (NHIS)** Division of Health Interview Statistics, National Center for Health Statistics http://www.cdc.gov/nchsww/nchshome.htm	Ongoing data collection and availability Provides incidence and prevalence of health conditions information Contains data for health condition risk factors Nationwide sample	2 to 5 years delay in data availability Large sampling errors of estimates for small populations Weighting software needed to obtain national estimates from survey data
CENTERS FOR DISEASE CONTROL AND PREVENTION **National Hospital Discharge Survey (NHDS)** Division of Health Care Statistics, National Center for Health	Ongoing data collection and availability Rich data source for use of hospital services information Data available for expected payment source, length of stay, diagnosis and procedures Nationwide data	Geographic specificity limited to region of country Limited number of race categories Race missing in 20% of records Ethnicity not included on public use tapes Represents number of events, not individuals

FEDERAL DATA SOURCES

DATA SOURCE	ADVANTAGES	DISADVANTAGES
Statistics http://www.cdc.gov/nchsww/nchshome.htm		Delays of two years or more in data availability Weighting software needed to obtain national estimates from survey data
CENTERS FOR DISEASE CONTROL AND PREVENTION • **National Notifiable Diseases Surveillance System (NNDSS)** • **Morbidity and Mortality Weekly Report (MMWR)** Editor, MMWR Series Mailstop C-08 Centers for Disease Control and Prevention Atlanta, GA 30333	Ongoing data collection and availability Weekly and annual reports available in Morbidity and Mortality Weekly Report (MMWR) Data available for conditions such as measles, mumps, pertussis, and rubella Nationwide data	Represents number of events, not individuals Limited race/ethnic specificity Reporting of sensitive diagnosis such as sexually transmitted diseases may be incomplete or inconsistent
CENTERS FOR DISEASE CONTROL AND PREVENTION **National Survey of Family Growth (NSFG)** Division of Vital Statistics,	Rich data source for contraception, family planning, prenatal care, fertility and sexually transmitted disease information Nationwide sample	Data collected in six- to eight-year cycles Limited race/ethnic specificity Sample size not adequate for reliable analysis of Asians and American Indians State of residence not available

FEDERAL DATA SOURCES

DATA SOURCE	ADVANTAGES	DISADVANTAGES
National Center for Health Statistics http://www.cdc.gov/nchsww/nchshome.htm		Weighting software needed to obtain national estimates from survey data
CENTERS FOR DISEASE CONTROL AND PREVENTION **National Vital Statistics System** Division of Vital Statistics, National Center for Health Statistics http://www.cdc.gov/nchsww/nchshome.htm	Ongoing data collection and availability Standardized manner of data collection Near complete coverage of vital events Many natality and mortality indicators may be derived from this source	Risk behavior, pregnancy condition and neonatal outcome data may be incomplete Not all state report all risk behaviors
CENTERS FOR DISEASE CONTROL AND PREVENTION **Pediatric Nutrition Surveillance System (PEDNSS)** Division of Reproductive Health, National Center for Chronic Disease Prevention and Health	Program based nutrition surveillance system Programs include WIC, EPSDT and Head Start Rich data source for nutrition status of low-income infants and children Nationwide sample	Program-specific data collection methods may impair comparability of data Data are owned by the participating state, territory or reservation and may be released only with permission from the participants

FEDERAL DATA SOURCES

DATA SOURCE	ADVANTAGES	DISADVANTAGES
Promotion http://www.cdc.gov/nccdphp/nccdhome.htm		
CENTERS FOR DISEASE CONTROL AND PREVENTION **Pregnancy Nutrition Surveillance System (PNSS)** Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion http://www.cdc.gov/nccdphp/nccdhome.htm	State-based surveillance system Data currently collected in 22 states Includes data on low-income women only Health status measures, prenatal care and risk factor data available	Data are not available for all states Data are collected using a convenient sample and therefore are not generalizable to the overall population Data are owned by the participating state, territory or reservation and may be released only with permission from the participants
CENTERS FOR DISEASE CONTROL AND PREVENTION **Youth Risk Behavior Surveillance System (YRBS)** Division of Adolescent and School Health, National Center for	Ongoing data collection and availability Data collected on injuries, tobacco, alcohol and other drug use, sexual activity, dietary behavior and physical inactivity Data collected using school- and household-based surveys	Data may not be available for all states Limited race/ethnic specificity Limited geographic specificity Self-reported data are not verified by medical record review, raising the possibility of poor data reliability and accuracy

FEDERAL DATA SOURCES

DATA SOURCE	ADVANTAGES	DISADVANTAGES
Chronic Disease Prevention and Health Promotion http://www.cdc.gov/nccdphp/nccdhome.htm		
DEPARTMENT OF COMMERCE **Census of Population** Bureau of the Census http://www.census.gov/	Ongoing data collection and availability Standardized data collection Data available for small areas Socioeconomic data available	Collected every ten years Does not have multiple racial coding
DEPARTMENT OF COMMERCE **Current Population Survey** Bureau of Census http://www.bls.census.gov/cps/cpsmain.htm	Outgoing data collection and availability Data available for health conditions affecting women and children Nationwide sample Public use data usually available 6 to 12 months following data collection	Due to data collection methodology changes made in January, 1994, data collected before and after that date may not be comparable
DEPARTMENT OF COMMERCE **Survey of Income and Program Participation (SIPP)**	Collects data each month over a 3-year period Standardized manner of data collection Provides information regarding the dynamics of health insurance coverage	Not a source of state level estimates Small sample Annual estimates of percent uninsured are half as large as the CPS

FEDERAL DATA SOURCES

DATA SOURCE	ADVANTAGES	DISADVANTAGES
Bureau of Census http://www.sipp.census.gov/sipp		
DEPARTMENT OF HEALTH AND HUMAN SERVICES **Medical Expenditure Panel Survey (MEPS)** National Center for Health Statistics and Agency for Health Care Policy and Research http://www.meps.ahcpr.gov/	2 years of information are collected over the course of 2.5 years Demographics, income, and health insurance coverage Nationwide sample designed to yield comprehensive data that estimate the level and distribution of health care use	Possible sampling error, bias, and other issues of systematic error due to survey technique A smaller representative sub-sample of respondents to the NHIS Comparison of results between other data sources, such as NHIS and CPS, are not recommended due to differences in definitions, e.g., insurance status Not a source of state level estimates Long delay in release of data Produces slightly higher estimates of the percent uninsured than the CPS
NATIONAL INSTITUTES OF HEALTH **Surveillance, Epidemiology and End Results Program (SEER)** Cancer Statistics Branch, National Cancer Institute	Data collected from 11 population-based cancer registries Data for all residents diagnosed with cancer Follow-up data on previously diagnosed patients	Data available for four major urban areas, six states and Puerto Rico only

FEDERAL DATA SOURCES

DATA SOURCE	ADVANTAGES	DISADVANTAGES
http://www.nci.nih.gov/		
NATIONAL INSTITUTES OF HEALTH **Monitoring the Future (High School Senior Survey)** Bureau of the Census http://www.nida.nih.gov/	Ongoing data collection and availability Data on drug use and related attitudes Data collected for 8th, 9th and 12th graders Self-administered questionnaire	Drop-outs and absent students are not included in the survey Often a two-year delay in reporting of results Limited race/ethnic specificity Limited geographic specificity
SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION **National Household Surveys on Drug Abuse** Office of Applied Studies http://samhsa.gov/	Ongoing data collection and availability Nationwide data for persons age 12 and over Allows reporting of substance abuse prevalence rates	Geographic location is suppressed

RESOURCES FOR DATA SOURCE EVALUATION

Other valuable resources to consider when evaluating data sources include:

ASPE Research Notes: Information for Decision Makers (Understanding estimates of uninsured children: putting the differences in context)

This document compares the different data sources of health insurance coverage for children and youth. Four (4) data sources are discussed regarding the fundamental differences between the estimates, the varied definitions of insurance coverage, the unique survey methods, and additional issues including recall bias and data inclusion/exclusion criteria. Additional caveats are provided regarding the strengths and weaknesses of the different data sources. Found on the web: http://aspe.od.dhhs.gov/rn/rn21.htm

From Data to Action (U.S. Department of Health and Human Services, Public Health Service, CDC. From Data to Action: CDC's Public Health Surveillance for Women, Infants and Children Hyattsville, MD)

This monograph gives information on public health surveillance and data programs at the CDC that are relevant to women, infants and children's health. It is organized into four major sections: the reproductive health of women, birth outcomes, child health, and adolescent health. Within each section, specific health outcomes are discussed. For each health outcome, the monograph provides information on its public health importance, a history of data collection, CDC surveillance activities, general surveillance findings, methodologic and interpretive issues, examples of using data, and future issues. An appendix includes contact persons for CDC surveillance and data programs relevant to women's and children's health.

Health, United States (U.S. Department of Health and Human Services, Public Health Service, National Center for Health Statistics. Health, United States, 1998. Hyattsville, MD. 1998)

This annual report provides information on the health status of the nation. It has a special section on women's health, as well as detailed tables covering the topics of health status (including fertility, natality and mortality) and health determinants, utilization of health resources, health care resources (personnel and facilities), and health care expenditures. An appendix discusses sources and limitations of data.

Needs Assessment: Resource Handbook (U.S. Department of Health and Human Services, Public Health Service, Health Resources and Service Administration,

Maternal and Child Health Bureau, Division of Systems, Education and Science. Hyattsville, MD. 1994)

The Needs Assessment: Resource Handbook provides information on various data sources including possible uses and additional information for specific data sources. In addition, the monograph provides an overview and brief bibliography of various primary data collection methodologies, including surveys, focus groups, nominal group technique, key informant interviews, participant observation, and community forums.

The Directory of Minority Health and Human Services Data Resources (prepared by Moshman Associates, Inc., Bethesda, MD. For the U.S. Department of Health and Human Services)

The Directory was developed as a reference document on more than one hundred data resources within the U.S. Department of Health and Human Services that contain race and ethnicity data. It is an extremely useful resource, documenting data source structure, data content, data limitations, onset of data collection, current status of data collection, data availability, data storage media, and the name and address of a contact person who can provide further information regarding the data source. A description and a copy of the Directory are available on the World Wide Web on the home page of the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE) at http://os.dhhs.gov/progorg/aspe/minority/index.html.

APPENDIX VI. BARRIERS TO THE MEASUREMENT OF PUBLIC HEALTH INDICATORS

The availability and accessibility of data and the methodological and systems barriers that may be encountered in attempting to analyze these data also have a significant impact on which indicators are selected. It is critical to evaluate each data source prior to the selection of an indicator to ensure that these data will be available and relevant. Even though each data source has very distinct characteristics, there are some criteria that apply to evaluating any data set. The following factors should be considered when assessing the feasibility of utilizing a particular data set.

TIMELINESS

Many population-based data sets are extremely useful when comparing state data against other state and national findings. However, due to the complexity of collecting, cleaning and preparing large data sets, there is frequently a 2 to 3 year delay in the availability of these data for use by local health agencies. Thus, in order to monitor the impact on health status or outcomes of the rapid transition of Medicaid enrollees into managed care plans, states may need to collect and/or analyze more timely data. For example, rather than use the NCHS Natality Data to monitor perinatal health, the state would choose to analyze state birth certificate data.

GEOGRAPHIC SPECIFICITY

Data sets differ in their level of geographic specificity. Some data sets, such as the Federal Census of Population and Housing, contain ZIP code and census tract level information. However, population-based data are frequently collected through surveys of only a sub-sample of population, e.g., the National Hospital Discharge Surveyor the National Health Interview Survey. Sample representativeness and generalizability may limit the utility of such data sets for evaluating local conditions. For example, national data set samples may not be representative of a local, state or regional population. States often address these barriers by using the standardized instrument from a national survey and sampling a much larger local population. However, additional local sampling requires additional financial resources.

SPECIFICITY OF DEMOGRAPHIC DATA

As in the section on geographic specificity, national population samples are often limited in the number of race/ethnic groups for which data are collected in large enough numbers to analyze with any degree of statistical validity. For example, the size and content of the samples in the Youth Risk Behavior Survey or the High School Senior Survey on drug use do not allow results to be calculated for Asian/Pacific Islander populations.

In addition, age is often reported as a categorical age group rather than a continuous variable (e.g., data on age group categories are gathered - rather than data on actual years of age). At the national level, for example, mortality reports frequently aggregate age into broad ranges such as 0 to 24 years for injuries, or 15 to 24 years for motor vehicle related indicators. This makes the age specific analysis necessary for program planning and evaluation more challenging, if not impossible.

As with geographic sampling, states often attempt to correct this limitation by using a standardized instrument and oversampling the groups of particular interest.

DATA CONSISTENCY AND STANDARDIZATION

To adequately compare health outcome measures from one jurisdiction to another, or to monitor changes in health outcome measures over time, it is necessary to compare similar groups using standardized variables. Standardization requires that state data collection efforts use identical definitions and standard instruments where possible. This may be a challenge given that the existing data available from multiple sources frequently measures the same construct in different ways. For example, race/ethnicity may be collected and/or coded using different categories: Asians may be reported as an aggregate or by specific categories such as Japanese, Chinese, Southeast Asians, etc.

Whether a measure is recorded by self-report or "assigned" by the data collector may also lead to discrepancies across data sources.

Differences in methodologies for combining variables (or codes) into groups, may also lead to inconsistent comparisons across data sets. This frequently occurs with grouping of diagnostic codes in hospital discharge data where, for example, different researchers measure heart disease using different diagnostic ICD-9 code groupings. Similarly, age groupings are frequently not comparable across data sets.

In some cases, the data may be collected in a more detailed fashion and reported in categories that are not useful or consistent with other data being utilized. In this case, obtaining the raw data and recoding the variables may solve the problem. In other cases, the data set may simply not be helpful and a primary data collection effort will be necessary.

A most useful project would be to initiate a data standardization effort for any future data collection at the state level, e.g. deciding on a uniform way to collect race/ethnicity data that will be used by all programs.

ABILITY TO PRODUCE UNDUPLICATED COUNTS AND CLIENT SPECIFIC DATA

Many service utilization data sources were developed for billing purposes. They contain records for encounters, admissions, or visits, as opposed to records for unique individuals and are therefore subject to duplication of information. For example, three types of duplication can be found in hospital discharge data:

1. More than one record for the same admission to a hospital.
2. Two or more records associated with one episode of care. For instance, if a person is admitted to a hospital and then transferred shortly to a second hospital, this may be considered one episode of care, rather than two distinct episodes.
3. More than one episode of care for one individual. Depending on the unit of analysis under consideration (billed claims, episode of care, or individual case), records may need to be considered separately as distinct episodes of care, or be linked to represent utilization for one individual.

Deterministic and probabilistic record linkage strategies would have to be developed and utilized to obtain client-specific data within and across data sets. A more long term strategy would include developing a unique personal identifier by utilizing, for example, client identification numbers or a set of standardized variables.

WEIGHTING OBSERVATIONS

National surveys that contain data only for a sample may need to be weighted to produce national estimates. For example, most national surveys produced by the National Center for Health Statistics require special software to weight records to produce national estimates. The cost of acquiring this software and the technical skill needed to use it represent barriers to the proper utilization of data sources for which weighting is required.

AVAILABILITY OVER TIME

Some data collection efforts occur at specific intervals and are not available every year. Most notable is the US Census, which is only collected every ten years. In order to supplement this, states collect intercensal samples and make projections for each year. However, these samples may not be detailed enough to provide data at the ZIP code or census tract level for all ages or race/ethnic groups. This limits the ability to generate rates for these groups between census years.

National survey data are also collected for specific time periods. Other surveys may be done only once due to the one-time availability of resources or the political climate. An example of this might be toxicology screening of newborns for inutero substance exposure to drugs or alcohol. In order to use a particular data set for ongoing

monitoring resources would have to be identified to repeat the data collection effort on an ongoing or periodic basis.

SAMPLE VALIDITY

Some national survey data are collected on convenience samples. For example, the High School Senior Survey collects self-reported data on students who are enrolled and in attendance at a school on a particular day. This methodology excludes those students who have dropped out of school or who attend school sporadically from participating in this survey. Thus, it would be inaccurate, for example, to use this sample to estimate overall teen drug use since it excludes those teens who are more likely to have frequent, chronic or severe drug use.

SYSTEMS BARRIERS

Often the most serious obstacles to the completion of a monitoring effort are those that result from a health department's lack of adequate systems for data collection, storage and analysis in the following eight areas:

1. Computing Facilities

Lack of adequate computing facilities may hinder surveillance and needs assessment activities. Storage space, processor speed, and memory are vital aspects of computing facilities. In addition, as more and more data files and information become available on the Internet, hardware and software that allow fast and efficient access to this medium are becoming essential. Many states rely on outdated mainframe technology, which is inadequate to meet the demand for readily accessible data.

2. Trained Personnel

Different tasks involved in data management and analysis require different levels of technical competence. As activities and methods become more complex, additional staff, including computer programmers, statisticians and epidemiologists, may be needed to manage and analyze data used in needs assessment and surveillance. In order to adequately measure the recommended indicators, a number of important skills and resources are required. For the analysis of large state data bases, for example, familiarity with statistical analysis software, data linkage and translation software and software that will interface between legacy systems and GIS packages are required.

3. Storage Media

Capacity to read and write to various storage media must be considered. Many data sets are extremely large and require expensive storage and retrieval methods. Data sets may be disseminated in various forms such as 9-track tape, 18-track tape, CD-

ROM disk, Zip drive or Jaz drive. Access to the appropriate storage media read/write equipment is important to consider before obtaining a data set.

4. Storage Format

In addition to storage media, storage format is another important consideration. Data may be stored in ASCII or text format, in a binary form or in a software-specific format. Software packages that can translate software-specific files to other formats are especially useful. In addition, operating system characteristics may hinder the transmittal of data from one storage medium to another. Many data sources provide hard copy reports of analyses that may be converted into electronic format. More and more agencies and organizations are placing data files, in various storage formats, on the Internet. To access data from the Internet, file transfer capability and appropriate software to open such files are needed. In addition, confidentiality and security of the data must be assured.

5. Data Security

Many government agencies will not release data unless data security requirements are met. Protection methods for computer accounts, files and storage media are necessary, especially when data sets contain confidential information. These methods include passwords, encryption, fingerprint or smart card "keys." In addition, physical storage media (computers, disks, tapes, hard copies) should be kept in secured and locked locations.

6. Confidentiality

Data sets and reports may include confidential information that could be used to identify individuals. Confidentiality standards and protocols for protecting the confidentiality of subjects must be implemented when these data are used. These confidential data are especially useful when analyzing data collected by more than one agency. The need for access to confidential data must be balanced against requirements for maintaining and protecting confidentiality and privacy.

7. Data Ownership

Adequate acknowledgment of data collection agencies and adherence to protocols for claiming ownership and allowing dissemination of data must be practiced. Many government agencies will not release data to "outside" analysts. Private agencies often charge prohibitive fees for obtaining their data.

8. Political Priorities and Limited Financial Resources

Health agencies have lagged behind other professional and business organizations in the utilization of information technology. Many legislatures have considered investing in

information technology as a luxury and have redirected resources to the delivery of services. In order to change this mentality, state program staff must be able to provide compelling evidence of the cost effectiveness of a needs assessment and monitoring system for directing a more effective use of limited resources.

APPENDIX VII. ANNOTATED RESOURCE LIST OF POTENTIAL INSTRUMENTS

ADOLESCENT HEALTH SURVEY

The Adolescent Health Survey is a comprehensive standardized instrument which elicits self-report information from adolescents. It was created by the Maternal Child Health Bureau in order to develop a comprehensive adolescent health database for program and policy development, planning and research purposes. The survey has been administered to over 60,000 adolescents nationally. The purpose of this assessment of adolescent health, risk behaviors and resiliency factors is to provide valid, timely information to key decision makers and information users including legislators, health, social service and education professionals, youth workers, parents and others involved with, or on behalf of, youth.

Domains included: demographic and biographical data, relationships with family friends and other adults, school performance and conduct, personal worries and concerns, body image, help seeking and utilization of services, nutrition and eating behavior, disordered eating, sexual behaviors, sexual orientation, substance use, mental health and suicidal involvement, physical and sexual abuse, anti-social behaviors, other risk-taking behaviors

To acquire survey:
The National Adolescent Health Resource Center
1313 Fifth Street Southeast, Suite 205
Minneapolis, MN 55414
Telephone: (612) 627-4488
Fax: (612) 627-4487
http://www.cyfc.umn.edu/youth/adoleshealth.html

CENTER FOR EPIDEMIOLOGIC STUDIES-DEPRESSION SCALE (CES-D)

The Center for Epidemiologic Studies-Depression Scale (CES-D) is a self-administered 20-item inventory designed to measure levels of depressive symptomatology, primarily depressed mood and affect. Validation studies indicate the CES-D scale helps to identify persons "at-risk" for clinical depression, and is a valuable tool for studying the relationships between depressive symptoms and other variables. Validation studies of the CES-D with adolescents indicate high internal consistency, validity and reliability.

To acquire survey:
NIH Neural Center
6001 Executive Boulevard, Room 8184 MSC 9663
Bethesda, MD 20892
Telephone: (301) 443-4513
http://www.cmwf.org/publist/index.asp#toc

CHILD HEALTH QUESTIONNAIRE (CHQ)

The Child Health Questionnaire (CHQ) yields a profile of 14 health concepts and summary measures of physical and psycho-social functioning and well-being for children ages five years and older. Both positive and negative health states and a wide range of objective reports and more subjective ratings are represented. The 50-item parent completed version (CHQ-PF50) has been tested in 7 condition groups, several clinical trials, population-based monitoring efforts, and has been translated/adapted for use in 16 countries. The analogous child completed version of the CHQ consists of 87 items and is designed for self-completion by children at least ten years of age. A parent-completed 28-item version of the CHQ (PF28), which yields a 14-concept profile and two summary indexes, is also documented. The CHQ has been shown to be useful in comparing groups of children within HMO's, doctor's offices, schools (including on-site clinics), clinical trials and large population-based research efforts (e.g. Medicaid).

Domains included: general health, change in health, physical functioning, bodily pain/discomfort, limitations in school, work and activities with friends, behavior, mental health, self-esteem, parental impact-time, parental impact-emotional, limitations in family activities, and family cohesion

To acquire survey:
640 George Washington Highway
Lincoln, RI 02865
Telephone: (401) 334-8800
Fax: (401) 334-8801
http://www.sf-36.com/manuals.chqorder.html

CHILD HEALTH AND ILLNESS PROFILE: ADOLESCENT EDITION

This instrument was developed specifically to assess health status among adolescents. Reliability and validity of the instrument have been reported on extensively (Starfield 1995 and Starfield 1993).

Domains included: discomfort, disorders, satisfaction with health and self-image, achievement of age-appropriate social roles, risks, and resilience. It is also appropriate for collection and analysis of trend data. The comprehensive nature of the CHIP-AE is essential to its ability to show the inter-relationship of different aspects of health. Further, this comprehensiveness enables researchers to explore the meaning and long-term impact of health-related behavior

To acquire survey[1]: Dr. Barbara Starfield
615 North Wolfe Street
Baltimore, MD 21205

MEASUREMENT OF DEVELOPMENTAL ASSETS SURVEY

The Measurement of Developmental Assets Survey was designed by the Search Institute to measure both the assets and risk variables from a variety of standardized and well-validated instruments used in national and state surveys of adolescents and other psycho-social research. There are 156 items on this survey measuring the 40 assets which assess support, empowerment, boundaries and expectations, constructive use of time, commitment to learning, positive values, social competencies and positive identity.

To acquire survey: The Search Institute
700 South Third Street, Suite 210
Minneapolis, MN 55415
Telephone: (800) 888-7828
http://www.search-institute.org/research/survey/ap.htm#the survey

MINIMUM EVALUATION DATA SET FOR EVALUATING PROGRAMS AIMED AT CARING FOR ADOLESCENT MOTHERS AND THEIR CHILDREN

This data set was developed by the Adolescent Family Life Program to measure antecedent, program and outcome variables of interest to programs for pregnant and parenting adolescent females in California. The instrument is self-administered and has been shown to be reliable and valid amongst adolescent women from 13 to 19 years of age.

Domains included: housing, education, employment, service utilization, risky behavior, self-esteem, obstetric and contraceptive histories.

To acquire survey: Sociometrics Corporation
170 State Street, Suite 260
Los Altos, CA 94022-2812
Telephone: (415) 949-3282
http://www.socio.com/data_arc/daappp_0.htm

[1] Starfield B, Riley AW, Green BF, et al. The Adolescent Child Health and Illness Profile: a population-based measure of health. *Med Care*. 1995;33(5):553-566.

MONITORING THE FUTURE: A CONTINUING STUDY OF THE LIFESTYLES AND VALUES OF YOUTH

Annual survey by NIDA-supported researchers at the University of Michigan of self-reported data on psychoactive substance use among 16,000–18,000 high school seniors.

Limitations: It excludes younger students and adolescents who are not in school, a group who may have higher rates of drug use and abuse. It also includes only small samples of nonwhites.

To acquire survey[2]:
SRC Director's Office
Survey Research Center
1355 Institute for Social Research
P.O. Box 1248-1248
Ann Arbor, MI 48106
Telephone: (734) 764-8365
http://www.monitoringthefuture.org

NATIONAL AMBULATORY MEDICAL CARE SURVEY (NAMCS)

The National Ambulatory Medical Care Survey (NAMCS) is a continuing national probability sample survey of ambulatory medical encounters. It collects data on physician-patient encounters in the offices of a sample of non-federally employed physicians classified as "office-based, patient care physicians." Sample physicians complete a patient information form for a random sample of office visits. Data include patient characteristics and medical information and health insurance information. Data are used to develop estimates of the use of office-based visits by the U.S. population.

Limitations: NAMCS does not collect data on visits to hospital-based physicians. In addition, because there is no stratification of the sample on race or ethnicity and the sample sizes are quite small for racial and ethnic minorities, NAMCS does not present reliable information on adolescents who are ethnic minorities. The survey also includes information only on those individuals who seek care, which excludes many adolescents, particularly those from low-income or non-white ethnicities.

To acquire survey:
National Center for Health Statistics
Division of Data Services
Hyattsville, MD 20782-2003
Telephone: (301) 458-4636
http://www.cdc.gov/nchswww/about/major/ahcd/namcsdes

[2] Johnston LD, Bachman JG, O'Malley PM, Schulenberg JE, Wallace J. Monitoring the Future Study. Institute for Social Research. University of Michigan.

NATIONAL HEALTH INTERVIEW SURVEY ON CHILD HEALTH (NHIS-CH)

The National Health Interview Survey on Child Health (NHIS-CH) is a continuous, nationwide study of a representative sample of U.S. households. Data are collected from a probability sample of the civilian non-institutionalized population residing in the U.S. on: personal and demographic characteristics, restricted-activity days due to acute and chronic conditions, injuries, and use of medical services. NHIS-CH is a subset (n=17,110) of the larger sample (n=122,000) and collects data on children up to age 17, reported by their parents.

Domains included: family dynamics, injury and physical health status, educational progress, and emotional functioning.

Limitations: The NHIS sample does not include homeless persons, persons residing in institutions, or members of the armed services. Proxy interviews are generally used for all persons under age 17, which may not reflect true health status and utilization of services of adolescents. The adolescent sample is too small to provide adequate measures of low prevalence physical conditions. Data are generally not reported using age groupings appropriate to describe adolescents.

To acquire survey:

Sociometrics Corporation
170 State Street, Suite 260
Los Altos, CA 94022-2812
Telephone: (650) 949-3282
Fax: (650) 949-3299
http://www.socio.com/srch/summary/daappp/dapi3-i4.htm

Data Dissemination Branch
National Center for Health Statistics
Centers for Disease Control and Prevention
6525 Belcrest Road, Room 1064
Hyattsville, MD 20782-2003
Telephone: (301) 436-8500
http://www.cdc.gov/nchs/products/catalogs/subject/nhanes3/nhanes3.htm

NATIONAL HEALTH EXAMINATION SURVEY (NHES) AND THE NATIONAL HEALTH AND NUTRITION EXAMINATION SURVEY (NHANES) III

The most comprehensive sources of national clinical epidemiological data on adolescents was NHES, which most recently collected data from 1966 to 1970 through interviews and physical examinations on a representative sample of 6,768 adolescents ages 12-17. NHANES I (1971-1974) and NHANES II (1976-1980) were initiated as

successors to NHES and use interviews and clinical examinations to gather data on a sample of the civilian non-institutionalized population of the U.S., ages 1 to 74. Neither NHANES I nor NHANES II had an adequate adolescent sample. NHANES III (1988-1994) includes a sample of 3,200 adolescents ages 12 to 19, including a large proportion of African American and Mexican-American adolescents. NHANES III consists of five separate files including Youth Household Data.

Domains included: dietary intake and nutritional status, anthropometric measurements, reproductive history and sexual behaviors, use of vitamin and mineral supplements and medications, tobacco and alcohol use, physical activity and sociodemographic characteristics

To acquire survey:
National Center for Health Statistics
6525 Belcrest Road, Room 1000
Hyattsville, MD 20782
Telephone: (301) 436-7068 ext. 174
Fax: (301) 436-5431
http://www.os.dhhs.gov/progorg/aspe/minority/mincdc37.htm

Operations Branch
Centers for Disease Control and Prevention
National Center for Health Statistics
Division of Health Examination Statistics
6525 Belcrest Road
Hyattsville, MD 20782
Telephone: (301) 436-8267 ext-148
http://www.cdc.gov/nchswww/products/catalogs/subject/nhanes3/nhanes3.htm

NATIONAL HOSPITAL DISCHARGE SURVEY (NHDS)

The National Hospital Discharge Survey (NHDS) is a continuing nationwide sample survey of patients discharged from a sample of non-Federal short-stay and specialty hospitals. In order to be included, hospitals must have a minimum of six beds and average patient stays of less than 30 days.

Domains included: personal information about the patient (e.g. birth date, race, sex, marital status), administrative information (e.g. dates of admission and discharge), and medical information (e.g. diagnosis and medical procedures performed)

Limitations: Relatively few adolescents are hospitalized each year. Because NHDS does not oversample for adolescents, the number of adolescents sampled in the survey is small. Consequently,

NHDS does not provide reliable information on the incidence of hospitalization among adolescents for any but the most frequent reasons for hospitalization and does not allow for finer breakdowns such as by race, gender, or socioeconomic status. In addition, data are not reported using appropriate age breaks for adolescents.

To acquire survey: National Center for Health Statistics
Division of Data Services
Hyattsville, MD 20782-2003
Telephone: (301) 458-4636
http://www.cdc.gov/nchswww/products/pubs/pubd/series/sr13/130-121/sr13_128.htm

NATIONAL HOUSEHOLD SURVEY ON DRUG ABUSE (NHSDA)

The National Household Survey on Drug Abuse (NHSDA) measures the prevalence of drug use among the American household population age 12-17.

Limitations: It excludes homeless or institutionalized adolescents, and those under age 12 or over age 17. The sample is also small and the number of non-whites surveyed is small.

To acquire survey: National Center for Health Statistics
Division of Data Services
Hyattsville, MD 20782-2003
Telephone: (301) 458-4636

The National Clearinghouse for Alcohol and Drug Information
P.O. Box 2345
Rockville, MD 20847-2345
Telephone: (800) 729-6686
Fax: (301) 468-6433
http://www.health.org:80/pubs/nhsda/97hhs.index.htm

NATIONAL LONGITUDINAL STUDY OF ADOLESCENT HEALTH (ADD HEALTH)

The National Longitudinal Study of Adolescent Health (Add Health) is a survey designed by the National Institutes of Health to measure the effects of adolescents' families, peer groups, schools,
neighborhoods and communities on behaviors that promote good health. It also collects information on health risks such as tobacco use, sexual activity, sun exposure and drug and alcohol use. Unlike other national studies of adolescent health and behavior, Add Health is uniquely designed to measure the determinants of health. The main premise

is that social context–such as relationships with families, friends, and peers and community characteristics-influences the health and health-related behaviors of youth.

The study independently measures such contextual influences on adolescent health through surveys of school administrators, students, and parents, and through collection of data on community-level characteristics. Items used in the measurement of the dependent and independent variables were identified from a variety of standardized, validated instruments used in national and state surveys of adolescents. Dependent variables were selected to capture the major indexes of adolescent health and risk behaviors. Independent variables were derived from a resiliency framework.

To acquire survey[3]: Carolina Population Center
University of North Carolina at Chapel Hill
University Square
123 West Franklin Street
Chapel Hill, NC 27516-3997
Telephone: (919) 966-2157
Fax: (919) 966-6638
http://www.cpc.unc.edu/addhealth/

NATIONAL LONGITUDINAL SURVEY OF YOUTH (NLSY)

The National Longitudinal Survey of Youth (NLSY) is a nationally representative sample of 12,000 males and females who were between 14 and 21 years of age in 1979. NLSY is a longitudinal cohort survey with a supplementary military sample. Data have been collected annually through 1994 and every other year beginning in 1996. The original focus of NLSY was on labor market behavior. It oversamples African American and Hispanic youth from socioeconomically disadvantaged families.

Domains included: family background and structure, fertility, marriage and divorce, educational progress, migration, health, delinquent behavior, and financial status, children born to female respondents (and related outcome data)

To acquire survey: NLS User Services
921 Chatham Lane, Suite 100
Columbus, OH 43221
Telephone: (614) 442-7366
Fax: (614) 442-7FAX
http://www.chrr.ohio-state.edu/nlsy79-childya/

[3] Resnick MD, Bearman PS, Blum RW, et al. Protecting adolescent from harm: findings from the National Longitudinal Study on Adolescent Health. *JAMA.* 1997;278(10):823-832.

NATIONAL SURVEY OF ADOLESCENT MALES (NSAM)

The National Survey of Adolescent Males (NSAM) is a longitudinal cohort survey of adolescent males with a specific focus on fertility and sexuality. The database includes a nationally representative sample of 1880 never married, non-institutionalized U.S. males between 15 and 19 years of age, with 956 variables. Two data collection cycles have taken place to date: 1988 and 1990, and the original cycle was oversampled for blacks and Hispanics.

Domains included: education, knowledge about human sexuality, reproductive history

To acquire survey[4]: Sociometrics Corporation
170 State Street, Suite 260
Los Altos, CA 94022-2812
Telephone: (650) 949-3282
Fax: (650) 949-3299
http://www.socio.com/srch/summary/daappp/dapk1-k2.htm

The Urban Institute
2100 M Street, NW
Washington, DC 20037
Telephone: (202) 833-7200
http://www.urban.org/

NATIONAL SURVEY OF FAMILY GROWTH (NSFG)

This tool is a replicated cross-sectional survey of females 15 to 44 years of age, including adolescents, with a specific focus on reproductive intentions and behavior. Analysis of trend data and cross-sectional comparisons between and within cohorts in the NSFG are possible due to the large age range sampled. The database includes 8450 women between the ages of 15 and 44 of all marital statuses. Data collection cycles have occurred in 1973, 1976, 1982, 1988, 1990, and 1995.

Domains included: housing, employment, education, childcare, service utilization, reproductive health

To acquire survey[5]: Sociometrics Corporation
170 State Street, Suite 260

[4] Sonenstein FL, Pleck JH, Ku L. *National Survey of Adolescent Males, 1988 and 1990-91: Original Instrument/Codebook: Data Archive on Adolescent Pregnancy and Pregnancy Prevention: Data Set K1-K2*. Los Altos, CA: Sociometrics Corporation, November 1994.

[5] National Center for Health Statistics. National Survey of Family Growth, Cycle IV 1988 and 1990 Telephone Reinterview": Original Instrument (1988) included ages 24 years and younger: Data Archive on Adolescent Pregnancy and Pregnancy Prevention: Data Set K3-K7. Los Altos, CA: Sociometrics Corporation.

Los Altos, CA 94022-2812
Telephone: (650) 949-3282
Fax: (650) 949-3299
http://www.socio.com/srch/summary/daappp/dapk3-k7.htm

Family Growth Survey Branch
National Center for Health Statistics
6525 Belcrest Road
Hyattsville, MD 20782-2003
Telephone: (301) 458-4636
http://www.cdc.gov/nchs/nsfg.htm

NATIONAL VITAL STATISTICS SYSTEM

This data set includes data on births, deaths, marriages and divorces in the U.S. Natality and mortality data according to age, race, marital status and state of residence is available on an annual basis and is of relatively stable methodology within states which enables longitudinal analysis. Data reports or tapes are often made available at the county, city and even ZIP code level.

To acquire survey: National Center for Health Statistics
6525 Belcrest Road
Hyattsville, MD 20782-2003
Telephone: (301) 458-4636
Telephone: (301) 436-8500
http://www.cdc.gov/nchs.nvss.htm

PREVENTION MINIMUM EVALUATION DATA SET (PMEDS)

The Prevention Minimum Evaluation Data Set (PMEDS) is an evaluation instrument developed for adolescent sexuality and pregnancy prevention and STD/HIV/AIDS programs. It is intended to assist programs in developing quality evaluation questionnaires to use in conducting an impact evaluation. It is designed for self-administration by teenagers 13-19 years of age.

Domains included: service utilization, risky behavior, self esteem and personal skills

To acquire survey: Sociometrics Corporation
170 State Street, Suite 260
Los Altos, CA 94022-2812
Telephone: (650) 949-3282
Fax: (650) 949-3299
http://www.socio.com/eval.htm#IV.C

REYNOLDS ADOLESCENT DEPRESSION SCALE (RADS)

This scale is a 30-item scale assessing symptoms of depression in adolescents. It is well suited for screening individuals or large groups of students in schools or clinical settings. Reliability and validity among 13 to 19 year olds has reported as excellent.

To acquire survey[6]: PAR, Inc.
P.O. Box 998
Odessa, FL 33556
Telephone: (813) 968-3003
Fax: (800) 727.9329
http://www.parinc.com/percouns/RADS24a.html
http://www.parinc.com/percouns/RADSPRS24b.html

ROSENBERG SELF ESTEEM SCALE

Developed over 30 years ago, this brief 10-item scale continues to demonstrate high reliability and validity, and has recently been tested extensively in various adolescent populations. The original sample consisted of 5,024 high school juniors and seniors from 10 randomly selected schools in New York State.

To acquire survey[7]: The Morris Rosenberg Foundation
c/o Dept. Of Sociology
University of Maryland
2112 Art/Soc Building
College Park, MD 20742-1315
http://www.bsos.umd.edu/socy/rosenberg.htm

SHORT FORM 36 (SF-36): THE MEDICAL OUTCOMES STUDY

The SF-36 was constructed to satisfy minimum psychometric standards necessary for group comparisons involving generic health concepts-concepts not specific to any age, disease, or treatment group. The eight health concepts were selected from 40 included in the Medical Outcomes Study (MOS) to represent those hypothesized to be most frequently measured in widely-used health surveys and those most affected by disease and treatment. They also represent multiple operational definitions of health including function and dysfunction, distress and well-being, objective reports and subjective ratings, and both favorable and unfavorable self-evaluations of general health status.

[6] Reynolds WM. *Reynolds Adolescent Depression Scale (RADS) Professional Manual.* New York, NY: Psychological Assessment Resources, Inc. 1987.

[7] Rosenberg M. *Society and Adolescent Self-Image*. Princeton, NJ: Princeton University Press. 1965.

Most items have their roots in instruments that have been in use for more than 20 years including the General Psychological Well-Being Inventory, various physical and role functioning measures, the Health Perceptions Questionnaire and other measures that proved to be useful during the Health Insurance Experiment.

The Child Health Questionnaire (CHQ) was specifically designed for use with adolescents and represents salient concepts not found in the SF-36 (e.g. activities with friends, self-esteem, behavior,
family). Prior to the development of the CHQ, the SF-36 was used to study the health of adolescents. However, comparison studies are now needed to empirically determine which instrument works best for this population.

To acquire survey[8]: The SF-36 Health Survey
New England Medical Center
750 Washington Street
Boston, MA 02111
Telephone: (617) 636-5000
http://www.sf36.com/general/sf36.html

TEEN HEALTH RISK SURVEY

This survey was administered to approximately 1000 students at high schools in Los Angeles, San Francisco, Oakland and San Jose in California to assess student health needs for the evaluation of eight school-based clinics from 1986 through 1991.

Domains included: school performance, service utilization, risky behavior, health promotion behavior, peer relations, reproductive health, traumatic events, and self esteem

To acquire survey: Dr. Claire Brindis
National Adolescent Health Information Center
Institute for Health Policy Studies
University of California at San Francisco
3333 California Street, Suite 265
San Francisco, CA 94118

TEEN QUESTIONNAIRE

This questionnaire is used to obtain data from approximately 14,000 subjects for the evaluation study of the Expanded Teen Counseling Program and Clinical Demonstration Projects, a pilot project funded by the Office of Family Planning, California Department of Heath Services from July 1991 through June 1995.

[8]Ware JE Jr. *The SF-36 Health Survey*. Boston, MA: The Health Institute, New England Medical Center.

Domains included: service utilization, reproductive health, school performance, traumatic events,
self esteem, locus of control and future orientation

To acquire survey: Dr. Claire Brindis
National Adolescent Health Information Center
Institute for Health Policy Studies
University of California at San Francisco
3333 California Street, Suite 265
San Francisco, CA 94118

YOUTH HEALTH PROVIDER

The Teen Health Advisor is an automated survey instrument developed by the Department of Pediatrics, University of Hawaii School of Medicine, Kaiser Permanente Medical Care Program and Tripler Army Medical Center. The computer takes a sensitive health history focusing on general health, stress, family peer and school problems, depression and suicide, use of illicit substances and desire to become a teenage parent, sexuality and sexually transmitted diseases. The program was written for a sixth grade reading level, requires no training or supervision and takes about 10 minutes to complete. This tool has demonstrated that a computer interview of adolescents is more capable than a clinical questionnaire of obtaining positive responses to certain sensitive information.

To acquire survey: David M. Paperny, MD
1010 Pensacola Street
Honolulu, HI 96814
Telephone: (808) 593-2950

YOUTH RISK BEHAVIOR SURVEY (YRBS)

The Youth Risk Behavior Surveillance System (YRBS) developed by the Centers for Disease control and Prevention has been used on a biennial basis since 1990 to measure health risk behaviors of high school students nationwide to assess whether those behaviors are increasing, decreasing, or remaining unchanged and to provide data that are comparable among national, State, and local samples of youth. The system has three complementary components: national school-based surveys, state and local school-based surveys and a national household-based survey. It was designed to focus primarily on health risk behaviors, rather than related knowledge, attitudes, or beliefs. Reliability tests indicate that the YRBS is best suited for students in grade 8 or above.

Domains included: intentional and unintentional injury, tobacco use, alcohol and other drug use, sexual activity, diet and physical activity

To acquire survey[9,10]: Centers for Disease Control and Prevention
4770 Buford Highway NE, MS K33
Atlanta, GA 30341-3724
Telephone: (404) 488-5330

[9] Brener ND, Kann L, Warren CW, Williams BI. Reliability of the Youth Risk Behavior Survey Questionnaire. *Am J Epidemiol.* 1995;141(6):575-580.

[10] Kolbe LJ, Kann L, Collins JL. *Overview of the Youth Risk Behavior Surveillance System*. Atlanta, GA: Centers for Disease Control and Prevention, 1993. Public Health Reports. 108(suppl 1):2-10.