

ISSUES RELATED TO THE LACK OF INFORMATION ABOUT ADOLESCENT HEALTH AND HEALTH AND RELATED SERVICES

In this Report, OTA was able to draw broad general conclusions about the prevention and treatment of adolescent health problems, but it is important to note that OTA's analysis was often severely hampered by insufficient information. A paucity of information about adolescent health concerns makes definitive conclusions about the extent of health problems among U.S. adolescents and about the availability and appropriateness of efforts to prevent and treat the problems (and promote positive adolescent health) difficult to draw. This paucity of information deserves specific attention in and of itself because it is an area particularly amenable to Federal attention.¹

The assessment of adolescent health and health care is impeded by a paucity of information in two main areas:

1. information related to the health status of adolescents, and
2. information on prevention- and treatment-oriented health services available to adolescents.

Limitations of Information on Adolescents' Health Status

Efforts to assess the health status of adolescents are universally stymied by at least two barriers: 1) limited conceptualizations of health, and 2) unusable and inconsistent aggregations of data by age, which in combination with small sample sizes, make analyses of available health status information difficult.

Indicators of health status are typically disease focused, with mortality due to natural causes and physician visits for disease being two of the few outcomes measured. Examples of such indicators appear in two publications of the U.S. Department of Health and Human Services (DHHS), *Health, United States, 1989* (289) and *Healthy People* (260).

As discussed elsewhere in this Report, definitions of health are in flux; thus, it is difficult to define all the parameters of health for any given Population.² Even for the parameters of adolescent health that have generally been agreed upon, however, data are rarely collected in any one place. For OTA's Adolescent Health Report (and similar compilations of data³), therefore, it was necessary to derive data from a variety of sources, and to request special data analyses.⁴ For many important adolescent problems (e.g., nonfatal accidents, sexually transmitted diseases, delinquency, mental health problems, hopelessness), there are no reliable sources of national data.

Aggregations of Data by Age Groupings

There is no single agreed-upon definition of adolescence, and chronological age is a poor proxy for developmental status (150); criticisms of current data collection by age groupings may therefore seem out of place. Currently, however, most published data make it difficult to disaggregate data for any semblance of an adolescent age group, especially if one considers the onset of puberty (which generally occurs between ages 10 and

¹As noted in OTA's 1988 report, *The Quality of Medical Care: Information for Consumers*, there is a consensus, if not unanimity, that the Federal Government should play a central role in the collection and dissemination of information (225).

²See box A, in 'Major Findings,' and ch. 2, "What Is Adolescent Health?" in Vol. II, for a discussion of the ways in which adolescent health has been conceptualized.

³Recent examples of compilations of adolescent health status data include the American Medical Association's publication, *America's Adolescents: How Healthy Are They?* (8); the Carnegie Council on Adolescent Development's publication *Turning Points: Preparing American Youth for the 21st Century* (29); the National Center for Education in Maternal and Child Health's publication *The Health of America's Youth* (150); and the National Commission on the Role of the School and the Community in Improving Adolescent Health's publication, *Code Blue: Uniting for Healthier Youth* (153).

⁴For information about adolescents' sexual activity, for example, OTA sought information from the National Survey of Family Growth conducted by the National Center for Health Statistics in DHHS; for information about deaths, national vital statistics maintained by the National Center for Health Statistics in DHHS; for information about health care utilization, the National Ambulatory Medical Care Survey and the National Health Interview Survey conducted by the National Center for Health Statistics in DHHS; for information about school attendance, the U.S. Department of Education; for information about drug use, the National Household Survey of Drug Use conducted by the National Institute on Drug Abuse in DHHS, the Monitoring the Future/High School Seniors Survey conducted by University of Michigan researchers under contract to the National Institute on Drug Abuse in DHHS, and school surveys sponsored by the Centers for Disease Control in DHHS; for information about delinquency, the Uniform Crime Reports of the Federal Bureau of Investigation within the U.S. Department of Justice.

14) to be the beginning of adolescence.⁶ Only recently has the Bureau of Maternal and Child Health in DHHS published a volume on the health of youth in which some limited data are reported for 10- to 14- and 15- to 19-year-olds (150).

Because of the many problems in aggregations of data, even the assembly of data to describe adolescent health using admittedly gross indicators such as age becomes a major task. Not surprisingly, therefore, there *is no regular monitoring of US. adolescents' health.*

Small Sample Sizes

The problem of unusable aggregations of data would be amenable to solution by interested researchers if sample sizes were large enough so that individual years of age could be disaggregated and reaggregated, although conducting these reaggregations would be difficult because of difficulties in gaining access to the data.⁷ Disaggregating and reaggregating data is sometimes possible (e.g., mortality data, arrest data). Often, however, that approach is impossible because the data have been collected by methods that do not oversample for adolescents. Surveys that do not oversample for adolescents include the National Hospital Discharge Survey (NHDS),⁸ the National Ambulatory Medical Care Survey (NAMCS), the National Health and Nutrition Examination Survey (NHANES III),⁹ and the National Drug and Alcoholism Treatment Unit Survey (NDATUS).¹⁰

The problem of small sample sizes becomes particularly acute when attempts are made to assess the health status of adolescents by region, residence,¹¹ race, ethnicity, age, sex, or socioeconomic status. Such analyses are important when one is attempting to identify groups of

adolescents or geographic areas in special need of services. NHANES III, currently in the field, illustrates the problem. NHANES III is scheduled to collect data from only 1,120 black, 1,120 Hispanic, and 980 "white and other" 12- to 19-year-olds. With an estimated 34.762 million 12- to 19-year-olds in the United States in 1989, each adolescent surveyed will have to represent 10,796 adolescents of that age group. Thus, one would expect that only broad generalizations about adolescent health will be able to be made from NHANES III.¹²

Information on Income Status

OTA was consistently frustrated in attempts to disaggregate differences in health status apparently associated with race and ethnicity from differences truly associated with family income, primarily because information on income (unlike information on race and ethnicity) is almost never collected along with health information. As a result, problems which are often attributed to problems associated with one race or another may in fact be more properly attributed to socioeconomic (or other) differences,

Information on Health From the Perspective of Adolescents

One of the hallmarks of adolescent development is the increasing ability to evaluate one's self and surroundings. A perhaps related hallmark is the tendency to withhold information from others in one's immediate environment, such as parents. Rarely, however, are U.S. adolescents asked to report about aspects of their health other than their engagement in problem behaviors.

⁵See ch. 2, "What Is Adolescent Health?" in Vol. II, for a discussion of adolescent development.

⁶Age groupings in widely available data sources included the following: ages 5 to 14 and ages 15 to 24 in mortality data published in *Health, United States, 1989* (289); ages 5 to 14 and ages 15 to 44 in National Health Interview Survey data on physician utilization published in *Health, United States, 1989*; ages 15 to 24 (with no younger ages reported) in information on methods of contraception from the National Survey of Family Growth published in *Health, United States, 1989*; ages 15 and under and ages 15 to 24 in various data published in *Health, United States, 1989* and in *Healthy People (260)*; less than age 18 and ages 18 to 19 in data on age of mother at birth of child published in *Health, United States, 1989*; under age 18 and ages 18 to 44 in data on specific chronic and acute conditions from the National Health Interview Survey (286); under age 18 and over age 18 in data on arrests from the U.S. Department of Justice (303); under age 18 and ages 18 to 64 in Current Population Report data on poverty status from the Census Bureau of the U.S. Department of Commerce (246); and 8th graders, 10th graders, and both grades combined in a unique national survey of adolescent attitudes (10). Other sources of data, with freer age categories are published, but are not widely available.

⁷More Federal data collection agencies are making data available electronically, but manipulation of the data requires special skills and access to appropriate computer software and hardware. Obtaining data from extragovernmental sources may be difficult because such data analyses are subject to long publication processes (if conducted by independent researchers) or because the analyses are kept by a local agency and not distributed.

⁸Technically, NHDS, NAMCS, NDATUS, and the National Institute of Mental Health's surveys of mental health organizations involve data about health care utilization not health status. Sometimes, however, data from these sources are used to make inferences about health status. If health care utilization rates are low, for example, it is sometimes inferred that a population has good health. One problem with such an inference is that it does not take into account the possibility that low utilization rates may be caused by barriers to access.

⁹NHDS, NAMCS, and NHANES are discussed in ch. 6, "Chronic Physical Illnesses: Prevention and Services," in Vol. II.

¹⁰NDATUS is discussed in ch. 12, "Alcohol, Tobacco, and Drug Abuse: Prevention and Services," in Vol. II.

¹¹In U.S. Census Bureau terminology, "residence" signifies metropolitan area, nonmetropolitan area, central city, etc. (109).

¹²The Centers for Disease Control in DHHS is instituting a cooperative program with State education departments to collect regular, locally relevant data on adolescent "risk behaviors" (277). It is important to note, however, that this effort is limited to self-report data on selected behaviors. Efforts like NHANES actually conduct health examinations of individual participants.

Limitations of Information About Health Promotion, Disease Prevention, and Treatment

Information on health care provided to U.S. adolescents is even more limited than information on such adolescents' health status.¹³ Surveys of private office-based physician visits and analyses of hospital discharge data, for example, do not oversample for adolescent visits (or practitioners who might see adolescents), so inferences about the utilization of mainstream health care by adolescents are difficult to draw. There is no single source of information about nonphysician providers and other sources of health care for adolescents, including hospital-based and freestanding emergency rooms, school nurses, and school-linked health centers. Despite the problems, some broad inferences can be made about adolescents' utilization of mainstream sources of health care, but when the topic of interest is health care utilization by racial and

ethnic minority adolescents, adolescents of varying levels of socioeconomic status, or adolescents in specific regions or residential areas, inferences are far more difficult to draw.¹⁴

Another problem is that numerical data on health care utilization do not address the important issue of whether care provided to adolescents is appropriate, effective, and satisfactory to the adolescent users. Either there are no or almost no evaluations (e.g., acne treatment, treatment for dysmenorrhea, substance abuse treatment, treatment in juvenile justice facilities, school-linked health services centers), or serious methodological flaws hamper efforts to draw conclusions from available evaluations. Many of the methodological flaws can be attributed to common problems (e.g., low base rate of the health problem, little funding for objective evaluations, inadequate requirements for methodological criteria).

¹³As noted above, health care utilization data are sometimes used as the basis of inferences about health status; therefore, some sources of health utilization data (e.g., NAMCS, NHDS, NDATUS) were referred to above in the discussion of health status information.

¹⁴Such inferences are presented in Vol. II, ch. 15, 'Major Issues Pertaining to the Delivery of Primary and Comprehensive Services to Adolescents.' For further discussion, see ch. 18, 'Issues in the Delivery of Services to Selected Groups of Adolescents,' in Vol. III.